

Negotiating Disease Perceptions: Experiences of Eight HIV-Positive Women in  
Mombasa, Kenya

By

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## **Abstract**

**Background:** Despite the large amount of existing research focused on what individuals know about HIV and AIDS, few studies explore how women living with the disease acquire and interpret information about it. This study attempted to gain such knowledge about a small group of HIV-positive women through a lens of social constructionism, a theory stating that how an individual comes to know, is socially constructed through their interactions and interpretation/experience of those interactions. I used this theory to inform how multiple influences in the social environment generate ideas in communities about HIV-positive people and the disease.

**Methods:** I collected qualitative data from a sample of eight HIV-positive women aged 20–25 living in Mombasa, Kenya. Combining both narrative inquiry and photo-voice methodologies, I used semi-structured interviews to solicit information about the women's experiences, including their reactions to discovering their status and the perceived differences between their lives pre-and post-diagnosis. I also gave each woman a blank journal and camera, with which she had a month-long period to take and describe photographs illustrating what HIV and AIDS looks like in her life. I, along with two translators, when necessary, transcribed the data from both the interviews and photo-journals. They translated data verbatim, first in Kiswahili, when necessary, and then English. I made regular field notes and kept a personal journal to delve further into the reflexive process. I used thematic analysis to analyze the interviews, as well as the captions and free writing in the women's journals. I also used visual analysis to analyze the photographs for content, temporality, and meaning. The amalgamation of these

methods provided a rich description of eight HIV-positive shared and differing experiences in negotiating new identities as people living with the disease.

**Results:** These women's identities have been shaped by their interactions and experiences of living with and learning about HIV and AIDS. Participants' self-images did not always match others' perceptions of HIV-positive people. However, the participants' related similar experiences in having to cope with externalized and internalized manifestations of stigma related to AIDS. These negotiations determined whether the women chose to share or bear alone the burdens associated with the disease.

**Conclusion:** Future research should capture the experiences of more individuals with a focus on how they form perceptions about themselves and the disease. Further understanding of this perception-forming process might help in the design of programs that address the sensitive discussions around sex, disease, and exclusion practices necessary to understand this chronic illness. Future research looking at individual experiences with HIV or AIDS could also help stakeholders learn how to create spaces for grassroots organizations working with community members to deliver culturally-appropriate education in communities vulnerable to infection. Such spaces could potentially allow individuals living with HIV to feel supported rather than morally stigmatized for their status. However, this study is only a first building block on the road to such programmatic goals. Given the small scale of this study more research is necessary to determine how broadly the lessons learned from these women's experiences might be applied and used effectively in program development.





I would like to dedicate this thesis to all the people who have helped shape my life narrative, but particularly my Kenyan family. Thank you for generously opening your home and always making me feel as though I was the seventh daughter in your household. My life story has been forever impacted by the valuable lessons about family, respect, and hard work you have imparted to me.

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## Table of Contents

ABSTRACT	ii
DEDICATION	v
ACKNOWLEDGEMENTS	vi
TABLE OF CONTENTS	vii
LIST OF APPENDICES	xiv
LIST OF TABLES	xv
LIST OF FIGURES	xvi
LIST OF ABBREVIATIONS	xviii
CHAPTER	
1 WHY HIV, WOMEN, AND RESEARCH IN KENYA?	1
Introduction	1
Global and National Context of HIV	4
Women's Vulnerability in the Pandemic	6
Women's Vulnerability to HIV Infection in Africa	7
Epistemological Framework: Social Constructionism	13
Position of the Researcher	16
The Story of Asha	17
My Experience	20
Objectives and Research Questions	24
Overview of Thesis	25

2	REVIEW OF LITERATURE	28
	Introduction	28
	The Social Construction of Health Knowledge Perceptions and Identity	29
	Women's Ways of Knowing	30
	Effects on My Research Practice	32
	Stigma and Disease	32
	Effects on My Research Practice	36
	Increased Health Knowledge Decreases Health Risks	36
	Effects on My Research Practice	43
	Socially Constructed Attitudes and Beliefs About HIV and AIDS	43
	Effects on My Research Practice	50
	Existing Power Relationships Informing Women's Understandings of Health Knowledge and Vulnerability to Infection	50
	Effects on My Research Practice	57
	Provision of Healthcare, Health Education and Its Effects on HIV Prevention: The Kenyan Case	57
	Effects on my Research Practice	64
	Chapter Summary	64
3	METHODOLOGY	66
	Introduction	66

Narrative Inquiry as Methodology	67
Theoretical Underpinnings of Narrative Inquiry	70
Key Concepts and Terms Related to Narrative Inquiry	73
Sociality	74
Temporality	74
Place	75
Story/Narrative	75
Voice	75
Metaphor	76
Photo-Voice as Methodology	77
Research Methods and Design	78
Research Site and Participant Recruitment	80
Interviews	82
Photo-Voice	89
Field Notes and Personal Journal	89
Data Analysis	90
Stages of Analysis	95
Obstacles to Engaging in Research	96
Limitations in the Methodology and Research Design	96
Sample Size	96
Lack of Prior Qualitative Research with HIV-	
Positive Women in Kenya	96

	Limits to Confidentiality	97
	Limitations of the Researcher	97
	Access	97
	Cultural and Other Types of Bias	98
	Fluency in a Language	99
	Ethical Considerations	99
	Scholarly Review	99
	Harms and Benefits	100
	Free and Informed Consent	101
	Deception	101
	Privacy and Confidentiality	101
	Conflict of Interest	103
	Inclusiveness	103
	Chapter Summary	104
4	NARRATIVES AND PLOT LINES	105
	Introduction	105
	Women's Narratives	105
	Mariam	107
	P. Diddy	115
	Tina	128
	Sabina	135

	Stacy	143
	Atoti	152
	Jane	165
	Whitney	172
	Summary of Story-Telling	183
5	THEMES AND TRANSFORMATIONS	186
	Overview of the Findings	186
	Arenas of Negotiation: Embracing, Negotiating, and Concealing the HIV-Positive Identity	191
	Fears of Infection: Infecting and Being Infected	196
	Domestic Stigmatization	196
	Tradition, Religion, and Punishment	208
	Death	213
	Disease and Disempowerment: Ways of Knowing HIV	215
	Social Death	216
	Metaphoric Representations of HIV and AIDS	221
	Rapid Contamination, Danger, and Ability to Defend the Body	221
	The Diseased Body	223
	Negotiating the Burdens of an HIV-Positive Status	231
	Actions to Protect Others	232



	Self-Preserving Behaviors	236
	Chapter Summary	238
6	DISCUSSION AND FINAL THOUGHTS	240
	Synthesis of Results	240
	Power Relations, Othering, and Defining Categories of Stigma	242
	A New Category of Stigma	245
	Negotiation of HIV-Positive Status	247
	Stigma and the Negotiation of Identity with an HIV- Positive Status	250
	Thinking Positively About A Future of Being Positive	252
	Reflections, Recommendations, and Concluding Remarks	255
	Reflections	255
	Growth as a Researcher	258
	Strengths of the Study	261
	Limitations of the Study	262
	Future Research With, By, and About HIV-Positive Women in Mombasa	263
	Conclusions	268
	REFERENCES	272
	APPENDICES	305

## **List of Appendices**

Appendix A: Interview Guide

Appendix B: Information Requested in Interview Guide

Appendix C: Letter of Support from Partner NGO

Appendix D: Letter of Information

Appendix E: Instructions for Creating Photo-Journal

Appendix F: Photo-Journal Release Form

Appendix G: Permission to Use Photographs

Appendix H: Initial Category Codes

Appendix I: Examples of Category Codes

Appendix J: Coding Chart Example

Appendix K: Cumulative Listing of Emergent Categories

Appendix L: Ethics Approval

Appendix M: Free and Informed Consent

Appendix N: Confidentiality Agreement for Translators/Transcriptionists

## **List of Tables**

Table 1. Category Codes

## **List of Figures**

- Figure 1. Data Analysis Flow Chart
- Figure 2. Untitled. Mariam. (October 2011)
- Figure 3. VVU ni kama moto. Diddy, P. (September 2011)
- Figure 4. Clothes. Tina. (September 2011)
- Figure 5. Untitled. Stacy. (October 2011)
- Figure 6. Orphan. Stacy. (October 2011)
- Figure 7. The insect bite. Atoti. (September 2011)
- Figure 8. Lion. Atoti. (September 2011)
- Figure 9. Leopard. Atoti. (October 2011)
- Figure 10. The toilet in my home. Atoti. (October 2011)
- Figure 11. Support family. Atoti. (October 2011)
- Figure 12. My cup. Jane. (October 2011)
- Figure 13. Sharing Stories. Whitney. (October 2011)
- Figure 14. Thematic Map: Emergent Themes and Sub-Themes from Analysis
- Figure 15. Arenas of Negotiation. Chubb., L. (October, 2013)
- Figure 16. Bed. Atoti. (October 2011)
- Figure 17. Glass. Atoti. (October 2011)
- Figure 18. Door. Atoti. (October 2011)
- Figure 19. Soap. Atoti. (October 2011)
- Figure 20. The body, the mango. Diddy, P. (September 2011)
- Figure 21. The crow. Jane. (October 2011)

Figure 22. Formation of Disease Perceptions and Self-Identity as a HIV-Positive Individual.

### **List of Abbreviations**

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>ARV(s)</b>	Antiretroviral Drugs
<b>HIV</b>	Human Immunodeficiency Virus
<b>NGO</b>	Non-governmental Organization
<b>PLWHA</b>	People Living with HIV or AIDS
<b>SSA</b>	Sub-Saharan Africa
<b>USAID</b>	United States Aid International
<b>WHO</b>	World Health Organization

## **Chapter 1: Why HIV, Women, and Research in Kenya?**

“Unless there is recognition that women are most vulnerable . . . and you do something about social and cultural equality for women, you’re never going to defeat this pandemic.” (Africa Recovery, 2001, p. 12)

### **Introduction**

Acquired immunodeficiency syndrome (AIDS) and its virus, the human immunodeficiency virus (HIV), have caused considerable physical suffering and emotional distress since its discovery (Tallis, 1991). Since its first formal confirmation in 1981, AIDS has increased the death rate in many communities around the world. It is impossible to understand the scale of this suffering without paying special attention to women within the pandemic. Approximately 60% of people known to be infected with HIV on the African continent are women (Gardner, 2012). Due to a number of contributing social, cultural, political, and economic factors, women are frequently in a position of increased vulnerability to HIV infection (Amuyunzu-Nyamongo, Okeng’o, Wagura, & Mwenzwa, 2007; Chacham, Maia, Greco, Silva, & Greco, 2007; Holtz, Sowell, & Velaquez, 2012; National AIDS Control Council [NACC] & National AIDS/STI Control Programme [NASCOP], 2011). In 2009, at the time of the last census update in Kenya, the HIV prevalence of women was also disproportionate to that of males—with 8.8 % of approximately 19.4 million of the total population of women in Kenya being infected with HIV. This can be compared to male prevalence for HIV infection with approximately 5.5% out of the 19.2 million men having a positive status in the country (Kenya National Bureau of Statistics, 2011). On average, in Sub-Saharan

African (SSA) countries similar to Kenya, the virus is twice as likely to infect a woman as a man (National AIDS and STI Control Programme [NASCOP], 2008).

Both the medical disparities between females and males infected with HIV (differences in prevalence of infection) in Africa, and the work of researchers to position women in HIV epidemics, have contributed to popular discourse which has counter-intuitively served to marginalize women further. Some past research has created contradictory perceptions of HIV-positive women—on one hand, research trying to situate women in the pandemic has intensified the perception of women (especially black women) as dangerous; on the other hand it has framed them as victims of violence or sexual and domestic oppression which increasingly silence their voices and limits their agency (Buvé, Bishikwabo-Nsarhaza, & Mutangadura, 2002; Jungar & Oinas, 2004; Joffe, 1999). Because of my concern about these competing discourses that place women in positions of increased vulnerability to HIV, I chose to approach this study through a social constructionist lens. Through looking at how HIV-positive identities are socially constructed, it is my hope that the reader will better understand each woman's individual experience of learning about and living with HIV in Kenya, while giving each of their stories a voice.

This thesis is an exploration of the ways in which eight HIV-positive women from Mombasa, Kenya came to understand their society's perceptions of HIV and AIDS. My purpose was to determine how these women understand and interpret the health ideas they have encountered in interactions with community members, family, friends, institutions, and their cultural environments. The women's understandings in the context of their social environment inform both their emotional and physical management of the



HIV infection and how they perceive HIV and AIDS within their community.

Additionally, I wanted to understand how ideas about HIV and AIDS influenced the women's decision-making processes about health behaviors, in particular those relating to sexual practices and life-long management of HIV-positive status.

This chapter provides the reader with a basic contextual framework from which to examine how these women formed their perceptions of HIV and AIDS. This chapter highlights how I came to pursue this line of inquiry, gives a rationale for the importance of studying the sociological aspects of women's experiences with HIV, and explains the overall goals of this research. I define the study's epistemological framework, social constructionism, and then discuss how interacting factors from the social environment play an important role in how HIV-positive women learn about and manage life with the disease (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013; Dahlberg & Krug, 2002; Van Neikerk, 2002).

I also introduce my methodological framework, narrative inquiry, in this chapter. Liamputtong (2010) asserts that this methodology opens up space for sensitivity, as the researcher is able to respond to and take part in the subjective experience of each participant. The opportunity to engage in dialogue and convey interest in participants' lives is an essential building block in developing trust between participant and researcher, which is crucial in cross-cultural inquiry (Davies et al., 2009; Liamputtong, 2010). By taking a social constructionist approach in shaping my questions about women's interactions with social environments, I was able to use the narratives of the women I interviewed to illustrate how their personal feelings and environments affected their understanding of, and beliefs about, HIV-related knowledge. Additionally, the narratives

provided a deeper insight into how the women subjectively experience and construct their own ideas about the disease.

### **Global and National Context of HIV**

To better comprehend the situation of women living with HIV in Mombasa, it is important to understand the larger national, regional, and global context of the pandemic. AIDS ranked as the sixth leading cause of death globally and the third in SSA in 2011 (World Health Organization [WHO], 2013). These statistics do not account for the deaths of people who were HIV-positive but undiagnosed and whose deaths were attributed to opportunistic infections such as tuberculosis or pneumonia. These diseases likely would not have occurred, or the effects would not have been as severe, if the individuals were not HIV-positive (WHO, 2009b). In 2009, the WHO reported the prevalence of HIV infection among people of all ages in Kenya to be 1.5 million people out of the 39.825 million total population, a number nearly unchanged since 2000 (WHO, 2009a). By 2011, it was estimated that the prevalence of HIV infection in Kenya will reach 1.8 million by 2015. This relatively static overall change is good news, but it does not change the fact that HIV still disproportionately affects women in Kenya (NACC & NASCOP, 2011; WHO, 2014). Understanding how social factors influence HIV-positive women's experiences may help to reduce the total number of Kenyan women infected with HIV over time (Kenya National Bureau of Statistics, 2011). This study is another step in gaining such an understanding. Listening to the women's individual stories will allow the research community to uncover women's experiences with the disease and understand the role of social factors. Because women aged 20–24 experience the highest

HIV prevalence of any age group among women, they are the key focus of this study (*Analysis of HIV/AIDS Policy Formulation in Kenya*, 2007).

While the aforementioned statistics serve as estimates of those directly affected by the disease, it is impossible to account for the total number of people living with HIV/AIDS (PLWHA) in Kenya, as in any country on the African continent. This is due, in part, to a lack of available professionals to process and report up-to-date statistics, the reluctance of individuals to agree to test due to apprehensions around discussing HIV or AIDS and fear of community stigma, and the lack of consistent interaction with the health system (Nolen, 2008).

Given that the prevalence of HIV infection in Kenya has remained relatively unchanged in the past decade, researchers need to further explore the effectiveness of current prevention and treatment strategies as well as disparities in healthcare and information access. Researchers need to study social factors related to those most affected and may benefit from incorporating elements of a global health perspective. Global health focuses on how national public health is managed across all sectors of the society, not only the health sector (Global Health Action, 2010). It looks at both publically- and individually-focused interventions and how they take into consideration the health of all members of society (Global Health Action, 2010). Though this study cannot be generalized globally, I have used the global health perspective to gain a broader societal focus when looking at how health information is transferred. I have endeavored to apply that focus to a very specific situation with HIV-positive in Mombasa.

## **Women's Vulnerability in the Pandemic**

Feminist theory within the study of AIDS works to uncover women's positions and silenced voices within the global pandemic. In African societies that were previously colonized, or where traditional cultures are active, AIDS research must take into account the tendency for gender roles to situate women as subordinate to males. This is due in part to the system of patriarchy entrenched in these societies since colonization, privileging men and male ideas over women and female ideas. British colonization of African societies, including Kenya, led not only to economic and political benefits for Britain but also to the export of religious and political beliefs including restrictions on women (Ochieng & Maxon, 1992). In colonies such as Kenya, values that underscored British social, cultural, and organizational structures at home were imposed on the native population (Ahluwalia, 1996).

In the early 1980s and 1990s, feminist scholars from South and North challenged fixed notions of womanhood and insisted on interrogating and recognizing differences (Rapis Response Service, 2013; Steady, 2005). This task depended largely on understanding the position of women in regard to their class, access to privilege, status, ethnicity, and race among others. Women with less privilege are more likely to experience powerlessness, despair, vulnerability and exclusion (Rapid Response Service; 2013; Steady, 2005). Thus, construction of social inequality leads to power imbalances, where some people get power unfairly at expense of others (Essed, 1990; Mohanty, 1991; Rapid Response Service, 2013). This affects how women interpret ideas about HIV or AIDS and can actively use them in their daily lives (Rapid Response Service, 2013; Steady, 2005).

Intersectionality encompasses the idea that social categories (e.g., ethnicity, race, sexual orientation, economic status, social status, gender) intersect in individual interlocking systems at social-cultural and macro levels such as sexism, heterosexism and racism (Bowleg, 2012; Rapid Response Service, 2013). The Black feminism movement brought intersectionality that focused on historically oppressed populations (Bowleg, 2012; Bowleg, Teti, Malebranche, & Tschann, 2013; Hankivsky & Christofferson, 2008; Springer, Hankivsky, & Bates, 2012; Rapid Response Service, 2013). In addition, intersectionality challenges existing prioritization of inequality in the society, where prevalence is given to a particular group of people because of class, sex, gender, or other categories that might constitute privilege (Hankivsky & Christofferson, 2008; Rogers & Kelly, 2011). Intersectionality is also embedded in economic and social political history such as colonialism (Rapid Response Service, 2013; Rogers & Kelly, 2011). Thus, feminism, as a school of thought, had major impacts on how researchers look at women in colonized societies, and determines their positions of vulnerability, especially in terms of HIV infection (Bowleg, 2012; Rapid Response Service, 2013).

**Women's vulnerability to HIV infection in Africa.** In Africa, women tend to experience the social impacts of colonization to a greater degree than men, especially when compared to former British colonies in the Global North (Soskolne, 2003). Larson (1990) attributes the intensified effect HIV and AIDS has had on women to the interplay of colonialist ideologies and those of the traditional cultures, both of which can subordinate women. Thus, women in comparison to their male counterparts tend to have decreased economic, political, and educational capital, further perpetuating a dependency relationship on males (Buvé et al., 2002; Strebel, 1995).

This dependent relationship has implications for the degree of control women have over how they use (or how others use) their bodies. Many traditional cultures in SSA place an emphasis on limited sexual experience before marriage and the expectation that women will remain faithful and submissive to their husbands' needs once married (Buvé et al., 2002). These traditional notions of limited sexual experience also contribute to women's lack of sexual education, leaving men responsible for educating themselves and assuring both parties' sexual health. The assumption that men are knowledgeable in sex is dangerous as it creates a risk for exposure to HIV infection for women if men are not aware of the health risks associated with sexual practices (Buvé et al., 2002).

Women who have not contracted HIV are also often affected in different ways due to the ripple effect that this virus generates. For example, those who have not contracted the virus are often the caretakers of children orphaned by AIDS. Children orphaned by AIDS, especially young girls, fall into a cycle of poverty that increases their risk to HIV infection while they are at the same time less likely to have access to resources and opportunities that would enable them to overcome this cycle (Tharao & Massaquoi, 2001). This, in turn, decreases their opportunities to access knowledge that includes AIDS-related information, making it harder make informed decisions about sex, relationships, and health (UNAIDS, 2010). A child orphaned by AIDS who often cannot afford education and training, has fewer opportunities to receive health information, and insufficient means of supporting their future families (Masanjala, 2007). Thus, those who care for children orphaned by AIDS and those who have been orphaned as a result of the disease are both vulnerable to infection. This perpetuates a cycle where their descendants

are also likely to be poor and unable to access health information, leading to vulnerability to infection in future generations.

In addition to caring for orphans, uninfected women and those who do not know their status often come into contact with the pandemic when they care for patients with HIV or AIDS. They may also be future mothers who must protect their children from mother-to-child transmission (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2009). Thus, women not only experience the burden of living with HIV or AIDS, but also may also become infected even if they do not experience problems from infection themselves.

Lack of agency, such as choosing whether to complete education, is evident in overall life decisions for women in the region. Contributing factors include the traditional female role in the home, a woman's cultural and religious identity, and her position in the socio-economic sphere. Female completion of secondary and tertiary education is thus much lower than male completion in many low-income areas where the virus still thrives. Women may be forced to discontinue schooling in these regions because they need to care for younger siblings or elderly members of the family who suffer from AIDS. This, in turn, decreases their opportunities to access knowledge that includes AIDS-related information, making it harder to make informed decisions about sex, relationships, and health (UNAIDS, 2010).

Women usually hold little power over sexual decisions (such as the choice to use condoms, male or female), which increases their vulnerability to infection (Gardner, 2012). As condom use is often non-negotiable in communities across several of the low-income and even high-income countries across the world, women's vulnerability to

infection increases as their autonomy decreases (UNAIDS, 2010). In addition to increasing negotiating power for HIV-negative women, a stronger sense of agency might also weaken the devastating effects that the virus can have on the physical and emotional state of an HIV-positive woman (Susser & Stein, 2000).

Young women in Kenya also often engage in inter-generational relationships with men to obtain material possessions such as cell phones, clothes, or money to support themselves and their families (NACC & NASCOP, 2011). In doing so, they expose themselves to the risks of engaging with older men in sexual relations, with up to a generation more sexual experience and a greater chance of having HIV. Compounding the likelihood of making uninformed or poor sexual decisions due to lack of agency, some women feel powerless and do not change their situations fearing abandonment, divorce, and domestic partner violence (Gardner, 2012).

The World Bank reports domestic violence as the most significant factor contributing to new HIV infections among women, making this a key topic for further research (Frazer, Görgens-Albino, & Nkongolo, 2008). One in five women in Kenya has experienced sexual violence. This rate increased from 15.9% in 2003 to 20.6% in 2010 (NACC & NASCOP, 2011). The Kenya NASCOP indicated that one in five men and one in four women think that it is not a woman's decision to withhold sex from her husband, despite his having sex with other partners (2008). The more sexual partners a husband takes, the greater his wife's chances of contracting HIV becomes.

Other factors contributing to a disproportionate number of women in Kenya being infected by HIV include common cultural practices. The practice of female genital mutilation, which has the potential to infect women with HIV via unsterilized cutting



instruments and open wounds during the healing period, has declined slightly in recent years but still remains common (Morison et al., 2001; NACC & NASCOP, 2011). Wife inheritance is another cultural practice that increases women's vulnerability to infection in Kenya, involving a husband's brother-in-law or cousin or a respected male community member assuming responsibility for a widow. Although tradition frowns upon sex between the new partners, it is increasingly being ignored and is thus another factor increasing infection risk.

Kenya's political climate, like its cultural practices, does not always place women in an equal position to men. Kenya has passed laws guaranteeing equal rights such as the *Consent to Marriage*, *Minimum Age for Marriage*, and *Registration for Marriage* laws, but loopholes allow for interpretation and ultimately leave women at the mercy of their families (NACC & NASCOP, 2011; World Bank, 2004).

Economic factors are also significant. While HIV infection affect individuals differently according to social position, Global South women as a group experience these effects to a greater extent due to lower standards of living (Holtz et al., 2012; Masanjala, 2007). HIV-positive women living in poverty are less likely than persons with a higher socio-economic status to seek out or have access to treatment (Wingood & DiClemente, 2000). Reasons for lack of treatment include lack of financial resources, lack of AIDS-related education, and lack of access to information or support services at the time of infection (Nolen, 2008). In addition, women and men living in poverty are often at a progressive stage of illness when they finally begin a therapeutic regimen. For women, who tend to live longer with HIV before it progresses to full-blown AIDS, delaying the start of a treatment regimen lowers the likelihood that the treatment will be effective

(Holtz et al., 2012). Finally, because of the nature of the female reproductive system as an area where lesions can occur and fluids can be held, women are twice as likely as men to contract HIV during unprotected sex (Joint United Nations Programme on HIV/AIDS, 2006).

In addition to their greater vulnerability to HIV infection due to the above factors, women have also been misrepresented in discussions of the pandemic by scholars, medical professionals, organization leaders, and religious leaders and by cultural and community norms or beliefs. When discussed in relation to AIDS, HIV-positive women have typically been viewed as a source of infection, as failures at maintaining their natural role as caregiver and nurturer, or as members of a deviant category such as prostitute or illicit drug user (Lawless, Kippax, & Crawford, 1996). As HIV is primarily sexually transmitted, it is frequently linked to other sexually transmitted diseases and their stigmas including promiscuity via sex work, dirtiness or unsanitary practices, and polluted bodies. This stigma exists in spite of past research that has shown the most common HIV transmission method for women is “normal” heterosexual sex (Lawless et al., 1996).

### **Epistemological Framework: Social Constructionism**

Epistemology, the study of knowledge, leads us to ask, “How do we know what we know?” (Denzin & Lincoln, 2003). A number of scholars have defined the term including Auerswald (1985), Denzin & Lincoln (2000), Hoffman (1981), and Keeney (1983). For the purposes of my research, Bateson (1994, p. 84) gives the best explanation of epistemology: “Every description is based upon, or contains implicitly, a theory of how to describe.” The particular theory I use in this study to describe the experiences of

women living with HIV is social constructionism. Social constructionism implies that individuals' realities are constructed or described through, and by, their social and cultural interactions (Berger & Luckmann, 1991).

Several assumptions underscore social constructionist thought. The first is that individuals exist in language and language is used as a means to define specific ideas (Speed, 1991). Shared meanings for these ideas or beliefs about the world are invented through social interaction or exchange and they can change and develop with time (Dickerson & Zimmerman, 1996). However, because ideas change with time and context, Anderson and Goolishian (1988) assert that all conceptions of the world are dynamic and that universal truths are non-existent. In addition to these assumptions, social constructionists assume that a person's understanding of a concept is influenced by the dominant discourse of their immediate social and cultural context, and, therefore, can change as time passes (Speed, 1991).

Although social constructionism is based on the principle that all experiences occur in social contexts, emphasis is placed on the importance of opening up spaces where individual stories can be told (Dickerson & Zimmerman, 1996). A social constructionist epistemology is particularly valuable to my study as it challenges the ways in which HIV-positive women in the Global South have been represented by not accepting the story of one woman as representative of all HIV-positive women's stories. Instead, this framework opens up the potential to explore previously unexamined perspectives and meanings. It also works to dismantle fixed conceptions of what it means to be an HIV-positive woman from a low-income country, and to show the multiple identities that one woman can assume to construct herself (Soskolne, 2003).

As a researcher, using the social constructionist framework has made me hyper-aware of my own social and cultural context. This is the context from which I have learned about and continue to receive ideas that shape my understanding of the epidemic in Kenya, and awareness of it has allowed me to critically reflect on how I perceive women with HIV in Kenya as a Canadian researcher. Using social constructionism has enabled me to evaluate Global North ideas about AIDS against both my pre-study encounters with HIV-positive individuals and my recent experience living and working more closely in the social and cultural contexts of the HIV-positive women I studied. Furthermore, a social constructionist epistemology informed my interpretation of the women's narratives in addition to my responses and interactions during the data collection process. It also helped to define the focus and clarify the aims of this study, as well as influenced the research design. I found that social constructionism worked well with a narrative analysis, highlighting the multiple ways a woman can construct her experience and how those experiences are influenced by socially acceptable norms. I aimed to make sense of and situate the multiple experiences of each woman in a meaningful account of what it means to be a HIV-positive woman in Mombasa, Kenya.

Through this social constructionist approach I posited that HIV-positive women arrive at their understanding of the disease through multiple social and cultural interactions. Using this theory to form my research questions, I attempted to better illustrate the meaning-making process of how the women learn about and live with HIV. This is based on the idea that each woman's understanding of the AIDS is affected by a range of her experiences, by the sources from which she receives and interprets

information about the virus, by her memberships, and by the societal locations she has inhabited throughout her life.

In his study of the moral and social complexities of AIDS in Africa, Van Neierk (2002) defines the complex relationship of interconnected social factors that influence how people come to know and understand their world. He does so by relating these factors to understanding the prevalence of AIDS across the African continent:

A complexity refers to a kind of problem that not only has no clear-cut or self-evident answer, but also may not be successfully addressed even through an analytical approach wherein we distinguish parts and whole, often with the expectation that addressing the parts with the whole. In complexities or complex systems, the whole is more than the constituent parts; the approach to the solution of complex problems often requires a consciousness and a sense of interactive influences that defy our natural intuitions or analytical prowess. (pp. 145-146)

Thus, when designing a study to understand the pandemic and why it occurs in certain places and affects certain sub-populations more than others, it is important to consider the complex relationships between social environmental factors affecting the individual. In turn, researchers must realize that these relationships are overlapping and cannot be described compartmentally.

Intersectionality theory posits that social identities are constructed by influences of power, social structures, and do change based on time, social location, and the individual formulating a certain identity (Bowleg, 2012). Thus, how women living with HIV understand the disease and their identities as HIV-positive women, is affected by a variety

of influences and linked factors including individual feelings, gender, age, education level, income, knowledge, and attitudes; relationships with family, friends, peers, and other social connections. It is also affected by the following factors: the experiences and ideas women receive from schools, neighborhoods, hospitals, workplaces, support groups, social institutions, organizations, and the media; institutional structures and their policies; and social or cultural norms and beliefs (Dahlberg & Krug, 2002).

To effectively examine the AIDS pandemic from a social constructionist approach, it is important to situate the aforementioned overlapping factors and influences within their appropriate context. For example, Van Neikerk (2002) notes that poverty is often stated as the main cause of AIDS. However, while poverty is a factor that creates the ideal conditions for the virus to be transmitted, poverty is not a direct cause of the HIV infection, but rather a social context in which it is more likely to flourish when other contributing factors are present. Similarly, I found it important to consider how the above factors overlap within the context of my participants' social environments in order to contextualize how the women in this study comprehend and use health knowledge (Van Neikerk, 2002).

Using social constructionism alongside the study's methodological approach, narrative inquiry, allowed me to lay the groundwork to examine HIV and AIDS from a social perspective of understanding. I was thus able to address where knowledge comes from, how it is interpreted, and how it is taken into practice through the narratives of the women I interviewed.

## **Position of the Researcher**

**The story of Asha.** “How do we know what we know?” This question is at the center of sociological research and is the starting point of my study. While working overseas in the volunteer sector with HIV-positive men and women, I have constantly contemplated this question. Through these experiences, I have become aware of the relationships of power that serve to oppress women and maintain traditional gender roles in many East African societies. Women are often the primary caretakers, undereducated because of their caretaking responsibilities and politically underrepresented. Thus they are less likely to own property or resources, and are less able to access accurate health information and services. Traditional social views on sex tend to glorify male promiscuity, even for men in a relationship, while accentuating female sexual restraint or submissiveness about sexual decisions (Nzioka, 2001). These positions affect how women protect themselves against contracting HIV, how they manage the virus once they have been infected, and their beliefs about why and how they contracted HIV. In other words, the context of being a woman in East Africa influences how she knows what she knows about AIDS.

Before my first experience of listening to an individual’s personal account of how she came to be HIV-positive, I had only ever associated HIV and AIDS with medical terminology and biological diagrams from a grade eight presentation by the school nurse. When I first arrived in Tanzania in 2009, I had not heard the alarming statistics about women and their increased susceptibility to the HIV virus—especially the most marginalized women (e.g., women in Global South countries with lower socio-economic status than those in the Global North; women with insufficient education or without

access or opportunity to any education; etc.). During the summer of 2009, I settled into a five-bedroom compound accompanied by seven other students from my university.

Together, as a student-run non-governmental organization (NGO), we decided to spend the summer on Pemba Island, Tanzania, teaching English, business, computers, and health. Our students for the summer were a group of men and women who all lived with a positive HIV status, and I soon became vividly aware of the complexity of this disease.

On the cement block in front of the small mud house where I had the opportunity to teach a few classes throughout the summer, Asha asked the question, “Is it possible for HIV to develop even if I had tested negative for two years after the last time I had sex?” Like all my students that summer, Asha was HIV-positive. Before even attempting to answer the question, I wanted to know why she had posed it. This was my first experience listening to a personal account of how someone came to be HIV-positive. Asha explained that when she was 14 living in Dar es Salaam, her father sold her to a man almost twice her age on Pemba Island. She vividly described how this man raped her at the beginning of their marriage until she finally became pregnant. When Asha was 20, after having a second child, the husband left her and the children, taking everything. When Asha was 25 she met, as she described him, “the man of her dreams.” After a five-year unmarried partnership, he became very sick and died. Even though they had used condoms throughout their relationship, after his death Asha immediately went to be tested for HIV. Despite rumors that her deceased partner had been infected, her test was negative. It remained negative for the next two years of her life.

Eventually Asha’s first husband returned, demanding that she was still married to him and therefore still “his property.” Asha became pregnant for a third time and, after



being tested during a prenatal care visit, found out she was HIV-positive, the same status as her returned husband. As a newborn, her daughter was also tested and shared the same positive status. Asha's husband blamed her for the virus, stating it was her punishment for being with another man. When she finished her account, I asked why she stayed. Her response was that he was her husband—she had to love him. Asha remained because of what being a wife meant to her within her specific cultural context.

This story raised several questions in my mind. How had Asha come to see life as she did? How had she arrived at her understandings of love, relationships, and sex? How was her husband able to blame her for a positive status after all his years of abuse and abandonment? How was her experience similar to, or different from, that of other women living with the virus? People of influence including Stephen Lewis, Stephanie Nolen, Joseph Kortarba, Dr. Paul Farmer, and Bono have been speaking, writing, teaching, and singing about AIDS as the world's largest problem for years. Staring into Asha's eyes that day, I too came to believe in the immensity of the problem. Asha's story, and others like it, inspired me to pursue this line of inquiry. Since women are disproportionately affected by the virus, I felt it was worth studying their experiences, especially since women are the mothers and primary caregivers in SSA countries.

**My experience.** These experiences, and others since that time, have influenced how I have related topics within the relevant literature surrounding the disease to the lived experiences of the women I interviewed. My understanding of their experiences has also been influenced by my exposure to how women live with HIV. As a qualitative researcher my own thoughts, feelings, experiences, gender, position within a middle socio-economic status, tertiary level of education, white privilege, and Canadian origin

are embedded in my research practices and chosen methodology. My identity and the experiences I have had are central to how I have approached this study and, in turn, interacted with the women who took part.

Many studies focus on the concept of a researcher's white privilege and how this privilege increases the difficulty of conducting research within a culturally or racially different community (Chávez, 2005; Eide & Allen, 2005; Karnieli-Miller, Strier, & Pessach, 2009; Wildman, 2005). However, I found that my status as a white woman allowed me to reach a common ground of acceptance with the women I studied regarding our differences (Lincoln & Guba, 1985; Kauffman, 1994; Williams, 1974).

Authors such as Corbin Dwyer and Buckle (2008) and Alder and Alder (1987) report that being an insider—having a familiarity with the research setting, a familiarity with the participants, or shared experiences with the participants—positions the researcher favorably in relation to the participants in terms of willingness to share and understand information. However, due to the sensitive nature of my research and the fears that surround having an HIV-positive status, I found that being an outsider was, at times, beneficial. My outsider status as a white Canadian woman placed me in a position where the women were willing to share their experiences and form a bond of trust with me, knowing that I would return to Canada one day. If I were a member of the women's communities, they might not have been willing to share their ideas about sex so openly because it is a taboo subject. But my appearance, the standard of living to which I was accustomed, and my ability to financially afford education, training, and travel placed me on the extreme outside margin of their communities, separate from their cultural norms and taboos. Factors aside from insider or outsider status also influenced the sharing

relationship that developed between myself and the women. Corbin Dwyer and Buckle (2008, p. 59) say, “The core ingredient is not the insider or outsider status, but an ability to be open, authentic, honest, deeply interested in the experience of one’s research participants, and committed to accurately and adequately representing their experience.”

I was, as these authors suggest a researcher should be, fully devoted to giving the women a space to share and project their own voice about their experiences of living with and understanding HIV.

Fay’s (1996) reasons for why being an outsider can be beneficial in the research process further help to explain how occupying this position worked for me. I found the distance I needed to acknowledge and appreciate each woman’s unique experience by not sharing the same experiences such as educational background, family structure, and social class. In addition, I did not belong to a culture collective by nature and I did not live with a chronic illness. Not growing up within the same contexts allowed me to listen to the complexities each woman conveyed without having lived them. Thus, the lack of emotional entanglement that shared experiences create might have allowed me to more accurately identify each individual’s unique characteristics, to see each of her experiences as a whole, and recognize meaning that could have otherwise been lost. Distinguishing these layers of experience and meaning enabled me to objectively identify the ideas and influences that shaped the women’s perceptions of HIV. This is in contrast to the barriers the women might have built or the restraints they might have exercised in discussing certain aspects of their experiences with an insider researcher due to fears of making themselves vulnerable. This vulnerability could result from an emotional response elicited while sharing or an insider’s judgments. Though it might seem risky to open up

about a stigmatized condition like HIV to an outsider, sharing personal stories with a member of the host community could be far more risky due to the increased likelihood of interaction between the researcher and other community members. If confidentiality were broken in the case of an inside researcher, consequences would be much more likely and more dire. I therefore believe that my outsider status allowed the women to break through cultural taboos and barriers of speaking about sex and HIV to speak more openly with me.

Nevertheless, this common ground was not reached without acknowledgement of our differences and my recognizing cultural humility. Cultural humility is the idea that researchers, no matter how much they educate themselves or develop close relationships with persons of a different culture, can never fully break down cultural barriers and differences to reach a place of pure insight (Tervalon & Murray-Garcia, 1998). Before my second trip to the African continent, I subscribed to journals containing only African studies and purchased entire sections at the bookstore that focused on different tribal cultures, the education and political systems of East African countries, policy formation, philanthropic programming, and personal accounts of being infected or affected by HIV or AIDS. I also listened in on webinars and attended AIDS conferences at different institutions across Canada. Despite these efforts, I was never fully able to relate to the women in my study, in part because I do not have immediate personal embodied experience of chronic illness.

I also have a different educational background from the women I studied. While I had completed more than four years of post-secondary education at the time of data collection, only two of the eight women I studied had begun their tertiary education and

only one was still studying. The other six had varying levels of secondary school education between standard six and eight (corresponding to ages 11-13). Growing up in Canada, I have always had the ability to question information I learned both at home and in school without having to worry about physical, emotional, or social ramifications. This questioning and eagerness to engage in critical debate and communicate one's feelings is welcomed and often encouraged in my culture. I have always felt comfortable sharing my thoughts and feelings or posing questions when I have a desire to develop deeper understandings. In contrast, the women I studied did not always have this opportunity because issues of sexuality and disease are not openly discussed in Kenyan culture. Therefore, I often had to reassure the women that they are the experts on their own knowledge, and that I was extremely interested in learning about their personal experiences. Relationships of power between the researcher and the researched often facilitate perceptions of the researcher as the expert (Elwood & Martin, 2000). At our first meeting, I communicated to the women I was there to learn their stories and that I did not consider myself an expert.

The interviews required a great deal of trust on behalf of the participants as they were sharing personal stories that were very sensitive in nature. While it was my goal to facilitate an open sharing environment free of power imbalances that might impose filters on how the women chose to share their stories, I could not guarantee that they freely told these stories. The differences in educational background, economic status, culture, religion, and familial context—in that I am not a mother or married—may have changed how they chose to discuss their experiences. The way I framed questions to inquire deeper into their stories may also have altered their narratives. The fact that I do not have

a chronic illness also meant that a truly reciprocal researcher/participant sharing relationship was not realistic. Instead, I encouraged the women to feel comfortable and as the research progressed, where possible and ethically appropriate, I worked to engage the women further to make sure I was portraying their stories as they had projected them. Despite these efforts, it is impossible to know for certain that the women did not construct their stories by sharing only the information they thought I wanted to hear. It is possible that part of why the women chose to share their stories with me was because of the position of power I held. I did not ask about this, and had I done so, the research process might have been different. While I made every effort to convey that this was not the case, and that they were the experts on their own experience, it is still possible that some of the women saw my position as “better than” their positions. This assumption may have influenced the narratives.

### **Objectives and Research Questions**

The purpose of this study was to uncover how women living with HIV in Mombasa come to understand HIV and AIDS, and how this understanding may have informed and continue to inform their sexual health practices as well as the management of the virus. In addition, I looked for potential links between different social factors for how perceptions of HIV and AIDS are constructed that might explain women’s particular understandings of HIV-related knowledge that significantly affect their burden of disease.

I met the objectives of this study by exploring my study’s primary research question: what are the experiences of eight young women living with HIV in Mombasa, Kenya? I used the following secondary research questions to focus my interview guide and to help me answer the primary research question:

- (1) How have eight women with HIV living in Mombasa, Kenya, adopted particular perceptions of HIV and AIDS in their lives and communities?
- (2) How have these women's social relationships with family, community, and institutional members contributed to their knowledge about AIDS-related information such as prevention, treatment, and the ability to live with the virus?
- (3) Does stigma impact discourses that influence how these women form their perceptions of HIV and AIDS?
- (4) How have influences from different social environments interacted with each other throughout the process of accepting their new health status to shape these women's attitudes about moving forward with an HIV-positive status?

It is my hope that the answers to these the four research questions will inform understandings of women's individual experiences living with and learning about HIV and AIDS. In addition, I hope the stories of the women in this study can serve as an example of one valid way to begin incorporating individual ways of knowing disease into future AIDS education for homes and communities.

### **Overview of Thesis**

Chapter One has provided an overview of where women in Kenya are situated within the AIDS pandemic. I explained the theory of social constructionism, which is the lens I have employed throughout the course of this research to better understand the interacting social influences that have affected how these women negotiate ideas about

HIV or AIDS and management of the virus. I presented statistics on HIV prevalence along with a personal account of my experience with the topic of AIDS to provide a foundation of understanding for why this research is important.

The second chapter provides a review of literature in the area of health knowledge and how understandings of health knowledge may affect overall well-being. I discuss the social constructions that inform what people in countries throughout the world, with a special focus on Kenya, believe and understand about HIV and AIDS. I then explore existing power relationships surrounding the pandemic that help or hinder a woman's ability to understand and effectively use health knowledge. I give a brief overview of the educational programs put in place by governments around the world with special emphasis on Kenya. In addition, I highlight the prevention strategies promoted within these educational initiatives. I finally outline the messages that those enrolled in the educational institutions and programs receive.

Chapter Three outlines my methodological approaches and the methods I employed in the present study. This chapter gives a brief description of the women and how they were recruited. I provide details about the site where the research took place and a specific timeline to illustrate the research process I followed. In addition, I cover how I analyzed the data, the limitations and challenges to this study, and the ethical issues associated with this study.

Chapter Four is a compilation of the narratives of each woman who took part in my study and the findings divided by emerging themes from the data. In the first section of this chapter, I aim to profile the women and to illuminate their life circumstances. Using quotations, recalling tones and body language, and incorporating photographs with



their captions and the women's free writing, I provide descriptions of the eight women's experiences with HIV. The women's accounts reveal how they have come to know and understand the disease, their agency as women in the pandemic, and how they self-identify as HIV-positive women. Further, I describe their hopes for the future in terms of living a full life with the virus and enabling greater prevention for others.

In Chapter Five I also present an analysis of the data. I identify three key themes and describe them in terms of disempowerment, empowerment, identity, and underlying currents of stigma. Each theme reflects how the women have negotiated their HIV-positive status and in turn the identities the women have created, adopted, or adapted for themselves.

In Chapter Six, I use relevant literature to help explain the patterns that emerged from my analysis of the women's experiences. I also discuss limitations to the study. I make recommendations to improve similar studies in the future, enabling more holistic approaches to understanding HIV/AIDS. I recommend that future AIDS-related research involve participants, their families, and communities, as well as members of government and other top-level influences. Based on the results of the study, I state that a societal change needs to begin to take shape around mistreatment of women and the way men and women are educated about their sexual health and agency. This will hopefully encourage the creation of meaningful action research that may facilitate changes in how HIV/AIDS is understood in communities that are vulnerable to infection.

## **Chapter 2**

### **Review of Literature**

#### **Introduction**

My literature review outlines previous research on what is known about HIV infections and the diagnosis of AIDS. It focuses on HIV and AIDS related knowledge, education, and relationships of power as they affect women's access to knowledge, treatment, and support and their experiences related to the disease. Additionally, it provides a foundation for comprehending how women's understandings of HIV/AIDS, particularly in SSA, are influenced by both external and internal factors ranging from the social environment to personal thoughts and feelings about the disease. My literature review shows that HIV and AIDS has been a subject of research across a wide range of disciplines including sociology, anthropology, humanities, psychology, educational studies, family planning, political science, social work, cultural studies, nursing, medicine, biology, public health, and women's studies. Researchers have used quantitative, qualitative, and/or mixed designs to examine the complex issues surrounding HIV and AIDS.

I chose to focus the bulk of my literature search on topics related to the theory of social constructionism—the idea that most of what we understand about reality is socially shaped. Based on this theory, I focused on social factors that have previously impacted how HIV, AIDS, and PLWHA have been perceived. I used this theory to gain further insight into how the HIV-positive women I studied in Mombasa constructed their experience with HIV and learning about the disease (Berger & Luckmann, 1991). The key search terms I used were “HIV/AIDS,” “knowledge sources,” “Kenya,” “HIV-

positive women,” “social construction of health,” “identity,” “culture & HIV,” “education,” “sexual behavior,” “SSA,” “stigma,” “deviance,” “identity construction,” “attitudes,” “beliefs,” “health behaviors,” and “prevention programming.”

First, I address the social construction of health and understandings ideas related to it. I then unpack the concept of stigma, its types as used in this study, and its effects. The concept of stigma is present throughout each section of this literature review. Next, I explore how knowledge about HIV/AIDS is socially constructed. I searched for and found many articles concerned with how understanding knowledge about HIV/AIDS impacts a woman’s quality of life. Additionally, I sought literature focused on women’s locations, or lack thereof, within the pandemic, as well as how the female body has been portrayed throughout the history of the disease. This line of inquiry included lack of female agency and patriarchal power relationships, both of which may inform how women develop ideas about HIV/AIDS. Finally, I review research related to the accessibility of health knowledge and the programs that have been implemented to encourage access, support, or education. Articles concerned with cultural beliefs and attitudes, stigma and discrimination, and health behaviors as they relate to knowledge and experience proved particularly useful in my research.

### **The Social Construction of Health Knowledge Perceptions and Identity**

The social construction of health denotes the ways in which the definition of health differs between societies. The meaning of “health” is constructed through a variety of interacting influences including race, gender, standard of living, ethnicity, religion, education, mortality and morbidity statistics, as well as class (Sharf & Vanderford, 2003).

As disease is socially constructed, ideas about disease are informed by the beliefs of the dominant society in which it exists. The surrounding stigma associated with illness in general, usually informed by misconceptions about people living with disease, can affect the way a disease is managed. Some forms of illness show very few, if any, physical signs, which helps to mask the fact that a person is infected. Some signs of illness can also be hidden or treated (Brown, 1995). Because many diseases, such as HIV/AIDS, are associated with a socially understood and constructed stigma, becoming infected and learning of one's positive status can result in an individual hiding from society because they do not conform to the social understanding of normalcy (uninfected). A high rate of community and social stigma almost always leaves a diseased individual with no option for disclosure, due to the expected reaction of surrounding peers and groups within the community (Brown, 1995). The level of associated stigma a person with a disease experiences greatly influences how that person understands disease and constructs their identity as a person with that disease (Walker & Millen, 2003). I will unpack the concept of stigma and its formal definition throughout this literature review.

**Women's ways of knowing and identity construction.** Belenky, Clinchy, Goldberger, and Tarule (1986) offer a way to understand how gender influences how we know and what we know. Belenky et al. (1986) presented five epistemological angles for how women come to know: 1) silence, 2) received knowledge, 3) subjective knowledge, 4) procedural knowledge, 5) and constructed knowledge.

*Silence* represents a way of knowing without having the opportunity or capacity to use one's own voice (Ashton-Jones, Thomas, & Belenky, 1990). *Received knowledge* is a

way of knowing through receiving ideas and taking them to be valid, then subsequently repeating them (Ashton-Jones et al., 1990). *Subjective knowledge* is based on the idea that a person comes to know through evaluating their personal experiences, thoughts, and feelings and the information they receive from others. The person then combines these factors to subjectively know an idea or experience (Ashton-Jones et al., 1990).

*Procedural knowledge* is understanding information as being valid from multiple perspectives, but also as being objective and formed through rational conclusions (Belenky et al., 1986). The final way in which a woman comes to know, as defined by Belenky's et al., (1986), is *constructed knowledge*. In this way of knowing, the person understands that they have responsibility for how their knowledge is constructed. These constructions are based on received ideas, subjective experiences, and a person's ability to validate knowledge by incorporating or rejecting existing ideas (Ashton-Jones et al., 1990). Examining ways of knowing from women's perspectives for a topic such as HIV/AIDS is important. It allows the researcher to place emphasis on examining a range of experiences that researchers have previously excluded (Ashton-Jones et al., 1990).

Taking Belenky's et al., (1986) ways of knowing into account, I use the phrase "ways of knowing" throughout this thesis to denote how women come to know HIV/AIDS (i.e., culturally, socially, individually) and how these understanding shape identity formation.

Identity theory looks at how identities are constructed (Kraus, 2006). How identities are constructed reflects the dynamic nature of socially accepted roles and beliefs (Wagner, 1994). Therefore, identity development is continuous and flexible in nature. Currently, identity goes beyond releasing and constructing the individual. Identity

actually involves reframing and rearranging one's selves, through constantly analyzing and re-negotiating how each is connected (Kraus, 2006).

Identity is not something inherently possessed by an individual without the influence of difference, perceived and actual, between the individual and others (Kraus, 2006). Identities are readable, socially embedded, and processed in self-stories through which they are expressed. Effective understanding of identity requires analyzing processes (how stories are told) and relationships, which develop between both the listener and the teller to understand how identity is constructed. The listener and the teller are crucial elements in self-stories, and thus the formation of identity, and their role cannot be assumed (Kraus, 2006).

**Effects on my research practice.** The variables that define how health is socially constructed are applicable to this study, as some will be used to explore how the eight women in this study came to construct their perceptions of health and disease surrounding what it means to be HIV-positive. *Ways of Knowing* from Belenky et al. (1986) is also relevant to this research study as its framework of how women come to know will be important when highlighting how the women I studied construct their perceptions of living with HIV, and in turn, negotiate their self-identities.

### **Stigma and Disease**

Goffman defines stigma as an “attribute that is deeply discrediting” that reduces the individual “from a whole and usual person to a tainted, discounted one” (1963, p. 3). This discrediting of the individual through the process of stigmatization produces a spoiled identity (Goffman, 1963). A person usually becomes subject to stigmatization when their behavior is seen as deviant or their membership in a certain group classifies

them as deviant (Goode, 2008; Rohleder & Gibson, 2006). Deviance is created when the behaviors or conditions of a person fall outside what is considered the societal norm, and are thus condemned by society. The behavior, condition, or person may not be bad or harmful, but deviance is socially constructed and so can be applied to something that is not necessarily a bad thing (Erikson, 1961).

From the constructivist perspective, deviance is a concept that may change according to time, place, and the people involved (Henry, 2009). In addition to attaching to deviance, stigma may also occur due to ignorance (Deacon, Stephney, & Prosalendis, 2005). This means that stigma around disease is not always enacted with the intention to police or reinforce normality, but may also occur when there is a general lack of knowledge, understanding, or exposure to disease (Deacon et al., 2005). Such a lack leads to fear of transmission through casual contact, fear of what will occur if one contracts HIV/AIDS, and fear of infecting others. Deacon et al. (2005) note that research studies on the content of stigmatizing beliefs are limited. They give two reasons for this. Either social beliefs are seen as contradictory to medical fact or individual beliefs are viewed as perpetuations of ideas that already create social divisions. Regardless of the source of stigma, Sandelowski, Lambe, and Barroso (2004) noted in their metasynthesis of qualitative studies focused on the effects of HIV-related stigma that women's experiences of living with HIV were almost always synonymous with stigmatization.

Fears associated with HIV/AIDS, regardless of whether the fearful group intends to stigmatize, can lead to two types of stigma: perceived and enacted. Perceived stigma is the fear of judgment, segregation, or disfavoring by others (Bogart et al., 2008; Gilbert & Walker, 2010; Scrambler, 1998). Enacted stigma refers to actual inferior treatment of one

person by another or a group of others. This can involve moral judgments that discredit one's character, exclude, or isolate and may take shape as verbal or physical abuse (Jacoby, 1994).

These effects described as enacted stigma most often result from stigma that is generated by fear (Lekas, Siegel, & Schrimshaw, 2006; Malcolm et al., 1998; Venable, Carey, Blair, & Littlewood, 2006; Zhou, 2008). What generates this fear? AIDS is a disease most commonly linked with sex. Sexual acts are often a taboo discussion topic associated with deviance and degradation. Individuals infected with the virus who experience enacted stigma may internalize shame or self-stigmatize because of the disgrace associated with acquiring a sexual disease (Mawadaza, 2004; Campbell, Nair, & Maimane, 2007). Assumptions about sexual diseases also serve to "other" individuals—to label those perceived not to fit societal norms as different (Grove & Zwi, 2006). Marginalization, disempowerment, and social exclusion can occur because of othering. Grove and Zwi (2006) suggest that the act of othering reinforces the normality of the instigator, creating a dichotomy of "us" (healthy, not diseased) and "them" (diseased) (p. 1933).

Stigma has severe detrimental effects on the prevalence, understanding, and management of health conditions. The most common reason for stigmatization of HIV-positive individuals by those who are negative or unaware of their status is the popular misconception that infected persons necessarily engage in bad behaviors (Lawless et al, 1996). These "bad" behaviors usually include sex work, unfaithfulness to one's partner, drug use, or other deviant behaviors that are commonly associated with sex. Stigma that marks PLWHA as deviant members of society accompanies assumptions of moral



uncleanliness and/or lack of education, and acts as a form of separation that creates an othering of PLWHA. Stigma can decrease an individual's agency and power while othering the individual relative to their social group (Deacon et al., 2005). Stigma has also served to intensify the biological effects of HIV infection and in turn the burden of disease (Deacon et al., 2005). Stigma can make individuals hopeless about their future. Inability to envision a future living with the virus breeds misinformation, and thus, stigma, about HIV as a death sentence or killer virus before someone even reaches the later stages of AIDS (Kalipeni, Flynn, & Pope, 2009).

Given my future goal of designing suitable interventions that work alongside the needs of society and the different cultures existing within it, I deemed it important to incorporate questions about how the women in this study understand and conceptualize the HIV/AIDS in their lives and communities. Deacon et al. (2005) found that, with the exception of some research conducted in South Africa, few studies actually examine stigma in terms of what constitutes beliefs about HIV/AIDS and how people arrive at these ideas. Rakotonanahary, Rafransoa, and Bensaid (2002) noted that in order to develop culturally sensitive HIV/AIDS interventions it is necessary to take into consideration how beliefs about the disease are locally constructed. This is important because definitions of the other vary from place to place, as do notions about disease, age, sex, sexuality, gender, the course of the epidemic, political environment, extent of medical knowledge, and standards of education (Alonzo & Reynolds, 1995; Brashers, Neidig, Reynolds, & Haas, 1998; Deacon et al., 2005). Variation in factors that affect the construction of beliefs surrounding HIV/AIDS determines the how powerful resulting

stigma will be in a given locality. How stigmatized people respond to stigma also plays a key role in how effective it is (Deacon et al., 2005).

**Effects on my research practice.** The preceding section provides a foundation for how I focused the interview questions to explore how each participant experienced stigmatization in relation to her HIV-positive diagnosis.

### **Increased Health Knowledge Decreases Health Risks**

The quality of life for a country's population can be measured by the extent of health knowledge—also known as health literacy—of its members. Researchers regard health literacy as a key determinant of a country's national success (Lynn & Vanhanen, 2002, 2006; Jones & Schneider, 2006; Rindermann & Meisenberg, 2009). Although researchers have examined HIV/AIDS through many different disciplinary lenses, past research has placed greater emphasis on the level of knowledge individuals possess about the disease than on how they come to understand these ideas. In addition, studies tend to be mixed-gender and predominantly use quantitative measures to assess knowledge, attitudes, and behaviors associated with HIV/AIDS. Research focusing on Kenyan women's experiences living with the virus and how they arrive at their understandings of the disease is limited.

Although some studies have indicated being knowledgeable about AIDS-related information is not necessarily an indicator, in the absence of other factors, that an individual will engage in safer behaviors such as using birth control and getting tested regularly, health literacy has been noted as a minimum requirement for change to occur (Onah, Mbah, Chukwuka, & Ikeme, 2004; Sallar, 2009). Healthy lifestyle behaviors have been positively associated with the acquisition of health knowledge, indicating that

education can help individuals to understand the connection between health behaviors (e.g., use of a condom, exercise) and health outcomes (e.g., contracting HIV) (Kenkel, 1991). Conversely, when understandings of risk factors for HIV/AIDS are minimal, individuals are less likely to employ safer sexual and lifestyle practices. Increasing health knowledge thus may reduce sexual behavior consequences and, as a result, has the potential to decrease the rate of HIV infection (Sallar, 2009).

Karama and colleagues (2006) determined that in order to provide sufficient HIV/AIDS education, it is important to assess recipients' initial level of knowledge as well as attitudes, behaviors, and practices employed to manage sexually transmitted infections. The researchers distributed self-administered questionnaires to 250 participants (134 males and 116 females) between the ages of 15 and 49 living in a rural community north of Mombasa. Their results indicated that approximately 98% of participants felt that maintaining good health was the most important aspect of life. In looking at the results by sex, the survey found that 91.4% of the females agreed that good sexual health was a matter of personal responsibility, while 88.1% of the males indicated the same. The researchers recommended assessing a person's knowledge of AIDS-related information and her or his understanding of that knowledge as a first step in developing an AIDS awareness program that can successfully increase health knowledge and decrease health risks.

The inability to understand basic health information is positively associated with increases in health risk (Burgoyne & Drummond, 2008; Kalichman et al., 2000).

Kalichman and colleagues (2000) examined the effect that level of general health literacy has on knowledge and understandings about HIV/AIDS. They found that individuals'

ability to understand prevention strategies, illness, treatment, and their own level of health is impeded by having deficient general health knowledge. The 228 participants in this study were adult men and women living with HIV or AIDS recruited from AIDS service organizations and HIV clinics in the United States. They were given the Test of Functional Health Literacy for Adults (TOFHLA), which is designed to test a patient's health literacy and their ability to apply what they know. In addition, researchers tested participants on their knowledge and understanding of their health status, their opinions of primary care givers, and their views of anti-HIV treatments. The test results indicated that individuals with lower health literacy are less likely to understand the meanings of health information. This finding relates directly to the ideas and beliefs about HIV that form when information about the virus is misunderstood. Lack of general health literacy leads to misunderstandings about HIV transmission and how it is prevented, along with misconceptions of risk and ideas about the disease, even when someone tries to communicate accurate HIV-related information to an individual with low health literacy (Kalichman et al., 2002; Bogale et al., 2010). These findings suggest that it is important to explore why individuals come to misunderstand information about HIV/AIDS.

Earlier studies have focused on how education in the area of HIV/AIDS predicts sexual health behaviors, attitudes, and misconceptions towards PLWHA (Hess & McKinney, 2007; Noden, Gomes, & Ferreira, 2009; Sallar, 2009; Yoo, Lee, Kwon, Chung, & Kim, 2005). AIDS-centered health research has also addressed the influence that health promotion interventions have had on low-income communities or sub-groups of the population. Netto et al. (2010) assessed health-promotion intervention strategies in

minority ethnic communities from the United Kingdom, United States, and one in Norway, suffering from chronic illness. They found that understanding barriers to access and participation was necessary to creating successful education and support programs for individuals with chronic illness or disease (Netto, Bhopal, Lederle, Khatoon, & Jackson, 2010). They also explored social factors, such as the financial capacity of the individual, that can inhibit or enhance the benefits a person receives from these programs. These authors suggested that when dealing with persons vulnerable to infection, population health models—which work to identify barriers to access and quality of information—are most effective in enhancing the quality of service in prevention programs.

Creating an environment where open communication about HIV/AIDS is encouraged is an important step to ensuring that AIDS prevention strategies increase healthy behaviors. One such effort that has shown progress took place in Uganda (Greene et al., 2002). During the 1980s and 1990s, the U.S. Agency for International Development (USAID) conducted a longitudinal case study assessing declining rates of HIV/AIDS in Uganda. The authors found that dissemination of AIDS-related information through media networks including the television, mobile phones, radio, books, billboards, music, film, and pamphlets successfully contributed to declining rates of HIV infection (Greene et al., 2002). The South Africa LoveLife program similarly held campaigns that combined use of mass media with direct involvement with community members. These campaigns were successful in increasing knowledge about HIV/AIDS, which resulted in an assumed decreased risk of infection, fewer partners for those reached, and increased condom usage (LoveLife, 2008).

A study that measured efforts to enact voluntary testing and counseling for HIV in Kenya noted that mass media campaigns, which involved radio broadcasts and mobile testing initiatives that emphasized the importance of knowing one's HIV status, helped to increase the number of individuals between the ages of 15 and 39 years who opted to know their status (Marum, Taegtmeyer, & Chebet, 2006). Another successful intervention among 15–30 year-olds in Ghana stressed HIV prevention and was effective in increasing habitual condom usage as well as awareness of AIDS-related information. The message of this intervention was well received and played a role in decreasing the number of adolescents who become sexually active at an early age in Ghana (McCombie, Hornik, & Anarfi, 2002).

While the results of these studies show positive advances in raising awareness around HIV/AIDS, these campaigns only reach certain members of the population. Since countries of the Global South account for 73% of the 5.3 billion people reached globally via mobile phone subscriptions, and because these devices are increasingly affordable, communication with a greater portion of the population has become more realistic in recent years. However, this reach is disproportionate in low-income countries, with more men than women using mobile devices (Chib, Wilkin, Ling, Hoefman, & Van Biejma, 2012). Moreover, the men who do own mobile phones in SSA are more likely to generate a higher income and have more literacy than those who do not (Blumenstock & Eagle, 2010).

In Uganda, mobile efforts to raise awareness about HIV/AIDS were also implemented via a Dutch text message campaign called Text to Change. The test design for the Text to Change campaign in Uganda had limitations in that it only provided the

correct health information to those who participated and answered questions incorrectly. Those who answered correctly were not given any additional information to reiterate health messages. In addition, the structure of the campaign only increased the knowledge gap by using methods that were expensive for the target population, thereby limiting equal access. For example, those with a higher socioeconomic status, usually men, are more able to access and understand such information. They are often better-educated than women or poor men and have the means to own a mobile phone. In addition, men have greater influence over sexual decisions and use health information to their own benefit (Chib et al., 2012). The result measured in this study—a high degree of AIDS knowledge—may be biased, as only one mobile phone provider was used in an area with advanced literacy, making results more encouraging than they might have been if a more unbiased sampling method was employed. Other factors that limited the participation of some groups included the need for a base level of education to use the program and a lack of social interaction with the program. Only those who could use a mobile phone could participate, and questions sent by text message could not be questioned or clarified. Reinforcement of AIDS-related knowledge did not occur when the question was answered correctly, and those who did not participate did not receive any information about the disease at all (Chib et al., 2012).

These public education campaigns have the potential to increase the knowledge level of large segments of the population, but they need to take into consideration the social and environmental factors that limit some members' participation. These limitations may include lack of access to a mobile device and lack of willingness to participate when a device is acquired. Uncovering barriers to participation in these mass

media campaigns may influence the number of people in the population who can access information about HIV or AIDS via these methods, especially women and other persons who are marginalized by economic status or geographic location (Netto et al., 2010).

Greene et al. (2002) suggest that social groups that create an open sharing environment allow for increased distribution of information, including knowledge surrounding HIV/AIDS. This increase in health knowledge-sharing has been linked to declines in infection rates and improvement in safer health practices such as knowing one's status before engaging in sexual activity or using family planning methods (Greene et al., 2002; Rindermann & Meisenberg, 2009).

Mensch et al. (2001) investigated the link between education and sexual behaviors and found that schools that promote gender equality reduce the chances that young girls will engage in sex before marriage, which may in turn reduce the girls' chances of HIV exposure. This study also found that girls' ability to pay school fees was a factor in access to health-related information, meaning that girls who could pay for schooling had better chances of protecting themselves against risks of infection than those who had to drop out of school (Mensch et al., 2001).

Previous research studies, conducted in various parts of the world, have primarily focused on statistical data surrounding pre-infection behaviors, such as frequency of contraceptive adherence and knowledge of how to properly use contraceptives, as well as age and number of sexual partners (Ajayi, Marangu, Miller, & Paxman, 1991; Blanc & Way, 1998; Kiragu & Zabin, 1993; Mensch, Clark, Lloyd, & Erulkar, 2001). Other researchers have taken a qualitative approach to examine women's experiences in relation to their education about HIV/AIDS. These studies have focused on how self-perceived



and self-enacted stigma surrounding HIV/AIDS occurs, the context of that stigma, and misconceptions about transmission (Bond, Chase, & Aggleton, 2002). Few studies have qualitatively examined how individuals with HIV or AIDS develop the ideas they receive about health- and AIDS-related information (Anderson et al., 2008; East, Jackson, Peters, & O' Brien, 2010; Hackl, Somlai, Kelly, & Kalichman, 1997; Varas-Diaz, Toro-Alfonso, & Serrano-Garcia, 2005). PLWHA understanding of this information may influence quality of life in terms of how they manage the disease or take precautions to avoid transmission. This may determine future prevalence of HIV infection and how PLWHA manage the virus.

**Effects on my research practice.** Understanding the relationship between increased knowledge and decreased health risk was a central concept when framing the questions for my research. One of the goals of the current study is to evaluate the sources of women's knowledge of HIV/AIDS and how this understanding has either enhanced or inhibited their quality of life with the virus. The reviewed studies provided the foundation for designing questions about the origin of participants' health knowledge, how it was interpreted, and how it was used in the daily lives of the women I studied.

### **Socially Constructed Attitudes and Beliefs about HIV and AIDS**

This section provides an overview of existing social constructions that are commonly associated with HIV/AIDS, as well as with PLWHA. It focuses on the social constructedness of the world—or the idea that meanings are not predetermined but rather constructed through a variety of interactions. People do not simply see the world and understand it as it is; their understanding is influenced by the moment in time, the mood they attach to the situation, and their knowledge of what is being observed. How a person

understands an idea or situation may change over time with increased education or modifications to context (Goldstein, Pretorius, & Stuart, 2003). These different social constructions become the ways of knowing reality (Shotter, 1993).

Two concepts central to this research are the social construction of stigma and the social construction of deviance. Throughout history, many illnesses and diseases have shared a connection with notions of impurity, unworthiness, and guilt (Lawless et al., 1996). AIDS remains one of those conditions. Rohleder and Gibson (2006) describe HIV/AIDS as a disease that is socially constructed. The authors relate the disease to notions of “evil,” “sin,” “plague,” “punishment,” “crime,” “horror,” “otherness,” and the HIV-positive individual as the “villain” (pp. 2–3).

A substantial body of research involving attitudes of the uninfected towards PLWHA exists. Uninfected people arrive at their attitudes about HIV/AIDS in a number of ways. These include personal connections with an infected person, placement of blame and responsibility on those with HIV/AIDS, avoidance of contact with PLWHA, and support for certain policies related to AIDS (Herek & Capitanio, 1999).

Attitudes towards PLWHA and beliefs about the disease may increase the prevalence of HIV infection (Baxen & Breidlid, 2009; Zhou, 2008). These attitudes and beliefs are influenced by interactions between personal thoughts and feelings and occurrences in a person’s social or cultural environment (Baxen & Breidlid, 2009). In a study conducted in the Kisumu district of Western Kenya by Ouma & Kalipeni (2009), the authors examined social locations and the socio-cultural predictors of HIV infection for women in relation to health and prevention behaviors. They found that the networks

to which a woman belongs may increase her risk for contracting HIV (Kalipeni et al., 2009).

Rohleder and Gibson (2006) found that existing social and cultural attitudes perpetuated the internalized stigma felt by the HIV-positive women who participated in their research. The study used in-depth narrative interviews with ten women (aged 16–47) from a black township of Cape Town, South Africa, to understand how spoiled identities were conceptualized. The resulting narratives indicated that some women internalized negative ideas about HIV as part of their identities, while others resisted the stigma—transmitting the deviant identity to those who do not test, who are unaware of their status, or who are thought not be taking care of their health. In doing so, some of the HIV-positive women in this study reframed their HIV-positive identity as healthy because they were on antiretroviral treatment (Rohleder & Gibson, 2005).

PLWHA remain stigmatized to such an extreme extent because of the traditional links of the disease with sexual deviance, and they are thus considered part of a deviant or marginalized subgroup of society (De Souza, 2010; Vanable, Carey, Blair, & Littlewood, 2006; Yebei, Fortenberry, & Ayuka, 2008). Yebei and colleagues (2008) concluded that group affiliations can influence an individual's felt stigma. Specifically, their study examined the differences in felt HIV-related stigmas experienced by 103 individuals (both female and male) living in a rural community versus the stigmas experienced by those living in an urban area of Kenya. The results from this study indicate that individuals experience stigma differently according to their gender and geographic location.

Contracting HIV is seen as a violation of one's morality, an idea supported by the women in Van Hollen's (2010) study in India and in other studies across the globe (Smith et al., 2008; Sarna et al., 2009). Van Hollen (2010) concluded that women face greater stigmatization than men due to cultural norms and expectations that equate womanhood with morality. Morality plays a role in several African communities' conceptualizations of what it means to contract HIV. It is often seen as breaking God's law and is considered a punishment for those sins (Varas-Diaz et al., 2005). Additionally, it is believed that those of moral character should not discuss AIDS (Hess & McKinney, 2007). As a result, open discussions about sexual topics are still taboo in many African cultures. Because HIV is primarily associated with transmission via sexual intercourse, it is not always openly discussed, creating a lack of exposure to AIDS-related information. This is especially true in Kenya (Tang, 2008; Varas-Diaz et al., 2005). Limited opportunities to talk about the disease create inadequate access to health resources for information and treatment, as well as widespread stigmatization of those linked to the disease.

In both rural and urban Kenya, AIDS prevention, disclosure of status, social interaction, and counsel-seeking are impeded by socially constructed stigmas about HIV/AIDS (Yebei et al., 2008). These stigmas may affect the way others interact with PLWHA because of fears of being infected through casual contact with an HIV-positive person (Varas-Diaz et al., 2005). In a South India study, 30 women with a positive status were interviewed. Researchers found that a fear of being stigmatized deterred the majority of the women from searching for outside support. They also found that these

women took on the primary responsibility of caring for their family members living with HIV (Joseph & Bhatti, 2005).

In countries other than Kenya, similar socially constructed attitudes and beliefs about the disease have been documented. In a quantitative study conducted by Hess & McKinney (2007) in Mali, West Africa, the researchers explored the effect of fatalism on HIV preventive behaviors using a mixed-gender convenience sample of 84 participants. The researchers assessed fatalism, the belief that one is powerless in designing one's own fate, and its effects on what individuals believed to be true about the disease and on the prevalence of HIV/AIDS. Hess & McKinney (2007) noted that prevention efforts are often discarded if a person cannot recognize a link between behavior and consequence. Participants whose fatalism scores were high believed that HIV/AIDS was a result or consequence of a variety of actions. For example, 47.5% understood AIDS as a punishment from God, 13.6% of respondents believed the disease is a curse, and 54.4% believed only immoral people discuss AIDS openly. The key finding in this study was that the participants who were better educated felt less fatalistic about the disease and practiced more preventative behaviors. This is due in part to greater exposure and different ways of conceptualizing the disease (Hess & McKinney, 2007). These findings are important to the current study as I wanted to uncover whether HIV-positive women in Kenya would express the same fatalistic attitudes towards infection and whether exposure to AIDS-related education—and thus degree of prevention practiced—had played a role in how the women contracted HIV in the first place.

In an ethnographic study conducted by Carr and Grambling (2004), nine European-American women between the ages of 27 and 52 were interviewed about the

effect of stigma on their lives and their ability to promote, maintain, and enhance healthy behaviors. Similar to De Souza (2010), results from this study suggested that stigma impaired a woman's ability to assume her true identity. Results indicated that women had been advised by doctors to withhold their HIV-positive status in order to avoid rejection by family, friends, and members of the community. Additionally healthcare providers, though educated about the disease, were not always supportive of these women. Unsupportive family members expressed constant disappointment and aversion to family gatherings where food would be shared because they feared that casual exposure to HIV-positive women might cause infection. In addition, friendships were reported to have suffered due to negative perceptions about the "infected." While some women experienced support after disclosing their HIV-positive status, the majority experienced stigmatization (Carr & Grambling, 2004). These results suggest a need for further investigation into the quality of healthcare to which women have access and into how this care influences the identities women assume.

Tang (2008) conducted an extensive review of studies focused on the Chinese AIDS epidemic that dissected the gender-related, social, cultural, and economic challenges faced by women living with the HIV/AIDS. In her review of 33 studies, Tang reported that Chinese women with living with HIV are impacted by stigmatization in a variety of ways. In one study, over half of the respondents felt that HIV-positive women should not be allowed to return to their place of work for fear of infecting others. Other surveys in the review reported that nearly half of the participants believed HIV to be a punishment from God, that contracting HIV brought shame to an infected person's family, and that infected people lacked morals (Bollinger, Cooper-Arnold, & Stover,

2004; Wang & Burris, 1994). One survey of healthcare workers indicated that 30% of respondents preferred to not work with PLWHA (Tang, 2008).

In a separate Chinese study, Zhou (2008) found that judgment of those infected with HIV decreased societal will to provide support to those with a positive status. These judgments discouraged those with the disease from seeking healthcare and support because they feared being stigmatized and the resultant shaming of their families (Zhou, 2008). The existence of stigma towards PLWHA in Chinese culture may point to similar stigma in Kenyan society because ideas about the disease are similar across cultures (Hess & McKinney, 2007). Understanding what women believe about HIV/AIDS, their perception of stigma, and who or what influenced their understanding of the disease is important to enacting social change. The misrepresentations of, and fear about, the disease need to be addressed in order to locate women in the pandemic and create a safe environment free of stigma (Vanable et al., 2006).

Viewing incurable diseases as the result of a curse is an idea (or traditional belief) held by several African tribes (Hess & McKinney, 2007). Male respondents who participated in focus groups conducted by Bond et al. (2002) were divided on their beliefs about the association of witchcraft with HIV/AIDS. The elderly population commonly believed that a person fell ill due to being cursed (i.e., being bewitched). The younger generation, however, attributed the idea of being bewitched to a person's denial of his or her disease. For some, it was easier to be seen as bewitched than to admit to having the disease because admitting to being infected would automatically stigmatize the individual. The disease is preventable in reality but it is often seen as being self-imposed, whereas "being bewitched" is considered unpreventable and out of one's control.

Therefore, those who attribute their illness to bewitching are more readily accepted by the community and are seen as unaccountable for their condition (Bond et al., 2002).

Often, PLWHA who are deemed to be bewitched spend financial resources on traditional healers to reverse their curse. This can deplete their financial resources and provide a false sense of hope for recovery. Ultimately, traditional healing methods/approaches create obstacles to obtaining information and support. This in turn weakens prevention efforts and increases risk of infection (Bond et al., 2002). Traditional healers who embrace medical information to help support prevention initiatives surrounding HIV/AIDS are in a position to reach a large audience and provide valuable knowledge that may help combat the disease (Rankin & Wilson, 2000).

**Effects on my research practice.** The literature reviewed above provided a context in which to begin developing the current research study. The attitudes and cultural beliefs found in previous research studies were used to develop questions to discover if and how socially constructed ideas about HIV/AIDS affect the lives of the HIV-positive women I interviewed. Specifically, I assessed how each woman constructed her identity as an HIV-positive person through discussing existing individual as well as community attitudes and beliefs. I considered the women's trust in, or disregard for, socially constructed ideas about the disease important in how they viewed themselves as HIV-positive individuals. Understanding how the study participants arrive at their beliefs may help to clarify how AIDS-related information is being interpreted and used in Mombasa.

### **Existing Power Relationships Informing Women's Understandings of Health**

#### **Knowledge and Vulnerability to Infection**



Gender scholars have argued that the global HIV/AIDS epidemic in women is largely related to women's inability to challenge male supremacy with their inherent inferior position in the heterosexual sexual relationship, in the family, and in the society that makes women less able than men in exercising control over their bodies and lives. (Tang, 2008, p. 342)

Imbalances in power dynamics have been a significant contributing factor to the spread of the HIV virus. Gender inequality, poverty, and illness as a result of the disease are challenges that women face living in countries where the prevalence of HIV infection is extremely high. Tang's (2008) analysis demonstrates that there is an imbalanced power relationship between men and women in China and that this power differential can increase women's risk of contracting HIV. She suggests that these imbalances should be addressed by governments, community organizations, and healthcare providers. This would allow women to gain better access to health, knowledge, and financial resources that would enhance their ability to make better sexual health decisions. The Chinese patriarchal system (like the systems of countries influenced by the colonial era) dictates that men are allowed to take multiple sexual partners while a woman must remain faithful to a single man (Tang, 2008). This is also the cultural ideal in some communities in Kenya (Luke, 2003; Yebei et al., 2008).

Caldwell's (1999) SSA study found acceptance for males having concurrent sexual partners. Both male and female participants believed that polygamous societies are rational based on a belief that men biologically need sex more than women and thus

should not be limited to having sex with only one woman. Because of this need, men were considered to be capable of maintaining multiple relationships at the same time. Studies including Luke (2003) and Sarna et al. (2009) found similar ideas. Women are often deemed incapable of controlling sex within the marriage, and thus are subjected to their husbands' unsafe sexual activities (e.g., concurrent partners, sex without a condom) and are ill-equipped to guard themselves from contracting the virus (Zhou, 2008). This practice of males having multiple sexual partners is present in Kenya (Yebei et al., 2008). While men are rewarded socially for these sexual encounters, women who engage in the same practices are subjected to increased enacted stigma from community and family members as they are often viewed as infection agents. In addition, women are seen as tainting their identity when they engage in promiscuity. Not only does this produce a double standard, but it also increases the chance of HIV infection for women who believe they are in monogamous relationships.

Women who do take multiple sex partners risk bearing the identity of being dirty. In addition, if they become infected these women are seen as diverging from social prescriptions of the "good woman" and are viewed as deviant and damaged. Meanwhile, men with concurrent partners are deemed more masculine (Rohleder & Gibson, 2006). Tang (2009) suggests that women who are unable to question ideas about sexual health practices they receive from their male partners are less able to prevent infection and maintain personal health.

Women's restricted access to job opportunities also increases their dependency on men through limiting their ability to pay for contraception or live independently. Men assume the role of the primary provider who makes the decisions about when and whether

contraception will be used. In addition, the opportunities for both general and sexual education afforded to Chinese men are far greater than those afforded to Chinese women, who are forced to learn information from predominantly male family members (Tang, 2008). Existing power relationships are disadvantageous to women, limiting their exposure to the topic of AIDS and placing them at a greater risk for infection. This Chinese patriarchal power structure, which favors males, resembles that of Kenya (Abuya, Onsomu, Moore, & Piper, 2012; Drimie, 2003).

A number of cultural beliefs and attitudes inhibit women's ability to access accurate health information. Commonly misunderstood ideas about sexual health practices involving contraceptives in Kenya include religious opposition to condom use and beliefs that contraceptives can damage male genitals and produce fatal side effects for PLWHA (Sarna et al., 2009). Throughout SSA there is limited availability of contraceptives and limited willingness of women to use them due to the insinuations resulting from cultural factors and norms placed on females who use condoms (Peltzer, 2000). These include associations with promiscuity as well as the idea that using condoms inhibits the woman's natural role as a reproductive vessel. The ideas that women should desire children and comply with sex can also inhibit a woman's agency over her body and in her intimate relationships (Peltzer, 2000).

In addition, women who request that their sexual partners use condoms may be seen as untrusting. This may inhibit their ability to negotiate and may cause male partners to cut off financial support (Ulin, 1992; Longfield, Glick, Waithaka, & Berman, 2004). The decision to use a condom or not is thus often ultimately made by the male, who may perceive that condoms reduce pleasure (Longfield et al., 2004). This power

dynamic has also been found in other parts of the globe where women's powerlessness prohibits them from taking precautions to prevent infection from their male partners (Zhou, 2008).

In some cultures, older men frequently engage in relationships with younger women (Longfield et al., 2004). Researchers in a Kenyan qualitative study used eight female focus groups and 28 individual interviews with men to understand the motivations behind participating in cross-generational relationships and the implications these interactions have on HIV in Kenya. The women stated that they felt obligated to exchange sex with the men who purchased them gifts. The men also admitted to using the women for sex (Longfield et al., 2004). Men participating in cross-generational relationships were often celebrated for that accomplishment, and family members were also reported to promote relationships between a young woman and an older man. They set up meetings without explaining the details of the arrangement to the young woman so that the entire family could financially benefit (Longfield et al., 2004). These practices, again, diminish a woman's ability to make choices about her body, her sexual relationships, and her health.

In her human rights brief, Andreeff (2001) concluded that women's vulnerability to HIV infection is dependent on several ideas that are all inherently linked to traditional cultural practices. These practices can cultivate discriminatory attitudes and actions towards women. She argues that these beliefs can expose women to higher risk circumstances, thus making them more vulnerable to infection. The first factor is the lack of economic power that can cause a woman to be financially dependent on a man. Often women who rely on a spouse or sexual partner for economic stability remain in abusive

sexual relationships, are more likely to take part in sex work, and if from a low-income country are more likely to be forced into prostitution. All these elements increase the risk of infection.

The second factor Andreeff identifies is women's lack of political power (2001). Andreeff (2001) suggests that unequal representation of women in the political sphere across the globe makes it less likely that governments will enact policies that inform, empower, and enable women to exercise their agency in terms of sexual activity and reproductive health. A third factor is the longstanding cultural belief that men are the dominant figure in intimate relationships. The perception that women should remain sexually passive, allowing their partners to dominate and make decisions within the sexual relationship, is one version of this belief.

Another belief that prevails in many low-income countries is the virginity cleansing effect, whereby men believe they will purge themselves of infection through sexual intercourse with a virgin, leading to increased risk of infection as condoms are not used in such an encounter (Andreeff, 2001; Human Rights Watch, 2003). In early stages of the pandemic, especially in South Africa, this myth was thought to be a driving force in the spread of the virus. Traditional healers were reported to have told PLWHA to have sex with a virgin in order to be cured. This resulted in many instances of rape of young women and children (Leclerc-Madlala, 2002). This violence stripped many women of their ability to choose how their bodies were used and exposed them to infection. Finally, the last factor Andreeff identifies is a woman's desire to elevate her status through pregnancy. This may influence a woman's decision to avoid using protection in order to procreate (2001).

De Souza (2010) conducted an in-depth examination of culture and power influences over the experiences of two women living with HIV or AIDS in India. She collected narratives in an attempt to understand each woman's individual experience with the disease. One woman, whose husband had died of HIV shortly after they married, was blamed by her in-laws for transferring the virus, accused of being immoral, and subjected to beatings that eventually led to her expulsion from the household. After returning to her original family who, like she, was unaware of her HIV-positive status, the woman began to pursue a career with an NGO that involved training in reproductive health and sexual education. This newfound knowledge opened the woman's eyes to the possibility that she, like her deceased husband, might be HIV-positive. After testing, her fears were confirmed. Once she disclosed her status the woman faced rejection and isolation from her own family, despite the fact that they had chosen the husband for her. She was ordered to leave the house where she had grown up. When she refused to leave, declaring that it was her parents' duty to care for their children, her family isolated her by refraining from physical contact, refusing to share food, and having little to no verbal interaction with her for a period of four years.

This woman's narrative contains evidence of the complex interaction between knowledge and power. Had this woman known the symptoms of HIV infection, she might have understood her husband's condition and, in turn, been able to discover her status earlier. The domestic hierarchical structure that originated in the colonial era, elevating the eldest woman in a position of power over other females in the household when the male is absent, still remains to this day in India. It is clear that the woman had little agency both over the decision to marry her husband and over decisions within that

relationship, and ultimately her health was adversely affected. Until she was equipped with the knowledge to understand, prevent, and manage the HIV infection, this woman had to follow the orders of family members.

Although the participant had unknowingly contracted HIV from her husband, she was still forced to live with the stigma associated with the disease and was seen as immoral and deviant. The woman came to the realization that the cultural system in which she lived had influenced her experience with HIV (i.e., the cultural practice of getting married and automatically having to entrust your sexual health to your husband) and that access to knowledge might have prevented the spread of the virus. This narrative demonstrates the impact of gender inequality on some women's experiences living with HIV or AIDS, as well as how stigma develops through a social context and is not just something one individual inflicts upon another (De Souza, 2010).

**Effects on my research practice.** Understanding these power imbalances between women and men, women and their families, and women and institutions is critical to understanding how women come to interpret information about HIV/AIDS. Power relationships were important to investigate in the current study to determine whether power imbalances had a significant effect on how the women in this study accessed treatment, support, and information about the disease.

### **Provision of Healthcare, Health Education, and Its Effects on HIV/AIDS**

#### **Prevention: The Kenyan Case**

In areas of Africa where people are infected with HIV at an extremely high rate, the NGO sector as well as many private citizens are creating facilities to provide healthcare to disadvantaged members of the public (Ouma & Kalipeni, 2009). In Kenya,

religion-based organizations have offered to care for orphans of those affected by the pandemic and have established treatment clinics for the disease. At the same time, larger NGOs such as the Clinton Foundation have provided funding to create facilities that distribute the antiretroviral (ARV) drugs that can treat the disease by slowing the growth and reproduction of the HIV virus. These institutions also endorse campaigns to obtain supplies for labs and fight for policy negotiations to lower the cost of drugs that help treat those living with HIV. In addition, grassroots agreements such as AIDS Population and Health Integrated Assistance (APHIA), an initiative of USAID in partnership with other international aid organizations and 87 local partners, have been created to administer lab testing and conduct research in districts around Kenya (Ouma & Kalipeni, 2009). Thus the question arises, if such health provision facilities are so abundant then why are new cases of HIV occurring every day and why do women remain disproportionately affected? The answers to this question are many and complex.

Halley (2004) reported in her study of the socio-cultural and structural factors that affect PLWHA access to health care in Mombasa that health care in Kenya is implemented through various sources. These sources include, but are not limited to, hospitals, district clinics and dispensaries, and private clinics. Some research studies also provide healthcare through partnerships with NGOs. In Kenya there is one hospital per district and several clinics or dispensaries with varying technology. Limited places to access health care also means a limited number of people with skills and training in specific geographic areas. Ultimately, this means that whether a person receives adequate healthcare depends on their geographic location.



Halley (2004) quoted a Kenyan newspaper from July 1996, *The Daily Nation*, stating that eight kilometers is the minimum distance from 25% of households to a healthcare facility in Kenya. Since these facilities commonly refuse care due to low doctor-to-patient ratios, limited supplies, and lacking up-to-date technology for specific procedures, many people will travel directly to a district hospital for minor illnesses. This places more stress on the already-strained district hospitals and their staff, leaving emergency patients and those with more complicated conditions such as HIV infection or full blown AIDS to receive a lower quality of care than they might otherwise receive.

Others who suffer from a chronic or complex disease and live in high-poverty situations are often forced to attend the closest medical center, due to a lack of reliable transportation and communication systems in Kenya. Access to adequate care in hospitals is also dependent upon the financial resources of the patient. If a person cannot afford private clinical care or travel to the district hospital, he or she must use the local facilities. These clinics are not always equipped with current technology or professionals trained to handle specific diseases, and they may lack the resources to provide adequate treatment to the patient (Halley, 2004). When thinking about the AIDS pandemic, this inability to properly utilize the healthcare system perpetuates the provision of low-quality healthcare and, in turn, limits a person's ability to access factual information and advice about the disease.

Only a limited portion of the Kenyan population can access information from alternative sources such as NGOs, treatment clinics for specific target populations such as PLWHA, and university research projects. Halley (2004) concluded that since these sources of healthcare do not provide sufficient care to the entire population, policymakers

need to take into consideration socio-cultural factors that constrain some people and not others in terms of accessibility and knowledge about health. It is also essential that the Kenyan government increase its healthcare budget and remodel overall management of the Kenyan health system to serve all citizens equally (Halley, 2004).

Halley (2004) examined both direct costs (e.g., costs of drugs, doctor's bills, and transportation expenses) and opportunity costs (e.g., availability versus scarcity of all resources needed for adequate care, measured according to the value of those resources to a patient such as a person living with HIV or AIDS) in terms of the utilization of the Kenyan health care system. While Halley (2004) did not place a specific emphasis on women, her objectives aligned with the current study in terms of exploring the impact that socio-cultural barriers have on a person's experience with healthcare and health ideas in relation to HIV/AIDS. Her findings demonstrated that the interaction between socio-cultural factors (e.g., stigmatization, prior experiences with modern medicine, personal health beliefs) and structural barriers to health (e.g., doctor/patient ratio, understaffed and under-equipped clinics) helps to establish the context in which PLWHA in Mombasa choose and access healthcare. Her study provided the background from which I began exploring women's experiences living with HIV in Mombasa.

In addition to a substandard healthcare system, researchers have also recognized that low levels of education play a role in the lack of prevention of HIV infection (Tang, 2008). The primary school enrollment rate for females in Kenya was estimated to be 76% in 2007 (Joint United Nations Programme on HIV/AIDS & WHO, 2008). For most females in Kenya the extent of their education is the primary school certificate, which equips them with practical skills such as counting money and reading but does not

provide opportunities to learn about sex. Sexual health education is not a required school subject in Kenya, nor is it a subject on which students are examined. Both teachers and students consider it to be of little importance, which has detrimental effects on students' reproductive health, especially females' susceptibility to HIV (Mensch & Lloyd, 1998).

Mensch and Lloyd (1998) conducted a mixed methods study to investigate how the type of school environment in Kenya might impede an adolescent's knowledge development depending on gender. The researchers placed a special focus on the opportunities that the education system might restrict or create for girls. They found that schools perpetuate traditional gender roles while acting as a space where both AIDS-related education and sexual violence simultaneously occur (Mensch & Lloyd, 1998; Leach, 2008). In the early stages of the pandemic, lower enrollment rates as well as higher school dropout rates for females were common in low-income nations. The researchers perceived this to have resulted from social factors such as early marriages, girls' household labor, traditional roles of the female, early pregnancy, preference for sons, and poverty.

Lloyd and Mensch (2006) found that teachers anticipated a lower success rate for females, favored teaching males over females, and generally felt that those females who became pregnant during school should lose their privilege to an education. Additionally, they found that harassment of female students by male peers occurred and went undisciplined by the teachers. Lloyd and Mensch (2006) also reported that sexual relationships between female students and teachers occurred, including incidents of rape, without consequences for the teacher.

In her article assessing gender violence and schools in low-income countries, Leach (2008) makes reference to a study where both young boys and girls reported female students exchanging sexual favors with teachers for better grades, money, or privileged treatment in class. Since limited encouragement is given to females to continue studies after primary school in Kenya, females often submit to gendered stereotypes about women's lack of intelligence and assume the socially prescribed role of the dependent woman in the home. This reduces their exposure to health education opportunities and, in turn, increases their susceptibility to infection (Mensch & Lloyd, 1998). The contradictory space of prevention and abuse, as well as the power dynamic created between teachers and students in SSA, may create an unsafe learning environment where both girls and boys are misinformed about sexual ideas. Girls can become confused about their degree of agency, and ideas about the inherent right of those in power to exercise authority are continually perpetuated. These concurrent findings suggest that educational systems are environments of male dominance over the female and may promote female dependency on men for support.

In addition to schools, both government organizations and NGOs provide a space to access AIDS-related knowledge. Physical activity-based organizations, such as the Ministry of Education and Sports in Ghana, have publicly supported exercise as a way to establish promotion campaigns for health issues related to AIDS education, female empowerment, and gender equality, as well as sexual and reproductive health (Right to Play, 2008, p. 141). In many African countries, including Kenya, a physical activity-based NGO known as Right to Play has provided an external means of health education in addition to enabling a destruction of gender barriers, specifically those barriers faced by

women. Peer educators engage young women in discussions concerning health, education, and employment while attending football games and tournaments that Right to Play has set up. In addition to building social relationships through sport and physical activity, the organization provides a safe space where young women can freely learn about sexual and reproductive health through educational videos and dramas (Right to Play, 2008, p. 141). Equipping women with skills that will allow for negotiation of sexual practices, which helps to prevent HIV infection, may increase both women's and men's ability and willingness to seek testing and counseling for the HIV infection (Rankin & Wilson, 2000).

Other organizations that promote health and general education such as Young Women's Christian Association of Kenya (YWCA Kenya), ActionAid International, Africa Women and Child (AWC), and Centre for Rights, Education and Awareness (CREAW) meet the challenges of negative cultural beliefs and practices. Despite the efforts of these programs, educational programs offering AIDS-related information have remained largely unsuccessful in SSA where infection rates have not declined; stigmatization still occurs; and unavailability and inconsistency of health care, in addition to lack of support, is commonplace (Rohleder, Swartz, Kalichman, & Simbayi, 2009). Furthermore, despite it being considered one of the most extreme barriers to successful prevention and support programs, stigma is still one of the last items to be addressed in HIV/AIDS programming (Mahajan et al., 2008).

By establishing programs that include training peer educators, providing counseling, and producing educational materials among other initiatives, these organizations advocate for legal reforms and increased dissemination of educational

information that will help to combat deep-rooted ideas about topics that destabilize the rights of women and their subsequent understandings of HIV/AIDS (Joint United Nations Programme on HIV/AIDS, 2009).

**Effects on my research practice.** The literature reviewed in this section was valuable in structuring questions to discover how the women I studied adopt and think about health practices in terms of HIV/AIDS. The studies presented here formed a platform for understanding the ways in which healthcare and education systems, as well as external prevention programs, prepare women to engage in sexual activity. The education and healthcare experiences of the women in the current study could be measured against the aforementioned data to determine whether these systems and programs have helped or hindered their experiences in living with the virus.

### **Chapter Summary**

AIDS is a disease that can be examined from many angles. This literature review demonstrates the importance of understanding health knowledge and why it is important that women have greater access to sources of knowledge about HIV/AIDS, as well as subsequent understanding of that knowledge, to decrease their risk of infection. Participatory environments that allow women to feel comfortable with sharing and discussing information create spaces where learning can flourish. On the other hand, environments where people are stigmatized because of their disease may influence PLWHA to avoid seeking support or treatment and may thereby inhibit their quality of life with the disease.

How a woman understands the risks of HIV infection may be influenced by a variety of factors. These may include the social networks of which she is a member; the

cultural norms, beliefs, and attitudes to which she is exposed; and the specific practices or ways of thinking she has learned through the process of socialization. These ideas, depending on context, may generate stigma surrounding women living with the disease.

This literature review also explored how education systems and programs have used specific initiatives to combat the pandemic, as well as the positive and negative educational environments that foster conditions that enhance or inhibit learning. These studies have provided a contextual background for why there is a need for more knowledge of how women are educated about HIV/AIDS. Finally, the literature review demonstrated why the experience of women living with HIV or AIDS needs to be explored through a lens where cultural, organizational, interpersonal, and intrapersonal factors are taken into account.

## **Chapter 3**

### **Methodology**

#### **Introduction**

My study involved examining the subjective experiences of eight HIV-positive women through topic-associating narrative inquiry. This style of narrative “consists of a series of segments or episodes which are implicitly linked in highlighting some person or theme” (Michaels, 1986, p. 103). This qualitative approach allowed me to gain a more in-depth understanding of the women’s experiences. The following sections of this chapter aim to explain the background, appropriateness, inherent assumptions, and limitations associated with narrative inquiry as a methodology for designing my research of HIV-positive women in Mombasa. Photo-voice is also explored as the second methodological approach I employed to compliment narrative inquiry. I provide details of the recruitment process, the participants of the study, and the methods I used to collect the data (semi-structured interviews, photo-voice, field notes, and journal). I define these tools and make their value to the current research clear. Using these methods allowed for a closer examination of both the similarities and differences among a specific group of HIV-positive women and their relationships with the disease.

Following this explanation, I discuss how I analyzed the different forms of data and detail the four stages of analysis I used. I then describe the obstacles that may have narrowed the scope of my study. Finally, I make transparent the ethical considerations addressed before and throughout the duration of the study.



### **Narrative Inquiry as Methodology**

Narrative inquiry, a subtype of qualitative inquiry, is the methodology I chose for the current study. The definition of narrative research differs between studies and disciplines, and can vary depending on how the researcher chooses to use the approach (Lieblich, 1998). Narrative inquiry has been adopted as a methodology across all disciplines within the social sciences as well as medicine (Lieblich, 1998). Academic fields including community studies (Huber & Whelan, 2001), nursing (Barton, 2006), cross-cultural studies (Andrews, 2006), occupational therapy (Mattingly, 2006), anthropology (Bateson, 1994), and teacher education studies (Clandinin, Pushor, & Orr, 2007) among others have used narrative inquiry as a research methodology.

A number of scholars have defined narrative inquiry. Among those definitions, best suited for my research are Chase (2005), Bates (2004), and Clandinin and Connelly (2000). Chase (2005) explains what contemporary narrative studies entail:

Many contemporary narrative researchers approach *any* narrative as an *instance* of the possible relationships between a narrator's active construction of the self, on the one hand, and the social, cultural, and historical circumstances that enable and constrain the narrative, on the other. (p. 667)

His approach to narrative inquiry is well suited to my research when applied alongside the interpretive lens of social constructionism to discover women's understanding and experiences of living with HIV in Kenya. The instances described in any one narrative are not reflective of all possible ideas about the topic. Thus, researchers using narrative inquiry rarely make claims of generalizability as they do not attempt to exhaust all

potential stories that might exist in a certain context, but instead conduct a thorough inquiry into a small sample (Chase, 2005). Clandinin and Connelly (2000), researchers in the education field, offer an alternative definition that highlights the ability of the narrative to represent a space where dialogues are constantly created and re-created within the process of the interview:

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

As people use narratives to construct who they are and how they build understanding, I believe narrative inquiry is an appropriate method to examine women's understandings of, and lived experiences with, HIV.

Riessman (1987) noted that narratives can develop from conversations, photographs, and written texts such as letters or diaries. As well, she notes that not all narratives need follow the standard formula for early definitions of narratives, which involves a main character, catalytic incidents that make the character conduct certain actions, and a climax. Narrative, in the context of my research, is not simply my retelling of HIV-positive women's stories. Instead, the narratives that have arisen from the interview conversations, photographs, and accompanied written texts illustrate how the women have come to create the reality of their experiences and recreate these realities in

the research-sharing process. Topic-associating narratives—a particular typology of narrative—are a useful framework to understand how each narrative in my study was organized and discussed.

Bates (2004) describes topic-centered or topic-associating narrative as an analytical process “where past events which are referred to throughout the interview are linked thematically” (p. 21). Michaels (1986) distinguished a difference between topic-centered and topic-associating, as two styles of narrative. She extended the definition of topic-associating narratives further by describing them as narratives that develop in a non-linear structure around a single topic through a sequence of indistinctly connected experiences. Michaels (1981) noted that topic-associating narratives were characterized by recurrent temporal, place, and character shifts, without an apparent or clear connection between each part of the story. Nevertheless, Michaels (1986) argued that this style of narrative is thematically consistent.

While themes are not typically extracted from narrative data because it risks depersonalization of participant stories, I have based my analytic approach on topic-associating narratives as the structure of the interview questions in my study tended to produce associations around certain aspects of how a person experiences the disease. Thus, influencing parts of the experiences of living with HIV, the women chose to share. I used themes to link excerpts from the interviews and the women’s photo-journals with my interpretations and assumptions, co-constructing narratives about where women receive, interpret, and understand ideas about HIV/AIDS.

Narratives take into consideration the multiple positions or realities of individuals (Chase, 2005; Mitchell & Egudo, 2003). For example, the women in this study may

occupy two or more spaces at any time: “Non-Western woman,” “Kenyan,” “person with a chronic illness,” “woman with a low-socio economic status,” “Black woman,” “mother,” “sister,” or “partner,” among others. Clandinin and Huber (2010) discussed the relevance of multiple realities within narrative inquiry by stating “differences in views of reality, knowledge developed from an inquiry, the relationship between experience and context, and the relationship between researchers and participants all shape borders” (p. 14). Thus, all narratives are shaped by the interacting influences of context and the social location of the individual.

A second assumption inherent in narrative inquiry is that narratives can exist in many forms and are shaped by elements such as plot, themes, key events, or protagonist (Creswell, 2007). The third grounding assumption of narrative inquiry is that of chronology—creating a structure within individual stories. In doing so, researchers may abstract themes (Creswell, 2007). The fourth assumption shaping narrative inquiry as a methodology is the concept of transformation. Transformation is based around the idea of participants recalling random ideas—or having an epiphany—and these ideas being passed through a process of re-telling, sometimes changing the original context in which the story occurred (Clandinin & Huber, 2010).

**Theoretical underpinnings of narrative inquiry.** There are four key theoretical roots of narrative inquiry. At the heart of this methodology is the late 20<sup>th</sup> century postmodernism movement. Postmodernism questions the philosophical assumptions of logic and the existence of universal truths. This movement stressed a shift away from understanding ideas as general and universal and towards recognizing the importance of local and specific knowledge (Creswell, 2007). Inherent in the postmodernist movement

is the idea that the socially constructed realities of individuals differ significantly depending on time, context, and culture (Gonzalez, Biever, & Gardner, 1994).

Postmodernism is important to narrative inquiry because it introduced the practice of identifying one's subjectivities and being reflexive throughout the research process.

Social constructionism is the second theoretical underpinning and the key theory used to understand the reviewed literature and themes that emerged in my study. This theory values the idea that a person's reality is constructed through their social and cultural interactions, as described above. The third theoretical underpinning of narrative inquiry is constructivism, which posits that an individual's reality is of one's own creation. Constructivism states that one's reality is shaped by past experiences and thus is a form of pre-existing knowledge that attaches meanings to ideas or events (Etherington, 2004). The fourth and final key theoretical underpinning of narrative inquiry is feminism. Feminism places significance on multiple ways of knowing and strives to disable power relationships that create gender imbalances in society (Delmar, 2001).

The main purposes of narrative inquiry as a methodology are 1) to act as a frame of reference to represent and conduct research, 2) to seek to understand lived experiences of individuals or a small group, and 3) to tell the stories of marginalized persons (Creswell, 2007). A narrative approach is helpful in the process of learning how to enact social, organizational, and cultural change (Beech, 2000; Boje, 1991; Chase, 2005; Faber, 1998). In studying the subjective understandings of individuals, narratives help highlight the social representation processes of the individual including thoughts, feelings, and the time and space in which stories take place (Mitchell & Egudo, 2003). Thus by joining events, perceptions, and experiences, the storytellers (in this case, the women) are able to

use the narrative to explain what they experienced and the meanings associated with those experiences.

Narratives can be used to communicate unspoken knowledge (Ambrosini & Bowman, 2001; Linde, 1993). Narratives also leave open the possibility to confront uncertainty, indecision, the intricacy of the stories being told, and the dynamic capacity of an individual and the experiences they describe. Rosenwald and Ochsberg (1992) note that researchers, through observing how a person speaks and constructs their story, can analyze cultural and historical conditions that influence how the narrative is constructed. Through evaluating how the women told their stories, I was able to make inferences about how culturally or socially dependent their beliefs and attitudes about HIV/AIDS were.

In addition to providing insight into lived experiences, Creswell (2007) states that another benefit of using narrative inquiry is giving the interviewee—each of the eight women in the case of my research—a voice of her own. Chase (2005) suggests that thinking of the interviewee as a narrator, rather than as a knowledge source with the correct responses to a set of questions, enables the interviewee to find her voice and to construct her narrative as she wants it told. Thus, studies using a narrative inquiry methodology increase the researcher's ability to understand in-depth experiences of a small sample of larger populations, within certain contexts, that have previously been measured using objective procedures (Greene, 1994).

As with any methodology, narrative inquiry is not without its limitations. Traditional research tools attempt to quantify truth and reliability, assuming that a subjective reality is not reliable, and that there is an objective notion of truth. The reliability of data collected within a study using narrative inquiry is an issue that has been

raised by past authors (Gergen, 1985; Messick, 1987). However, while some view this as a limitation, others view it as an added layer. The Personal Narratives Group (1989), which uses feminist theory to discuss issues of truth, notes that people who participate in interviews construct their narratives through a variety of processes including lying, exaggeration, forgetfulness, exclusion, confusion, and misinterpretation or miscommunication. Therefore, the past is constructed not how it actually occurred, but how it was experienced by the individual. In this way, it is not always possible to seek accurate answers from the information presented in narratives. Instead, researchers are encouraged to frequently remind themselves how the narrative was constructed in its particular contexts. This enables researchers to engage with social locations outside of their own, and to rethink how they arrived at their own constructions of certain beliefs and attitudes. In addition, it allows researchers to recognize how their personal understandings influence the interpretation of results (Personal Narrative Group, 1989).

My research design used triangulation—the use of one or more methods to collect data—to increase the credibility of the findings by taking into account multiple standpoints of how the women understand HIV/AIDS (Jick, 1979). In this research, semi-structured interviews in conjunction with photo-journals created by the women were used to collect information that might reveal potential answers to the research questions. These methods and their implementation procedures are described in the succeeding sections. In addition, the contexts in which the women lived are described in a participant profile of each woman.

**Key concepts and terms related to narrative inquiry.** Narrative inquiry is a broad methodological approach that uses various tools and ideas for how researchers and

narrators interact. Three structural conditions shaping narrative inquiry are the concepts of sociality, temporality, and place. Following these, I also define how I have used the terms story/narrative, voice, and metaphor.

***Sociality.*** Xu and Liu (2009) referred to sociality in narrative inquiry as “both personal conditions, which indicate the feelings, attitudes, and moral dispositions of a person toward events, and social conditions, which include the context of administration, policy, and community” (p. 506). Sociality is important as it encourages the researcher to pay attention to both the personal and social aspects of the narrator’s story (Clandinin & Huber, 2010). Clandinin and Connelly (2006) note the existence of a second dimension of the sociality commonplace. This takes into account the relationship between researcher and narrator, incorporating how the researcher’s own thoughts, feelings, and emotions, as well as their own cultural or social contexts, influence the way in which the narrative is communicated.

***Temporality.*** “Events under study are in temporal transition” (Connelly & Clandinin, 2006, p. 479), thus experience occurs in and over time. This idea stems from Carr (1986), who indicates that the stories an individual tells are continually being reshaped and changed as new experiences occur with time. Focusing on the temporal nature of events, places, things, and people discussed by the narrator helps locate narratives in the past, present, and future. Narrative inquirers consider temporality to be central to understanding the setting, the things, and events being described within the narrative, as well as central to their own lives and those of their participants (Clandinin & Huber, 2010). Thinking narratively about the experiences of the women I studied in Kenya, I considered the social, cultural, personal, and organizational factors influencing



the environments in which their experiences with, and subsequent understandings of, HIV occurred. Attending to temporality, I assessed the particularities of the spaces in which each woman received knowledge such as their homes, schools, and communal environments. In addition, I attended to the women's relationships with HIV and how they constructed ideas about the disease using specific moral, emotional, and physical frames.

***Place.*** All events occur in some place. Place has been described by Connelly and Clandinin (2006) as “the specific concrete, physical and topological boundaries of place or sequences of places where the inquiry and events take place” (p. 480). The identities we embody are often specific to the context in which a story is told, and thus that identity can change as place changes (Silko, 1996). It is a critical concept to narrative inquiry as all stories start, develop, and end in a place (Connelly & Clandinin, 2006).

***Story/narrative.*** I use the term story in my research in reference to any account that attached significance to the past occurrences that have shaped the women's experiences living with HIV. I followed the ideas of Polkinghorne (1988), who asserted that stories serve to locate the experience within a specific context and situate the events in a temporal space. Stories can be taken to be true accounts, but can sometimes be unintentionally imagined or embellished (Polkinghorne, 1988). Throughout the study I have used the terms ‘story’, ‘stories’, ‘narrative’ and ‘narratives’ interchangeably when referring to the discourse women used to describe their experience. Each of the stories (or narratives) worked to sketch a grand narrative for each of the women's individual experiences living with and learning about HIV.

***Voice.*** Voice is the way in which individuals choose to express their thoughts, feelings, or emotions about an experience. Elements of voice include finding the right words, ability to speak for oneself, and the feeling of being heard by others (Connelly & Clandinin, 1990; Maple & Edwards, 2010). Connelly and Clandinin (1990) assert that it is difficult to distinguish an individual's voice and that this difficulty emerges when a person attempts to share her story, or communicate the significance of a particular event, to another person. In my research I use the term *voice* when referring to the voices of my participants and myself, as both are present in the co-construction of the narratives in chapter four.

***Metaphor.*** I used metaphor in this study during the analytic process of bracketing. This involved the recognition of my own biases and interpretations of the information conveyed by each woman. Throughout the analysis, I was cognizant of my personal prejudices but always tried to understand them in relation to what the women were saying and how they told their stories. I used bracketing to reveal these assumptions, in order to preserve the reality of what the women chose to share with me and not contaminate their stories (Maple & Edwards, 2010). Upon completion of the transcripts, I jotted down specific ideas, writing all relational concepts to map out definite themes emerging from the data. Anne Bell (2003) notes how important metaphors are to the everyday construction of stories:

Metaphors are not simply part of poetic, fanciful, or rhetorical language, but are also part of ordinary literal language and, fundamentally, part of the way we conceive of things and structure our everyday activities.

Metaphors are thus pervasive in everyday life, in thought and action as

well as in language, and because they are so pervasive, they are often taken literally as self-evident, direct descriptions of phenomena. (p. 98)

Maple and Edwards (2010) describe this process as follows: “Metaphors provide a mechanism to relate, compare, and make meaning of new knowledge with lived experiences” (p. 40). Thus, metaphors proved to be a valuable tool when retelling and situating the narratives around the photographs taken by the women.

### **Photo-Voice as Methodology**

A second methodological approach used in my study was photo-voice. Its primary uses are to inform policy and revolutionize our conceptions about everyday experience through images. The term photo-voice, originally “photo novella,” was first used by Wang and Burris (1994) in a study to enable rural women in a Chinese province to critically analyze, as a collective, the social factors that inhibited or enhanced their health status and to enact health/education policy. It was rooted in empowerment, education, feminist theory, and documentary photography (Wang & Burris, 1994). The camera provided an alternative lens to the verbal conversations of interviews and focus groups.

Photo-voice is modeled after Brazilian educator’s Paulo Freire’s (1970) “education for the critical consciousness” philosophy. In this theory, Freire (1970) posits that individuals should critically analyze the situation in which they are being educated with a focus on what they are being educated in, how they are being educated, and the motives behind that education. Becoming hyper-aware of how one exists in one’s environment involves resisting or advancing past predominant societal norms and beliefs. Arriving at this realization of where one is positioned in society (e.g., the person being

oppressed or the oppressor) was a process Freire termed “conscientization” (Freire, 2004, p. 66). This process encourages the individual to become an active participant in their daily experience through critical thinking and to play a role in taking constructive action to make changes in the world. He believed that people should be active evaluators of their social environment, making connections between individual problems, experiences, and the social contexts in which they occur (Freire, 1970). Photo-voice was built on the foundation of Freire’s desire to provide a tool in research for participants to immerse themselves more critically in their experiences. Wang and Burris (1994) described photo-voice as a valuable tool in stating: “Just as Freire developed word lists for literacy classes from the life experiences of his students, and avoided a vocabulary removed from their experience, photo novella’s curriculum is the women’s own portrayal of their lives and community” (p. 172).

Using photography, text, and discussion through combining photo-voice and narrative inquiry methodologies the women were empowered to use their own voice, providing a deeper insight into their experiences. It enabled the eight women to create artistic representations documenting their individual experiences with HIV as part of the research procedure.

### **Research Methods and Design**

I collected the data in this study over a period of four months beginning in late August 2011. This decision was based on a variety of factors including time to adjust to my new surroundings as well as time to develop relationships with the partner NGO and the women involved in my research. This was necessary as I am a Canadian, white, educated female researcher, placing me in an outside location in relation to the women in

my study. However, through the discursive nature of narrative inquiry I made every attempt at leveling power imbalances by constantly encouraging each woman to tell stories of how she understood HIV in her own way.

The recruitment process took approximately three weeks. This included a week before I arrived in country where the program officer of my partner NGO and two translators distributed information about my study, a week I spent introducing my study to groups around Mombasa, and a third week personally meeting with the women who expressed interest in participating in the research. Once a participant agreed to be involved, I scheduled an interview with her where we spent 40 minutes to an hour discussing her experience with HIV.

Member checking is the process of the participant affirming the authenticity of the work (Lincoln & Guba, 1985). Researchers usually conduct member checks to confirm that the researcher's interpretation of the data are a true representation of how the participants intended to discuss their ideas (Lincoln & Guba, 1985). To be able to engage in member checking before leaving Kenya I, with the help of the translators, translated and transcribed all the interviews. After reviewing the photo-journals and transcripts, I scheduled a second meeting. I gave each woman a copy of the interview transcript integrated with some of my interpretations. I also returned the original photo-journals to each woman and we discussed whether I had correctly interpreted what they had told me. At this time, the women were told they could make adjustments to what had been said, but most were content with what was there. In some cases, the women added to their descriptions and further explained their photos. The following sections give a detailed over-view of the recruitment process and the particular methods used in the study.

**Research site and participant recruitment.** I implemented this study with the help of the program manager of a partner NGO in Mombasa. A group of volunteers founded the NGO in 2000, wanting to enact community change by using participatory educational theater to teach the community about the negative effects of HIV/AIDS and offer reproductive health education. The organization was supportive of the research project and its purpose (see Appendix B). In addition, the partner NGO's building was a space where all participating women felt they could receive reliable education about HIV, among other topics.

Criterion sampling, which involves selecting participants based on specific criteria important to the research, was the method used to identify potential research participants (Teddle & Yu, 2007). This type of sample is valuable to the current study as it helped to identify those women who had data-rich narratives for the specific demographic being studied. Because women aged 15-24 are considered most vulnerable to HIV infection in SSA, and the age of consent is 18 years of age, I chose women aged 20-25 as this population was readily accessible to the NGO and its partners and a guardian's consent did not have to be obtained (UNAIDS, 2009). Thus, the inclusion criteria for this study included Kenyan women between the ages of 20-25 with a known HIV-positive status, residing within the city or a surrounding district of Mombasa. Because women in SSA are eight times more likely than men to be HIV-positive in this age demographic, and because I had committed to a focus on issues related to women vulnerable to HIV infection, I was interested in the female population and all men were excluded from this study (UNAIDS, 2009).

As this was qualitative research, I did not specify the size of the anticipated sample because greater quantities of data do not necessarily translate into larger quantities of information about the study topic in a qualitative study (Ritchie & Lewis, 2003). Instead, my goal was to collect data until I reached saturation—the point at which no new information was imminent or data became redundant (Lincoln & Guba, 1985). Generalizability of my findings was not a goal. As such, frequency was not an objective in data collection because one data point was all I needed for information to be considered salient or important (Mason, 2010). Ultimately, I did not reach true data saturation in my study. As Mason (2010) noted, qualitative research requires a great deal of effort. Analysis of qualitative data can be demanding and very time consuming. Thus, large sample sizes were unrealistic given the time constraints imposed on the data collection period for my study.

While there were many potential sources for contacting HIV-positive women in Mombasa, participants for this research were associated with the partner NGO through women's organizations affiliated with clinics as well as testing, support, and educational HIV/AIDS services in Mombasa. This recruitment took place before and after my arrival in Kenya. The translators and the program officer of my partner NGO helped to distribute information about my study. At the study's onset, I met with 23 women with a positive status. Some had opted to meet with me in a group, while others preferred to be one-on-one during our first meeting. After the three-week recruitment process, nine women agreed to participate in my study.

The ninth woman in my study chose to withdraw after her partner damaged her journal when he learned of her participation in the study. She asked that her initial

interview disclosures not be included in the findings. I therefore removed the information she conveyed from the study completely.

The eight women who ultimately agreed to participate in my study had varying backgrounds, educational training, and experiences of living with HIV. It is important to note that the women in my study likely had different perspectives than other women in the area who do not seek out health information. All women who chose to participate had basic knowledge of English but spoke in their native tongue, Kiswahili, when they were unable to effectively communicate their experiences in English. Upon request by the participants, translators were present during the interviews for clarification.

**Interviews.** The first data collection method consisted of a sequence of two individual, semi-structured interviews in which each participant discussed her understandings of health and how HIV or AIDS specifically affects her life. I conducted these interviews in a private room inside the NGO office and recorded them with an audio recording device. The NGO office was located centrally to the smaller communities in which the women lived and worked. The initial interviews were approximately 40-60 minutes and I centered my questions on narratives pre-and-post diagnosis. I also asked questions about the sources of knowledge from community, family, friends, institutions, and media, and about their sources of support. Finally, I wanted to capture their opinions about the provision of, as well as access to, AIDS-related knowledge and education in Kenya (see Appendix A for the interview guide).

I, along with my two translators, transcribed all interviews verbatim, in both Kiswahili and English, while I was still residing in Mombasa. I also took notes during and after each interview. Although participants had some ability to converse in English,



one of the two female translators was present for all interviews upon the women's request, in order to clarify any communication barriers. The second interviews were scheduled once I had collected the photo-journals (outlined below). The second interview occurred approximately two-and-a-half months after our initial meeting. Time was needed after collecting the photo-journals to construct the transcripts and compile them with my interpretations along with further probing questions about the experiences the women had conveyed.

Developing and maintaining a relationship with each woman throughout my four-month stay in Mombasa was imperative to ensure that the photo-journals captured a deeper picture of their lives and how their understandings of health knowledge influenced the way they lived with the virus. My relationships with the women established trust, a mutual understanding of the goals of this study, and the knowledge that I respected each of their ideas. In addition it was necessary to provide them with a clear option to change, add, or void sections of our recorded conversations and their written text at any time in order to produce trustworthy results (Bates, 2004). This trust created a level of comfort where, if a woman wanted to add or change her narrative, she was able to contact me at her convenience to set up a meeting time to make alterations.

**Photo-journaling.** The second data collection method was photo-journaling. As a tool for data collection, photo-journaling provides an excellent platform to begin unpacking how women construct and understand existing ideas about HIV/AIDS. Berger (2008) also declared photographs to be an alternate means of seeing and thus understanding:

An image is a sight, which has been recreated or reproduced. It is an appearance, or a set of appearances, which has been detached from the place and time in which it first made its appearance and preserved—for a few moments or a few centuries. Every image embodies a way of seeing. Even a photograph. For photographs are not, as often assumed, a mechanical record. Every time we look at a photograph, we are aware, however slightly, of the photographer selecting that sight from an infinity of other possible sights . . . The photographer's way of seeing is reflected in his choice of subject. (pp. 9–10)

Using social constructionism theory as a means of comprehending the eight women's perceptions of HIV, photo-voice helped to illustrate how the women constructed ideas about HIV/AIDS based on connections between their emotions and interactions with their social, cultural, and organizational environments. As I had given the women guidelines for creation of their photo-journals (see Appendix D), this meant the content of the journals was a co-construction between them and myself. My guidelines may also have influenced the content that remained absent, which became a focus of some of the questions during the second interview.

As was the case in the Wang and Burris (1994) study, photo-journaling was a useful method in this study because it allowed the women to be more than just passive participants. The women were able to choose how they decided to represent themselves and their ideas through photography. They were able to choose the setting of the photographs and the people who were included in their images, and they were able to describe the issues most important to how they construct perceptions of HIV/AIDS.

I invited each participant to construct a photo-journal about the meaning of HIV/AIDS in her life over the time span of one month. The women took photographs and I asked them to describe the photographs' meanings in terms of how they represented HIV/AIDS in their world. The participants created these photo-journals during their own time within their homes and surrounding communities. This allowed me to understand how each woman interacted with the ideas in her environment to reach a certain comprehension of AIDS-related information. The photo-journals provided a unique window into how each woman understood and used knowledge about HIV/AIDS and were used to add to the in-depth perspectives of women in this field of research.

After the conclusion of the first interview, participants were given a disposable camera and journal with a set of guidelines and possible topics they might want to focus on to convey their experiences with HIV (see Appendix E). Wilton (1999) reports that participants' voices, conveyed through both photographs and journals, enhance participation and empower participants when combined with the process of research. The use of photo-journals also provided a means to overcome communication barriers and further illustrated both the unique and similar experiences that each woman has with the disease (Bijoux & Myers, 2006; Wilton, 1999).

Collecting the photo-journals and cameras from each participant presented some difficulties. Many of the women were traveling on the submission date and two participants asked to begin new journals, calling for a re-organization of the original time frame for completion of data collection. One journal was destroyed in the Mombasa rains, and the other by a violent partner who found and destroyed the journal. The possibility of negative implications when collecting personal information and sensitive

research, such as data related to HIV/AIDS, makes participants inherently vulnerable and thus such collection needs to be approached with special care. Castleden and Garvin (2008) discussed the challenges using photography in research posed:

The act of taking pictures in any community is a political act and, as with other methods, the resulting data both disclose that which is photographed and hides that which is not. As such photography can be an intrusive activity and may lead to unintended consequences. (p. 1396)

In my research, confidentiality was imperative. Especially since I was using photography, it would be inappropriate to identify participants in any way. While the participant who experienced violence did not wish to convey the full details of what happened and why, she did explain briefly that her partner was angry at her for sharing details of their personal lives and that he stated their HIV was their business. Eventually, she withdrew from the study. I had to recognize the cultural intrusion and the power relationships present when this occurred. Her partner might have been fearful that her involvement, and the methods used in the research, might in some way publicize their status.

In hindsight, I could have altered aspects of data collection, specifically protection of the women. The local family power structure, which places the man as head of household, means that he has a certain level of influence over his wife's behavior. The camera represents a research tool to a Western researcher, but the meaning associated with capturing still images of people's organic lives raised concerns among participants and others in their personal lives. Partners and families could have been integrated into the study, at the very least, by informing them of the study, its goal, and the roles of the

women. In some cases, trying to find consenting families may have created more challenges, but on the other hand it would have demonstrated my respect for the culture and the adaptability of my research project to local circumstances of the women's communities.

Providing a convenient and private location was important, but it was not the only necessary precaution needed to protect the participants. Instead of offering to store the journal and cameras after each day, I could have made this a mandatory stipulation of the research to minimize any potential harms to the women (i.e., avoid disrespecting male partners of the women and in turn, minimize risk for any resistance to participation). However, the women did agree that meeting every day for a month to create the photo-journal would involve time lost in travel, would be expensive, and would take away from time in the home or at work. As well, the women indicated that finding a spare 20 to 30 minutes to write and take pictures would be easier without schedule restrictions. In the end, after input from each of the participating women, a decision was made (individually by each woman, as I stated my flexibility), that the benefits to keeping the journal for a month-long period versus visiting the NGO office each day, or arranging an alternate meeting place, outweighed the harms.

All the journals were submitted to me by the third week of October. I collected signed release forms for the intellectual property of the women (See Appendix F) indicating permissions to use the images. Permission was also obtained from those present in the photographs and not participating in the study (See Appendix G). The photos were then developed and placed in the correct position in each journal by the order in which they were taken. Each woman in her second interview confirmed the placement

of the photos. Two paid translators, both women, translated the written description of each photograph and the accompanying stories in each photo-journal verbatim from Kiswahili to English. The Kiswahili descriptions were then entered into Google Translate® to verify these translations and their corresponding meanings were as closely matched as possible. Google Translate®, a Web-based program reputed for its accuracy and natural translations, was a valuable and economical tool in the process (Balk, Chung, Chen, Trikalinos, & Chang, 2013) (See further description in the data analysis section).

All second interviews with participants occurred throughout the second and third week of November and transcription began immediately following each interview. During the second interviews each woman, the translator, and I reviewed the photo-journals and interview transcripts in conjunction with interpretations from my initial analysis. This allowed the participant to clarify any unclear statements made in the initial interview and gave her an opportunity to fully describe the meanings behind each photograph in her journal. Transcription of all interviews and journals was fully completed by late November 2011.

Immediately after data collection and transcription I contacted each woman to ask if they were interested in looking at the transcript before our second interview when we would review the photo-journals, interviews, and my initial analysis of the documents. Three out of eight women availed themselves of this opportunity, while the other five opted to wait until our second official meeting. During both meetings I shared the transcript with the interviewee to enable the participant to review the transcripts and to add, change or delete information as she saw fit.

Throughout this process I also gave each woman the transcript along with some samples of my interpretation of their responses linked to the themes described in Chapter Five, thus providing them with the opportunity to confirm or change their intended meaning. The women also checked the transcriptions to ensure the Kiswahili responses they had given were in fact what they wanted to say about the topics discussed. I also asked unstructured questions about points in the narrative where I was unsure of the meaning.

For the interviews recorded with Kiswahili responses, the translators were required to include both Kiswahili and English translations. Once the women had confirmed the Kiswahili answer was in fact what they wanted to convey on each topic, I entered the Kiswahili response into Google Translate® to check if the web-generated conversion matched that of the translator. This member checking enabled me to develop skills in cross-referencing data and also provided participants with the opportunity to share any follow-up information, to validate and clarify, and to comment on the data collected.

**Field notes and personal journal.** My field notes and journal gave me the ability to recall the events that occurred before, during, and after each interview. My field notes were particularly beneficial upon deciding to retell each interview in story form. For each interview I wrote a brief two-to-three page narrative about what happened in the interview along with my own thoughts and feelings. I used the notes as a means of tracking limitations within my study and how I could improve how I conducted research. In addition, the notes were useful in acknowledging the challenges I encountered and how resolutions were reached. The details of my personal journal captured my emotions at

certain points in the interviews and at different stages of the research process. The writings in my journal placed a particular emphasis on my thoughts and feelings as I experienced them after each interview rather than the content of what was discussed in the conversations with the women. I used captions from each source to situate the reader within the context of the interviews and to help convey the emotions that emerged during our conversations. Both the field notes and journal enabled me to reflect and focus on what was occurring in the environment as well as focus on interesting data emerging in each story.

### **Data Analysis**

I initially began data analysis after the conclusion of my first interview, when I started drafting a narrative of the experiences shared by the participant. This was a process I engaged in after each meeting with the women. Following the completion of the first round of interviews, I worked with the translators to begin the transcription process. Together, we listened to the audio files that had been recorded on a personal computer, while typing the English portions of each interview verbatim into a Microsoft Word document. Both translators were instructed to first transcribe the interviews verbatim in Kiswahili, in cases where the participant chose this language as her preference, and then translate to English. In all cases, each woman's name was replaced with her chosen pseudonym.

After all data were collected I studied the translated interview transcripts, photo-journals, my field notes, and my personal journal. I presented the women's experiences with, and understandings of, HIV in narrative stories that recounted details disclosed during our time spent together and integrated many of my own assumptions. This was



achieved first by the re-storying of the participants' narratives. Re-storying is the practice of making sense or assigning meaning to each woman's experiences (Mulholland & Wallace, 2003). This process revealed the depth of the women's HIV/AIDS perspectives conveyed throughout the interview, development of the photo-journal, and our meeting where the woman examined and validated or rejected my interpretations of the actual data. This highlighted each woman's experiences, significant relationships they developed based on interacting environmental factors, and personal thoughts and feelings about the experience of living with HIV.

In my analysis and presentation of the narratives, I used an authoritative voice to communicate the ideas of the women as narrators of their understandings and experiences with HIV, and to express my interpretation of these narratives as a researcher (Chase, 2005). I used this tone as it has been noted to make "visible and audible taken-for-granted practices, processes, and structural and cultural features of our everyday social worlds" (Chase, 2005, p. 664). In telling the stories using my voice I was aware that I might, to some extent, silence the voices of the women. I made every effort possible within the time constraints given to have the women review my interpretations and offer more details where they felt necessary. However, upon re-analysis of the data back in Canada, I had to acknowledge that further questions elaborating on religious background or cultural beliefs in the women's lives could have been included. In a country where cultural and traditional beliefs are so intertwined with how people live their lives, it would be beneficial to have in-depth knowledge of the beliefs to which each woman subscribes. This knowledge would hopefully create more insight into how they have come to know what they know about HIV/AIDS. With more time and access to more

research in this area I recognize the difficulty of telling someone else's story, and realize that having more background would create a fuller picture.

Data from both my field notes and personal journal were also integrated into the narratives. The writings in both were coded and compared to the codes found in the interviews and photo-journals of the women. Through open-ended coding, thematic categories were established and labeled. Following this, axial coding established the relationships among the thematic categories. Based on previous research (see Hess & McKinney, 2007; Longfield et al., 2004; Noden, Gomes, & Ferreira, 2009; Ouma & Kalipeni, 2009; Sallar, 2009; Tang, 2008; Vanable et al., 2006), possible themes such as the accessibility of knowledge, influence of social relationships (e.g., between women and their peers, partners, and family members), individuals' experiences with health education, cultural backgrounds, socio-economic status, and geographic location were anticipated to emerge as key aspects of the women's lived experiences with HIV. Although narrative inquirers tend to disregard thematic analysis to avoid reductionism, others such as Ellis (2004) treat narratives as data where thematic analysis is beneficial in revealing content that can hold across stories or provide more depth to explanations of certain phenomenon. This was my strategy while still presenting the women's narratives to illuminate their individual voice.

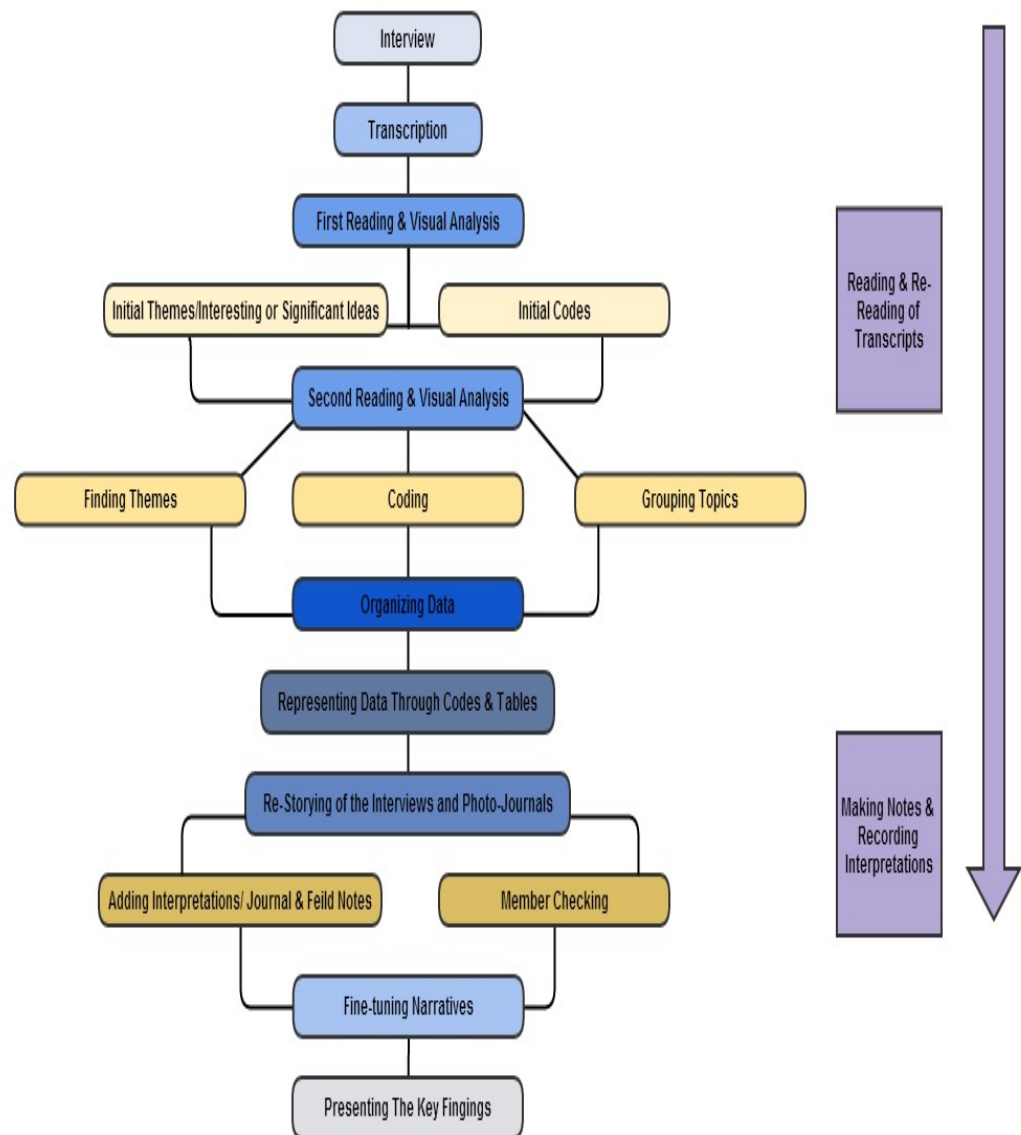
Initial themes arose from the categorization in the interview guide (see Appendix H). Each thematic category was assigned a color and letter code to identify the most valuable aspects of the data (see Table 1 Category Codes for an example in Appendix I). I also constructed a coding chart for each woman's narrative, giving me a better idea of how the narrative was created and the significant, salient, and interesting ideas that arose

from each interview (See Appendix J for Coding Chart Example). I found a constant overlap in thematic (i.e., what was said) and structural (i.e., how it was told) approaches to my data analysis of the interviews.

I began data analysis of the photographs by first asking the women what their pictures meant to them during an audio-recorded interview with each woman. I then asked the women to elaborate on the written captions that accompanied most photographs. I also assigned numbers to the images, which allowed me to match the recordings to their corresponding photographs. After the interviews, I used Riessman's (2008) Visual Analysis guidelines for analyzing photographs by focusing on 'how' and 'why' images were produced. I examined what was included in the photo (the image itself), the different interpretations that could be given to each picture based on the image itself, and the corresponding description given by the woman. In addition, the circumstances surrounding how the image was produced were also built into each discussion of a photograph. Themes for each photograph were later generated and related to those present in the interview data. The analysis of these photographs and their subsequent descriptions were included among the narratives that emerged from the interviews.

**The stages of analysis.** I carried out my analysis in four stages. During stage one I analyzed the original drafts of the narratives. I developed initial categories that identified experiences that were both collective and individual to the women. I analyzed each woman's narrative for how her experience shaped the stories she told and how those experiences connected with various interactions with ideas within her social environment. Social constructionism provided a guiding framework to develop themes emerging from

both individual and collective narratives. I then connected the narrative excerpts with my interpretations, titling the emerging themes for the data and linking them to relevant literature. Figure 1. Data Analysis Flow Chart illustrates the steps in this process.



**Figure 1. Data Analysis Flow Chart**

The broad thematic categories originally identified reflected narratives of “Fear and the type of stigma it generates” and “Thinking positively about a future of being positive” (See Appendix L for Cumulative Listing of Emergent Categories). The second stage of my analysis involved re-mapping the categories to discuss the overall effect of how women’s individual thoughts affected their perceptions of disease and how they were influenced by the beliefs, attitudes, and ideas that existed in their social environments.

The third stage of my analysis involved grouping common categories, highlighting the negative cases (or categories specific to only one woman), and determining the main influences on perception of disease the women reported in their environments. This enabled me to discover if a primary level of influence shaped how one or more of the women formed their perceptions about the disease. In the fourth stage I reviewed the narratives, photographs, field notes, and my journal line by line choosing quotes to represent the emerging themes of 1) contagion; 2) burdens of disease; 3) perseverance 4) bodies, representation, and construction of the self.

I then sub-divided themes based upon the relationships each of the women’s stories had with one another, the amount of information disclosed about a specific topic, or an idea discussed that provided substantial insight into the lived experiences of women with HIV in Mombasa. In each instance, I worked to retrieve the women’s voices and situate them within a particular setting, time, or place (Connelly & Clandinin, 1990). The fourth stage of my analysis was also comprised of writing the findings up in relation to existing literature. In making these comparisons I drew associations based on the contexts in which my study and previous HIV research were conducted. I linked concepts and theory surrounding HIV, the body, and self and enacted stigma. I also

acknowledged negative cases in my study that either did not correspond to previous literature or were particularly unique among the women who participated. Throughout the entire process I aimed to be reflexive, making my own assumptions and interpretations known.

### **Obstacles to Engaging in Research**

Researchers do not conduct studies without obstacles. The data collection process was trying in many instances. However, these challenges have given me a greater appreciation for the data I collected. For clarity, I have divided the obstacles I faced in this study into two sections: 1) Limitations in the methodology and design and 2) Limitations of the researcher.

#### **Limitations in the methodology and design**

***Sample size.*** The current sample size of eight HIV-positive women has generated interesting information about experiences with the disease in Mombasa, Kenya. Given a longer period for data collection a larger sample, including more women who have completed different levels of education, would help to authenticate the experiences of women in this study. However, the nature of narrative research places strength on the depth of information contained within a smaller sample, and thus I believe the stories of these eight women are sufficient for the scale of my study.

***Lack of prior qualitative research with HIV-positive women in Kenya.*** Due to the exploratory nature of this study, the research I originally reviewed focused on women affected by HIV/AIDS, their education level, and common sources of knowledge and existing ideas about the disease. A significant amount of research has been conducted on HIV/AIDS, as well as several topics that are important to the prevalence of HIV infection

such as stigma (Esplen, 2007). However, while studies exist concerning AIDS-related education levels of women, there is a lack of qualitative research taking an in-depth look at how women in Kenya interpret the information they receive about health and HIV/AIDS, and how their understandings may influence how they live with the virus.

***Limits to confidentiality.*** I treated the information collected in this study in a respectful and private manner. There are, however, limits to confidentiality. I could obtain assurances that participants would not be treated differently by the NGO; however it was anticipated that both the participants and the NGO would maintain their previous relationship, irrespective of the research project. I made the women aware of this fact during the briefing and before the commencement of the interview process. I undertook every step necessary to safeguard the confidentiality of individual discussions, however, I could not guarantee confidentiality. If a woman were to reveal, for any reason, that her health was in jeopardy, I would have sought advice and informed the appropriate professionals. Fortunately, this was not the case. In addition, I may have secured more women for this study than I otherwise would have by not considering explaining to partners or families the implications of participating in photographic research, or my duty as a researcher to ensure confidentiality of the females participating.

### **Limitations of the researcher**

***Access.*** As an international researcher, I had to rely on my in-country contact with the NGO to that ensure the details of my study were circulated to potential participants before my arrival in Mombasa. Since the partner NGO was a non-profit organization that relies on the time of its volunteer members, recruitment was not always a central focus until a time closer to my arrival date in the country. Had I been in the

country at the time of initial recruitment, I might have had more time to access women living in different districts, with a wider range of educational experiences, and a larger sample in general. Future research projects conducted internationally should consider establishing an in-country research team that can aid with the recruitment and scheduling process.

***Cultural and other types of bias.*** I found that there was a major difference in how the women and I held expectations around time. For example, a participant might explain that she would be arriving at 2 p.m. in an afternoon phone call and then proceed to show up at 4 p.m. This occurred for a number of reasons relating to how the women organized their daily activities including cooking and cleaning for the family, bringing their children to and from school, going to the hospital for treatment, visiting a friend, or feeling ill and needing a day of rest. Several interviews were therefore postponed and in other cases cancelled completely.

In addition to cultural differences, some bias might have been eliminated through recruiting more participants, thereby increasing confidence in the results. This proved to be a difficult task. Many of the women who participated in an original meeting where I introduced them to the goals of my research and their potential roles in the study had complicated home lives in terms of childcare or job commitments. Some also feared getting involved, despite my explaining my commitment to confidentiality, because they did not want partners and family members to react violently if they learned the women were sharing their status with a stranger. By not including the women with the most burdens/responsibilities, a separate bias was created. A future study where researchers



could meet the women at home, for example, might allow greater access to a wider pool of individuals (though such a method would also raise other concerns).

A greater number of women would have also increased the diversity among the women in terms of education level and their personal history with the disease. This would offer a wider range of perspectives to compare on how women in Mombasa understand knowledge about HIV and use it to inform management of HIV-infection and other health practices.

***Fluency in a language.*** It was sometimes a struggle to communicate the objective of my questions effectively during the interviews due to the Kiswahili-English language barrier. This often added to the duration of each meeting. In addition, including a second language other than my own also slowed the transcription process and reduced the amount of time I was able to spend with each woman reviewing the transcripts. It also meant that multiple layers of interpretation occurred. My limited training in the language, inclusive of a week long vocabulary/phrase course as part of my first volunteer experience in East Africa, did not make this obstacle any easier. While the translators present in this study were educated in both Kiswahili and English as national languages, for a future study with greater financial resources using a trained translator would increase reliability of results and the ability to meet deadlines with more punctuality.

### **Ethical Considerations**

**Scholarly review.** A supervisory committee consisting of Dr. T. A. Loeffler (academic supervisor, School of Human Kinetics and Recreation, Memorial University) and Dr. LeAnne Petherick (previous academic supervisor, Faculty of Kinesiology and Recreation Management, University of Manitoba) reviewed this research idea. The

Interdisciplinary Committee on Ethics Review in Human Research of Memorial University reviewed and approved this project in June 2011.

In order to conduct research in an international setting, ethics approval from the country of research was also required. I obtained ethics approval for a period of three years in the Mombasa area from the Ministry of Education, Science and, Technology in Nairobi, Kenya (See Appendix M). The following sections indicate the ethical considerations I took into account while designing and implementing my research.

**Harms and benefits.** I asked the women who agreed to participate in interviews to share only what they felt comfortable discussing in relation to the topics covered within the face-to-face interviews concerning HIV/AIDS and health. While there are minimal harms associated with this study, I made contact with appropriate sources in case professional or medical advice would be required. I informed the women of the counseling services available to them within the NGO and with other women's organizations in Mombasa. In addition, I made the women aware of the health education sessions delivered by the NGO that are specifically related to HIV/AIDS prevention and treatment, as well as health and wellness issues.

The benefits of participating in this study were minimal. The environment in which the collection of stories took place provided a safe space where the women were able to openly discuss health topics and how these topics affect their living conditions. This discussion may not have otherwise occurred in their regular life experience. In addition, the women kept their original photo-journals. While the benefits were minimal for the women, it is my hope that the findings of this study will help to share the personal side of living with illness and contribute to a greater body of research that increases the

level of action being taken to promote awareness about, as well as the prevention and spread of, HIV/AIDS.

**Free and informed consent.** I acquired written consent from every woman participating in the study prior to the commencement of the initial individual interview, stating their agreement to partake in both interviews (see Appendix N). The women also communicated the details of this form to the individuals who agreed to appear in the pictures found in women's photo-journals, along with providing a copy of the photograph release form (See Appendix G).

In addition, each woman signed a consent form stating their willingness to create the photo-journal and to follow the instructions clearly stated in the photo-journal guidelines (see Appendix D). Signed consent forms were also required of any individuals who appeared in the women's photographs. I made the women aware of the audio recording format of the interviews and their right to withdraw at any time without any negative repercussions. A woman's decision to withdraw at any time had no impact on her membership with the partner NGO.

**Deception.** Deception in any capacity was not an aspect of this study.

**Privacy and confidentiality.** I could guarantee privacy and confidentiality within the interview setting and in terms of storing the collected information. However, I could not guarantee that the women would refrain from talking about what was discussed during the interview with friends or other members of the public. Steps were taken to reduce these issues, which included:

- Participants and translators were reminded of the importance of keeping all information discussed in the interviews confidential and

free and informed consent was given;

- Both of the translators also signed a confidentiality agreement for transcribers and translators, stating their cooperation in not disclosing any details of the interviews or revealing the identity of the participants (see Appendix O).
- Consent forms were stored in a cabinet at the office headquarters of the partner NGO, which was a secure location separate from any of the information obtained during data collection;
- Only, I, the researcher, and my academic supervisor had access to the audio-recorded information, apart from the translators during the language verification process, in addition to the photocopied replicas of the photo-journals of each woman;
- Upon return to Memorial University, data were stored in a locked cabinet in my office;
- The women were addressed (verbally and in text) by their pseudonyms and immediately following the completion of the interviews and construction of the photo-journals the data documents were coded according to these pseudonyms as well;
- The women were asked only to share what they were comfortable with sharing;
- Audio data collected from each individual interview was transcribed and kept in hard copy form as well as electronically. It will be stored

for five years after my study has been completed, at which point all data collected in this study will be destroyed.

**Conflicts of interest.** There were no conflicts of interests within my study.

**Inclusiveness.** My proposed research study invited only women living with HIV/AIDS between the ages of 20 and 25, living in or around communities in Mombasa, Kenya to participate. The women were affiliated, through communal ties, with the partner NGO. My research focused specifically on this group because I determined, based on the research and my personal experience volunteering in the neighboring African country of Tanzania, that these women have a unique perspective to offer on how individuals living with HIV/AIDS come to develop different understandings of health.

### **Chapter Summary**

In all aspects of the research process I experienced delays and obstacles such as rescheduling of interviews, waiting on participants who said they followed “African Time,” power outages, flooding, and the participants’ ability to access transportation to and from the interview site. It is important to remember that I, the researcher, have a duty to relay the stories of these eight women while doing my best to ensure their voices remain intact. While the purpose of my research was to allow these women to share their stories about how they have come to understand knowledge about HIV/AIDS and, in turn, manage the virus, it is important to recognize that I was a subjective and active participant in the research process.

In the initial stages of data collection, I developed temporary relationships with each woman in the study. As the research process unfolded and I met with the women outside the interview room, spent time alongside them in their daily lives as they received

treatment, cooked for their families, and interacted at social gatherings, I was able to better understand the amount of work that is needed to manage a chronic illness.

As an educated, upper-middle class, white woman from the Global North, my knowledge of HIV/AIDS was limited to my educational background, volunteer experiences, and my prior research and review of existing literature. My work in the overseas volunteer sector with men and women living with HIV/AIDS has made me aware of the relationships of power that surround this disease. It has shown me how the women with whom I have interacted protect themselves against contraction, how they manage the virus once they have been infected, and what their beliefs are about why and how they have the virus. Establishing relationships with my participants gave me a more in-depth perspective of their daily lives with HIV. In the following chapter I introduce you to the eight women: Mariam, P. Diddy, Tina, Sabina, Stacy, Atoti, Jane, and Whitney. Each of their narratives helps to answer my primary research question, “What are the experiences of young women living with HIV in Mombasa, Kenya?” I have attempted to share their stories as I have heard them through my own lens.

## **Chapter 4**

### **Narratives and Plotlines**

#### **Introduction**

It is important to keep in mind that the eight narratives presented in the first section of this chapter describe the life stories of the HIV-positive women I interviewed. Each narrative illustrates how one woman interprets and understands the disease. Each woman has told a unique story. I used data collected through each method (interviews, photo-journals, field notes, and my personal journal) to re-story their experiences. Taken together, combined with my interpretations, their stories present a dialogue around what it means to be an HIV-positive woman in Mombasa, Kenya.

Using my selected methodology, narrative inquiry (discussed in Chapter 3), I have inserted quotes from the interview transcripts throughout the narratives, in addition to descriptions of the gestures and expressions the women made during interviews (e.g., laughing, smiling, crying, nodding, clapping), to give a sense of the non-verbal forms of communication through which the women also shared their stories. The photographs and their accompanying descriptions, as well as some of the women's free writing in their journals, have also been integrated into these narratives. Together, the written, visual, and verbal representations of the women's stories present a rich documentation of the experiences with HIV they chose to share during the research period. Some of the first stage of analysis is represented in this storytelling component.

#### **Women's Narratives**

In this section I introduce the women who took part in my study. I present the narrative of each woman, as she conveyed it to me during our interviews, shared here in

story form. I have intertwined each woman's story with my interpretations and thoughts at the time of the interview. The narratives help provide a deeper context of the ways in which eight HIV-positive women receive, interpret, and use knowledge, beliefs, or attitudes about the disease. In restorying the experiences of the women, I ordered their stories chronologically based on the past (How they learned about the disease, recounting their moment of diagnosis), the present (the disjuncture the diagnosis was causing in their lives), and the future (hopes for their futures with HIV and how they would like to see changes in their communities).

Lieblich et al., (1998) stated that stories are important because "stories not only reveal, but also shape identity because identity stories are "told, revised, and retold throughout life. We know or discover ourselves, and reveal ourselves to others, by the stories we tell" (p. 7). The aim of the following descriptions is to situate the participants within their cultural and social contexts including their HIV status, social relationships, and understandings of the disease. I also note their hopes for the future in terms of what it means to be a woman with an HIV-positive status.

It is imperative for the reader to realize that the narratives provided here do not aim to capture the intricacies of each woman's life and her diverse realities as an individual; instead, I offer a brief sketch about each woman's experience with, and understanding of, living with HIV. Although the circumstances surrounding the lives of each of the women in my study are different from each other in some respects, they do share similarities in terms of age, education level, economic status, access to treatment, understanding of the disease, and the time at which each discovered their positive status. It is my intention that these women's life circumstances will provide a glimpse into how



some women from countries of the Global South, falling at the less-privileged end of the economic spectrum, come to understand and live with HIV.

### **Mariam**

The following are fragments from a poem that I had originally thought had been written by Mariam but it is an adaptation of a poem which originated from the national curriculum development center in Uganda (NCDC, 2008). Incorporating her cultural ways of knowing HIV/AIDS, Mariam free-wrote this version of the poem in her journal:

AIDS ooh AIDS

You are a deadly-monster.

You have taken our Fathers, Mothers, Sisters, and Brothers.

Children are Orphans.

Men are Widowers. Women are Widows.

WHY?

It's because of Mr. Slim.

Others call you "Kill me quick".

Scientists have gone to the Moon; have made nuclear weapons;

Yet your cure defeated them—

AIDS DO YOU HAVE MERCY?

Setting aside all the details of Mariam's life with HIV, I was left with stories of a young, vibrant, and witty woman. Although Mariam was the first woman I met, she was also the last and most hesitant to participate in the research. However, she did not seem hesitant at all by the end of her first interview, as she bravely disclosed her story to me, initially fighting back tears and then eventually laughing at the fact that she was still alive

and hopeful about living a long life. Having discovered her status just under three months prior to our first meeting, our discussion of the purpose of the study and the role she might play in it was a very emotional conversation for Mariam. This was because discussing this topic openly was a new experience for her, and openly admitting her positive status to me caused an intense array of emotions. Working through the tears and worries that accompany such a diagnosis, Mariam eventually arrived at a degree of acceptance and hope for her future.

When I first asked Mariam about her life before finding out about her positive status, she explained, “Before I knew that I was infected, I was still affected because of my mother.”

“So you were passed . . .” I struggled with how best to ask her about her infection story. “HIV was passed to you by your mom?” I finally asked, assuming this had been the case.

“I am not sure, but . . .” Mariam, it seemed, was also searching for the right words. I waited for a moment to see if she could find them before asking, “You think so?”

“Yeah.” She said this so quietly that I could barely hear her. Mariam later told me that her mother, who has lived with a positive status for many years, has given her hope about her life with the virus. “I believe I can live as long as my mom. She was positive, let me see, twenty years ago.” Mariam told me proudly. Despite the significant amount of time her mother had spent living with the virus, Mariam had never discussed the disease with her and, until recently, did not know of her mother’s positive status. It seemed as though, watching her mother live through bouts of sickness, Mariam thought of her mother’s condition the way most people would the common flu. “Okay, so if you

are comfortable sharing with me, can you tell me about how you felt when you found out?” I was greatly intrigued by her story.

“Hmm, I was at home. My uncle called us,” she said, “and he said that there were visas; we needed them to go to Saudi Arabia to work. So I decided to go to the clinic and I found that I was infected, but they didn’t give me the results. They just called my uncle and told him because they knew him.” I was shocked by her story. How could such a confidential issue be handled so poorly?

“So they didn’t tell you first?” I asked, still in disbelief.

“Yeah,” she said, shaking her head to convey the fact that she, too, did not understand why they had breached her confidentiality. Mariam began to tell me about what followed her clinic visit. “So after three days I was asking, ‘What’s happened? Why am I not travelling?’ Then my uncle called my mom and told her.” Recalling the details of that day, Mariam placed her head in her hands and began to cry as she finished the story. “And my mom called me and told me. So I said, NO!” She raised her voice as she revealed the worst part of her story. “I can’t believe this, let me just go, I’ll check and see for myself.” Mariam spoke to me as if I were her mother, and as though it were the very day she had been told of her diagnosis. “Yeah, so that is why I decided to go by myself,” she finished. Tears streamed down her face as Mariam recounted the events of that day. Her ability to wipe each falling tear and continue to share her experience with the virus and her subsequent understanding of it was a display of unfaltering bravery.

“So you went by yourself,” I repeated, thinking how lonely and scary this must have been for her. “You did a brave thing,” I said, smiling at her to attempt on some level to convey how incredibly strong a person I thought she was, after only knowing her for a

few brief minutes. “And then how long ago?” I asked Mariam, regarding her trip to the clinic by herself.

“Just three months back,” she replied. To this day, Mariam is unsure of how she contracted the virus. However, she remembers knowing the acronyms “HIV” and “AIDS” for a very long time, though she had not fully understood their meaning. “Did your mother ever talk to you about her HIV?” I inquired.

“No,” Mariam said firmly. “She travelled sometimes and my brother was sick.” Mariam later explained that he, too, had the virus. “So I decided to go with him to the hospital and I just found the stories there.”

“Okay. And is that the first time you heard about HIV?” I asked.

“No. I heard about it, but it was like, HIV is there and no one has it.” Mariam later confirmed she had intended the last part of this statement as a reference to community members and friends, believing themselves and their friends to be safe from infection. “So it was just something that happens to people you don’t know?” I asked this to ensure that I understood what she was trying to tell me.

“People you don’t know,” Mariam repeated, nodding in agreement. “Just some people, but I don’t know them. Ah, I think my mom, when she gave birth to our last, you know, our last brother?” she raised her eyebrows, asking if I understood.

“Yes,” I said, hoping she would continue.

“I don’t remember the age, but I was just little.” She stopped for a minute to recall her first encounter with the terms “HIV” and “AIDS.” “I just heard my grandmom telling my mother, ‘hawana mnyonyeshe huyo motto.’” Mariam said this so quickly that I do not think she realized she had said it in Kiswahili, and there were no translators

present. I must have looked confused, because when I didn't respond, she said, "It means, 'Daughter don't feed that baby!' And I was shocked. Why could she not feed the baby? I remember asking myself. She gave birth to me so why can't she feed the baby?"

"Breastfeeding," I said, mulling over the situation in my head and saying the words aloud.

"Yeah, and I just keep quiet and didn't ask anything. After he grew up and I knew all of this stuff and I just decided to sit down and think. See, HIV, HIV, oh it's this." She snapped her fingers, recalling the moment she put the pieces of the puzzle together.

"Your brother was born with it?" I asked, wanting her to finish the story and making sure that her understanding was that it had probably been transferred during breastfeeding.

"He wasn't born with it, but now he has it," she said, to make sure I had understood. Mariam had given thought to this after she had heard the term used in school. She informed me that she had only received formal education up to standard six. HIV had been discussed, but she remembers it being presented as though very few people had the virus at that point; because of this, many people did not consider information about the HIV/AIDS important. "HIV, it wasn't like now when there could be a crowd of people, perhaps there were only two [in the crowd], but now we are so many." Her voice trailed off and I felt as though she was reflecting on her recent diagnosis and the discovery of her membership in a collective of PLWHA. Focusing on the years before her diagnosis, I asked her with whom she had talked, prior to her diagnosis, to gather information about HIV/AIDS.

“I just went to the hospital and found a nurse. Her name was Sister Stacey, and I called her when I wanted to know the answer to a question. She is my friend and asked someone from the clinic to help me, because I am still here.”

“And this is when you found out that you were positive?” Mariam nodded.

“Okay, what about before? Did you ever talk to anybody about HIV, just to find out information?” I asked, trying to establish the extent of her knowledge of the disease prior to her diagnosis.

“Yeah, I used to talk to my aunt, or my brother who is sick. What shall I do, what shall I do? I would ask. Should I just treat her, treat him like this, do this—What?”

“So how should you treat someone with HIV/AIDS, that’s what you used to talk about?” I asked this question to make it clear that I understood what she was telling me.

She nodded and continued to share the advice she had received from her aunt and brother. “Just treat her, him or her, the way you need to treat other people, ‘because you never know today it’s me, tomorrow it could be you.’”

“Are people in your community aware of your status?” I asked, trying to gauge if she had sought support yet, or if she was still struggling with acceptance.

“No. No one knows. It’s only in my family. And I don’t know if they have already gone and told some people. But if I have it, I still have it, and will have it,” she said, matter-of-factly.

“People will know eventually, is that what you are saying?” She nodded and I continued. “Okay. Now that your family knows and this may be hard to talk about, but now that they know you have HIV, do they treat you any differently?”

“No. Still they treat me exactly the way they used to.” She said this quickly and I hoped that she did not think I was accusing her family of mistreating her. I decided to change the subject.

“I want to talk about some of the ideas you’ve heard about where HIV comes from. In your community, people don’t know your status, but do they ever talk about people who have HIV?” I asked.

“Yeah,” Mariam responded, but offered nothing more. I probed further.

“And what do these people say?” I asked.

“Just bad stuff, they say, you know, perhaps she is a prostitute that is why she got infected.”

“Even though she isn’t?” I questioned.

“Yep. I used to think the same, like that. But after all, I wasn’t a prostitute, and I am now HIV-positive, see? People they think if you are infected you are unfaithful, and have many men,” Mariam clarified. When I asked her why she supposed people thought this way, she said she did not know.

“What changes do you think can be made in your community to make people more educated about the disease?” I asked.

Mariam paused before answering, “My hope for HIV/AIDS in the future is that the government, health organizations, and educational institutions will place a greater effort on communicating the facts about the disease and create support in my community.” When I asked what the main educational message should be she stated, “Just to be honest and straight with the people—how people can be affected. Let us stick together and we can do it!”

When I asked Mariam about the age at which she believes education surrounding AIDS-related information should be introduced to children, she replied, “10 years.” She believes this is the appropriate age because she knows of children this young who are already affected and infected. When given the journal, Mariam was encouraged to write in it and add photos to it as often as she wanted. She used the camera only three times. The first photo she took (see Figure 2) connected very well with her hopes for the future. Mariam took the picture above inside an orphanage managed by a neighbor who provides shelter for needy children, most of whom have been orphaned by AIDS. The children in the photo lost their parents to AIDS. She said, “If the children could receive education at a younger age, they will better understand their life, the situation they are raised in. Then they can prepare themselves better. This will hopefully prevent them from getting the



*Figure 2.* Untitled. Mariam. (October 2011).



HIV.” She hopes that if communities work together more positively, prevention will be possible.

### **P. Diddy**

It was apparent by her choice of pseudonym that my hour with P. Diddy (also the name of a rapper of the 1990s) would be anything but boring. She strolled into the office I had designated for interviews with the brightest smile I had ever seen. “Hi dada, nice to see you again,” she said as she shook my hand to say hello. The translator entered the room and was about to assume her seat, but P. Diddy shook her head and said, “No, no, I can speak for myself; I want to do this by myself with you.” P. Diddy shot me a very “I am serious” look, as she motioned with her hands for the translator to exit. I nodded at the translator and we immediately began to talk about our days and I reiterated what the interview would involve. She agreed to the process and we were off!

When I asked P. Diddy to tell me about how she found out about her positive status, who told her and how she felt about the diagnosis, she laughed. When I asked if she understood the question, she nodded and said, “Yeah,” then proceeded with a short and blunt answer that seemed to capture her experience with the virus.

“I knew about my status when it was last month. Last month, the date of twenty-seven. That’s when I went to the hospital, and then I was found out positive.” P. Diddy said the last sentence as though emphasizing its factual nature, as if saying it aloud were admitting it was true.

P. Diddy, now 25, completed her entire schooling, primary and secondary, in a public school system—a higher level of education than 56% of the young girls in her country receive (World Bank, 2004). Unfortunately, her exposure to AIDS-related

information occurred when she was in standard seven, one year after her parents had passed away. Besides never having had an opportunity to discuss the disease with her parents, P. Diddy did not have a mother to talk to about what it is like to be a teenage girl or to ask for advice on how to navigate those years. Thus, the facts she learned in high school about HIV/AIDS were not something she discussed, revisited, or even spent a whole lot of time thinking about, as little emphasis was placed on the subject.

P. Diddy was made aware of her positive status after visiting a clinic to take the necessary tests in order to travel for work.

“So you went to the clinic?” I repeated what P. Diddy had just told me.

“Yes,” she said while nodding.

Despite thinking I was asking an obvious question, I decided to proceed.

“Because you were feeling sick?” I asked.

“No,” she responded. “I just wanted to travel south.”

“So you needed to be tested [for HIV] first? I asked, surprised. P. Diddy later explained that it was a requirement to obtain the results before she was hired to work. She sat up straight, with a huge smile on her face as though she were being interviewed for a job. I continued asking her personal details about her life.

“Do you have a boyfriend or a husband?” I asked, thinking that the level of comfort I felt around her was strange, as we had only met once before.

“Yes,” she beamed. “Just a fiancé.”

“Okay. So did he tell you or did you ask him about being positive? Does he know?”

“No,” she replied, without any emotion in her voice. Taking a mental note that it was still early in the acceptance stage for P. Diddy, I decided to ask her the question again. I remember that at the time, I wanted to know if she was still struggling with the diagnosis or if she was taking steps to reach acceptance. Of course, I wanted to do this without creating a sensitive situation. I re-worded the question and asked it a second time in hopes that she would elaborate further.

“He still doesn’t know then?” I asked again.

P. Diddy responded, “Yes, he does not know.” She then proceeded to look toward the floor as she twiddled her thumbs. I decided to change the subject, thinking I might ask more questions on her feelings about disclosure later. “So, you found that out a month ago?” P. Diddy nodded. “So before you found this out, can you tell me a little bit about what your life was like?” Again, she nodded in her agreement for me to proceed. “Did you go to school?” I asked.

“Yeah,” P. Diddy said in her playful manner, as if she were asking, “Isn’t that obvious?”

Smiling, I asked pleasantly, “And you finished high school?”

“Yes,” she said, this time with a proud smile. I decided to take her friendly demeanor as a signal for me to ask for details that were more personal about her life before HIV. I wanted to know the context in which she understood sex, relationships, and disease.

“And did you date in high school?”

“To date?” P. Diddy asked, looking puzzled. I stumbled for a second, searching my brain to find the words to describe the concept of dating. This was something I had never really had to do before.

“Date. Ahhh, were you seeing any men in high school?” Again, I saw confusion on her face. “Did you have any intimate, or how can I put this? Romantic relationships? Where you were more than friends?”

P. Diddy laughed before telling me no. Seeing that the relationship question did not stimulate a conversation about the circumstances of her infection, I consulted my interview guide. Looking back, it was presumptuous of me to assume that she had contracted HIV during sex, because she could have been born with it or contracted it through some other means. “No relationships in high school?” I repeated. “Well, when you were in school did your teachers talk about HIV/AIDS?”

“Yes, just a little,” she offered.

“And do you feel like before you found out about your status that you understood what HIV was and where it came from?” I inquired. P. Diddy paused as if she were reflecting on her grade school experience. When she finally responded, I was sure she had misinterpreted the question I was asking.

“HIV can come maybe through blood transaction and mother to child,” P. Diddy stated matter-of-factly.

“Yes,” I said, pausing to allow her to continue.

P. Diddy listed modes of infection. “Blood transfusions and sex without any, without any . . .” She was struggling for the English word.

“Protection,” I answered for her, wishing I had let her come to the response on her own. But she smiled, clapped her hands, and rose out of her seat in her excitement. “Yes!” she shouted and began to giggle at her actions.

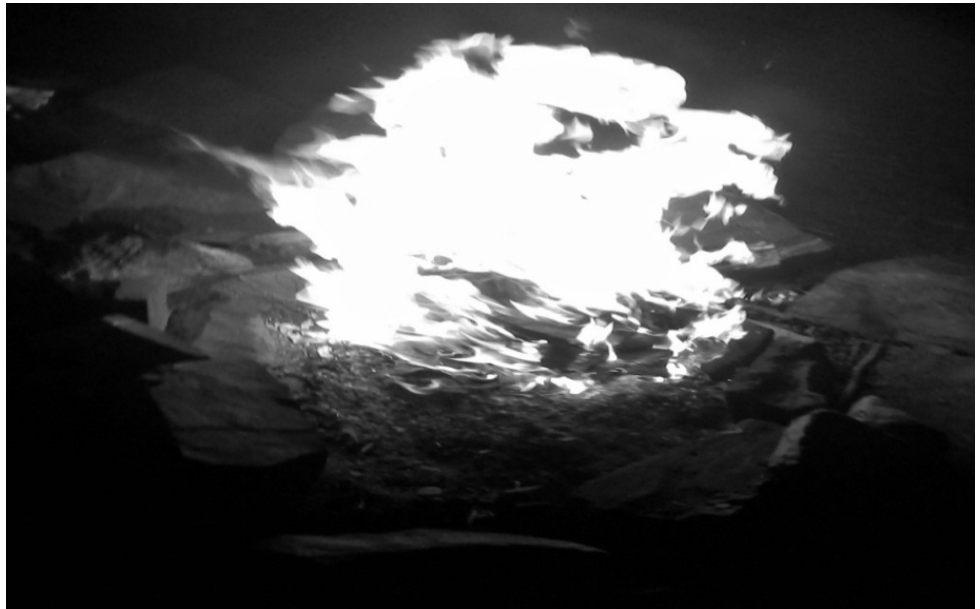
P. Diddy also responded in the affirmative when I asked, “Did you learn that in school then?” I posed this question to confirm that her secondary education experience had indeed been an informative source of knowledge about the disease. While she explained the facts she had learned in school, she made no mention of learning about the emotions a person with HIV might experience. In her journal, however, P. Diddy used imagery to convey what it was like to have HIV. In her photo-journal, as seen in the picture of fire, (see Figure 3), she wrote “VVU ni kama moto,” which is Kiswahili for “HIV is like fire.”

In her journal description of the fire photo, P. Diddy further equates the virus with fire by writing:

In our lives, some things we use, but they end up harming us. For example, FIRE. Fire is something, which was brought to us by God for our daily use. That is, cooking, lighting the dark, and so on. This same fire can bring a lot of harmful effects to our society.

For example, burning our houses or getting electric shorts—that lead to loss of so many people’s lives. When I try to relate fire to HIV or AIDS, it is like saying that having sex in a tender age or in the wrong time is the same as getting into a fire by yourself. Everyone must be afraid of fire; even if it’s a spark, you can be harmed.

P. Diddy’s cleverness always shone through in our conversations and in her



*Figure 3.* VVU ni kama moto. Diddy, P. (September 2011).

written work. Her ability to convey the fear of the virus through literary imagery to take me deep into her emotional process with the disease in one instant, then nonchalantly shrug off her diagnosis in the next, provided me with yet another vivid reminder of how similar we were in terms of the desire to be creative. Yet I was simultaneously reminded of how different we were, as I could not fully comprehend the internal struggles she must be battling with at the same age. Eager to learn more about how she had first come to understand the terms “HIV” and “AIDS,” I asked P. Diddy, “Who did you first learn about HIV/AIDS from? Who was the first person or group that you ever heard speaking about the disease?”

P. Diddy pondered for a moment. “So many people talk about HIV/AIDS nowadays.”

“When you were younger did they?” I wanted to know. Secretly, I think I wanted P. Diddy to say that her peers or family members spoke of the matter, to agree with some of the literature I had read prior to coming to Mombasa. However, she responded with a simple, “I was just in Class seven.” Immediately after I had posed the next few questions, I almost wished I had not.

“Class seven?” I repeated her answer and P. Diddy nodded in confirmation. “Um, did your parents ever talk about it?”

Her smile faded as her eyes drifted to the plastic shutter window of the room. Gazing upon it, without turning to look toward me, in a detached tone she said, “My parents died when I was still in Class six.”

Blurting out the first thing that came to mind, my researcher hat fell off, hit the ground, and stayed there. I was a listener and this was not just an interview. I was

learning about the hardships of another human being—a woman a little older than myself.

“Oh no, I’m sorry. So you never had the chance to ever talk about . . . .” The words stumbled out of my mouth, but before I could finish, P. Diddy interjected a flat “No.”

She must have identified my struggle for words through the statue-like expression and pose that had taken over my face and body. P. Diddy reached out and touched my hand. A soft smile began to develop at the corners of her mouth as she gave me a look and said, “It’s okay, let’s move on.” I returned the smile and pretended to look through my interview guide until I felt ready to continue with the questions.

“Okay, so, um, what do community members who are not HIV-positive, do they know about your status?” I asked.

“No.” P. Diddy responded quickly, and I knew immediately that I had touched on another sensitive subject. I proceeded with caution anyway, because I felt that her story was important. I reminded myself she would not be here if she did not, on some level, want to share her experience.

“No? No one does?” I asked, surprised.

“Just a friend,” P. Diddy stated. In disbelief that this confident young woman, who seemed so sure of herself, had the ability keep such a complex emotional diagnosis almost completely to herself, I asked for clarification.

“So right now, the only person who knows about your status . . . .” P. Diddy nodded so I did not have to finish my sentence. “Are you afraid of how others will treat you if you decide to tell them?”

Again, the one word answer: “Yes.”



“What do you think your fiancé will say?” I asked this in a tone of curiosity and not condemnation. P. Diddy shook her head and communicated she did not know how her future husband would respond. With the same inquisitiveness, I proceeded to ask, “What do you think your family would say? Is there a reason for not telling them?”

P. Diddy quietly uttered the word “Yes” in a tone barely audible.

“Why is that?” I asked with a little too much urgency. I badly needed to know what she was going through.

After a long pause and some laughter on her part, I tried to assure P. Diddy that the interview was a safe space. “Take your time, feel comfortable,” I offered. She thought for a minute or two and then explained.

“Ah, they will not be sure if I would have gotten that disease . . . .” Eyes wide, she gestured her hands towards me, followed by a questioning, “Yes, yes?” to ask if I understood what she was talking about.

“Oh,” I said dragging out the syllable, communicating that I thought I understood. “So they won’t be sure where you got it from? They won’t believe you got it from your fiancé?” I posed the question in a slightly confused tone, indicating that I needed more information.

“Yes. Maybe they will think that he is the one who give it to me.” She said this as though she was not sure he had.

Trying to understand further I asked, “Okay, but what else will they think? That it was someone else?”

“No.” P. Diddy answered. She turned her gaze towards the window once again, signaling me to move on to another subject. Perhaps I would come back to this.

Wanting to know about her relationships that might influence her perceptions of the disease and her experience living with the virus, I asked P. Diddy, “Before you knew your positive status, who could you or would you go to in order ask a question about HIV or AIDS?”

“My friend,” she responded, “My best friend.”

“She knows a lot about . . . .” I paused, “She’s very educated?” I asked, restating my question.

“Yes,” P. Diddy replied. In my head, I began to ponder the practicality of a friend as an accurate source for medical information, but I did not know her friend’s background and could not make assumptions.

“Could you ask the doctor? Did you ever go to one for advice?” I decided to ask.

“Yes, I have one; one of my friends is a doc.” P. Diddy indicated that these were separate friends. For advice about health information, she visited her doctor friend, whom she felt was very helpful. After asking her what sorts of things they discuss, P. Diddy explained that her friend always encourages her to disclose. “She asks me how can I live without anybody knowing I am infected?”

“Does she tell you how you can talk to your fiancé or that it is important for him to know?” I asked in a tone almost urging her to talk to someone. I had read contradictory articles on the benefits and harms of disclosure, most written from a Western perspective, and without knowing the cultural, religious, or social norms that guided her household, I had no right to urge her to do so.

“She says ‘go to talk to your friends and your fiancé’ and then maybe if he refuse to go to the clinic together, I can decide for myself to leave him because it’s my life.”

“She sounds like a good friend. Okay, besides your friend have you ever received any education from ads on television, the radio, or newspapers?” I asked, wanting to know other ways in which she had learned about the disease. She nodded in the affirmative. “What kinds of ads, or what did they say, or do you remember?”

“They say, you have to, when we’re sharing sex, when you’re sharing love with them, with a person you have to ask about their status.” I asked about other information sources, such as computers, but she hadn’t accessed them for AIDS-related information.

P. Diddy did indicate that there were several socially accepted norms associated with HIV and that it was from people in her community that she received certain ideas about HIV/AIDS. I asked her to elaborate.

She answered immediately. “They say that getting HIV/AIDS is not the end of life.” I was happy to hear her hopeful tone and that some encouraging ideas seemed to exist in her community.

“Do community members ever say bad things about people with HIV?” I inquired.

P. Diddy explained that bad things were not necessarily said but, “If a friend was diagnosed positive, one is expected to say sorry because anybody can get it, and maybe one day it could be you, a person is unable to know until it happens.”

“Okay, and are people ever afraid of others who have HIV?” I asked.

“Yes,” she said. “How it affects you, yes?”

Needing clarification, I asked, “So how it makes you sick or what?”

“Yes, like shivering, maybe you lose,” she said, meaning weight. “The body becomes gross.”

P. Diddy laughed when I asked if people from her community ever thought HIV was the result of a spell or witchcraft. “Some they say it’s a curse. Yeah?” She questioned to see if I understood.

“Why? Who curses you?” I wanted to know. She laughed again and I began to offer ideas I had read in the literature. “By God? I’m just trying to understand.”

P. Diddy interrupted before I could finish. “Maybe. Maybe it is a punishment.”

“Okay, so that is what some people believe?” I asked again.

“Yeah.” Her answer confirmed these were not only her thoughts, so I decided to ask more about societal beliefs about the disease.

“What are some existing ideas about death and fear of death surrounding HIV/AIDS that you have heard from people in the community, P. Diddy?”

“Every human being must die. But some people, they are fearing death, but it is a must. All human being at the last day, they must die.” She laughed at this remark.

“That’s true,” was all I could say, because, well, she was right.

“Yes for some they are fearing,” she continued.

“And they fear the disease because of death?” I asked.

She nodded before adding, “They fear.”

“So knowing how other people think about HIV/AIDS, do you think they think positively, negatively, or they think, ‘Awe, it’s a disease you can just live with it?’” I asked.

“Some they don’t care, but some do,” she replied. “Some they say it’s better you live poor than get the disease.”

“Do some people in the community think you can get rid of HIV if you do something?” I asked, not sure if she would understand my question.

“Yeah,” she replied. “Some of them think that women, like so many women who has men, they will get the disease.” I nodded and began to ask her questions about how the education system and how government and health organizations that had a presence in her community could make changes to improve access to and delivery of AIDS-related information. “Educate the community and let them know how the disease can affect them. Some are illiterate,” she stated bluntly. “So they have to be taught,” she continued with conviction.

“What do you think is the right age to tell somebody about the disease?” I asked.

“The age of ten. Ten or fifteen.”

“Why is that? Is that when people become sexually active?” I questioned, trying to understand her justification for this early age.

“Yes. Boys and girls nowadays, I have seen them around my area.” When I later asked her to clarify, she confirmed that she was talking about youth in her community who were engaged in romantic relationships involving sex.

“What about parents? Do parents usually talk to their children about HIV?” I asked.

“Some they are talking with their children, but some they don’t care about it. They don’t have the time to talk with their children.” She said this last part in a bit of an angry manner.

“So they don’t think it’s important?” I inquired. She nodded to confirm this was true.

“Do you think teachers believe it is important in the school system?” To this question, she also responded in the affirmative. “Do they test you on it? Or do they just talk about it?” I asked, curious.

“They just talk about it,” she said. I asked P. Diddy more about the changes that she thought were needed. “I know the disease transmission but would like to learn more. In the future, I hope that a deeper understanding of the disease in my community will reach everyone. If there was more AIDS education in schools, children would be better prepared to make safer choices.”

### **Tina**

“I don’t know how I got HIV, how I was infected with the HIV.” These were the first words Tina spoke when I asked about her life before she discovered her positive status. Tina requested to have a translator present on the day of our interview but was adamant that when she felt able, she would speak in English. She sat in a chair close to the window, looking like she was hoping for a breeze to pass through to cool her down. Tina was holding her baby while simultaneously wiping beads of sweat off her forehead. The weather was beginning to heat up in Mombasa and I knew she had traveled a long way to take part in this interview. I offered her a bottle of water, which she gratefully accepted before sharing the story of the day she found out her positive status.

“It was 2007, in September, when I went to the hospital to be tested for TB [tuberculosis]. I was also tested for HIV and found out that I was positive. This is how I found out.” She paused as she recalled the happenings of that day. “I was taken back to my husband but he refused me. He said I should get out of my own home because he didn’t know where I got the HIV. He chased me away after he refused to get the test. He

said he doesn't want to be tested. My aunt took me in after he chased me away, and there I continued with my treatment."

"That must have been hard," I responded, trying to grasp the gravity of the situation.

"It was," Tina said, "but I stayed with my sisters and my aunt until I was feeling better and could stand on my own. I even started a small cooking business. As I was going on with my business, that is when I met my second husband. I thank God I got my Papaa [pseudonym for her husband] and was able to get my own house."

"Okay, and was Papaa ever tested?" I inquired, trying to piece together the workings of her new partnership.

"Yes. Papaa has been tested also, but he is not HIV-positive," she said, with a smile forming as she looked down at the baby and gently rocked her back and forth. "We stay with Papaa now; he accepts what I have and cares much for our baby."

"That is nice to hear, Tina. What about before having HIV? When you were younger, did you go to school?" I asked and waited patiently for the translator to communicate the meaning of the question to Tina.

"I went as far as Class eight, but when it was time to go forward, my mother realized that I was pregnant with my first husband's pregnancy. So I could not go to school anymore, since my mother asked, 'Are you going to take care of the pregnancy or are you going to go to school?' It forced me not to go to school because of the pregnancy." Tina seemed as though she were deeply reflecting on the choice she had made as a 16-year-old. She gently rocked her second child back and forth and stared off

in a daze. She further explained how in 2007, after dropping out, she had married her first child's father. That was the same year she discovered her status.

“When you were in school did your teachers ever talk about HIV?” I asked, interested in what knowledge she had encountered about the disease before her actual diagnosis. She explained how up until finding out her status, HIV/AIDS had remained a topic only covered in her primary school class, where her teachers had placed little emphasis on the disease and disregarded its seriousness. She also recalled the disease being equated with the Ebola virus, which, like HIV, is normally transmitted through bodily fluids.

“People used to call it Ebola. They were saying ‘EBOLA IS IN OUR COUNTRY, EBOLA IS IN OUR COUNTRY!’” Tina rose off her chair and lightly began to bounce her baby. She told me this bit of her story as if she were transported back to the classroom where her mates were shouting about the disease.

I smiled at her actions and was happy to see that some of the shyness was starting to fall away. “What about community members who are not HIV-positive, or whose status is unknown—what do they think about the people who have it?” I asked, and waited for the translator to clarify the question so that Tina could form a response.

“People are talking about it [HIV/AIDS] to be a very bad disease. They know that I am positive, but most of the people in the community are talking about it as a very bad disease. In fact, some days back I was abused by some people and somebody told me, ‘You are going to die. Do you think we don’t know you are using the drugs, we know you are using the ARV drugs and we know you are going to die. Don’t tell us anything,



you are just going to die.’ They think I can even affect them by sitting with them, because they don’t have any knowledge about how HIV is transmitted.”

I asked Tina if there were any other ideas that she was able to remember existing in her community about HIV. She had little to say on the subject during the interview. She explained how she does not think people were overly concerned with contracting the virus. To this day, she does not understand exactly how she came to be HIV-positive. However, in Tina’s photo-journal, she further described several ideas related to the stigma and fear surrounding infection that were present in her community. The following is a list of some of the ideas Tina documented:

- Home utensils—like cups, plates, and spoons—they are separate and keep yours away.
- If you go to the toilet, people fear to use that toilet again.
- People fear to greet you.
- People think that they can get infected by using your clothes.
- People [who are not positive] cannot eat with you.
- If you are a teacher—when parents get to know your status they take their kids out of that school—they transfer them.
- When students get to know the status of their fellows they stigmatize him or her, even they fear to play or sit with him/her.
- People fear to wash your clothes.
- People fear to use a basin or a soap, which has been used by you.

The following photo (Figure 4) was taken in the home of Tina and Papaa. Tina explained that the lighting was not the best in her kitchen, but that the photo includes the laundry and the dishes, as well as the plastic water storage jugs in which she retrieves the water to do the washing each week. Tina's sister took the photo of her washing, as others are afraid to help do the laundry when Tina's clothes have been mixed in with the rest of the clothes. It is the same case for her utensils and dishes in the home, of which Tina said, "I take extra care while washing, so that my family is not at risk."

"You said people talk about you when you walk so what do you mean? What do they say?" I asked, wanting to know why she wrote about it in her journal and if the things that had been said to her were as awful as the comments I had heard peers make in my own country. In addition to the fears and discourses surrounding infection, Tina described being openly stigmatized by community members who know her status and equate her as a carrier of death.

Tina was ready to answer. "For example, somebody has known your status; it could be a person who knows me very well. You can pass somewhere and you will hear people saying, 'eeh, that one, she has it, she has it and she is going to die very soon that is why I decide to write it here. When you walk, people spread rumors about you and fear you carry death.'"

Tina explained how she has seen people who have the opportunity to attend just one, two, or three sessions of HIV education training and how their discriminatory opinions of PLWHA drastically decreased following training. This training covers essential health information and life skills for sexually active persons, issues of stigma, and all aspects of treatment, support, and care for those who are HIV-positive.



*Figure 4.* Clothes. Tina. (September 2011).

She also communicated that those who have not received training continue to believe that HIV can be passed via causal contact or by sharing spaces with an infected person.

“But people who have not gone for trainings . . . do they think things? For example, that it can be passed through the air or that just by looking into your eyes you can pass it to them?” I asked.

“Some people think like that, but not all, but most. I passed through a lot, me I passed through a lot of people who discriminate.” Tina seemed to have few ideas left to share about the AIDS-related information she had heard in the community. The baby began crying and it was hard to hear Tina’s voice, and the translators, over the sobs.

“Is she hungry?” I smiled.

She laughed and gave me a nod. It had been a long day for the baby and Tina, so I decided to end the interview with one last question. “Before you go, I want to ask about what changes you think can be made by the government to educational policies, education curriculums in schools, and programs in your community to increase knowledge, access to resources, and support for people living with HIV?”

After my question had been translated for her, she took a moment to construct her answer. Looking at her child while she spoke, Tina said, “Bringing this subject to school will help because there are some kids who their parents died a long time ago and they need to know how their parents died or what from. Now, it’s good if they get tested and they get knowledge about HIV and how it is being contracted and they will know how they are going to protect themselves if they have the HIV virus and they will know how to protect themselves and live a happy life. Child become at an adolescent stage, they become higher [meaning it is a time for learning] so when they are being told about HIV

and how it is transmitted they will know how to protect themselves so they cannot get infected with HIV.”

Tina is hopeful that a higher quality of AIDS-related education will be integrated into the school systems, so that her five-year-old son and baby will one day receive the formal education about the subject that she did not. Despite this hope, she did not indicate whether she would share information with her own children in the event it is not addressed in the classroom.

### **Sabina**

“Up country,” in a tiny Kenyan village, was the childhood home of now 25-year-old Sabina. There, she attended a small public school until she reached Class six. At the tender age of 12, Sabina and her sister were orphaned after the loss of both parents. Unable to afford the transport and fees, she discontinued her education. Sabina began her story by taking me back to her early years, describing her village, and recounting details from her childhood.

“I came from a tiny village, up country, near the Lake Turkana. It was only me and my sister together, alone, we came here together to find other family. I went to school up to Class six, which is when my parents passed away. I have suffered a lot since I am an orphan, that is my level, Class six. I am a Class six leaver.”

Despite parts of her dialogue being translated to me during the interview, I paid close attention to her expressions, trying to read her body language. When she spoke of her parents’ death and leaving school (and later the village), the emotion in her expression conveyed a longing to go back, the desire to be able to have everything start over again so that somehow, the outcome would be different.

“I am sorry about your parents,” I said earnestly, looking Sabina in the eyes. “Do you know how you contracted the virus?” I asked, feeling horrible about the possibility of dragging up more bad memories.

“I can’t recall how I got the disease. I am not sure if it was my boyfriend or who else because my boyfriend was not around and I was suffering from the illness and tested.” This test took place in June of 2011, when she fell very ill and went to the doctor to find out the cause. After being tested and diagnosed with typhoid fever, she was also found to be HIV-positive and was immediately started on treatment. In the midst of the interview, I did not think to ask Sabina to elaborate on her statements, but when she returned weeks later to discuss transcripts and interpretations, I asked her what she had meant when she said, “or who else.” Tears formed in her eyes and the translator sat close and held her hand.

What followed was a brief discussion, and Sabina spoke so quickly in between tears that the transcripts were barely audible. However, the translator did explain that Sabina had been raped by a man she did not know, prior to leaving her village. Despite this horrible circumstance, it is impossible to know whether this was how Sabina was infected by the virus, as she did not go to the clinic in the rural village at the time. It is clear that she did not know the source of her infection either, as she continued with her story. “I called him,” she said, referring to her boyfriend at the time. “I tell him that I am on drugs [for HIV]. He told me he would be back, but the second day he didn’t show up. I don’t know . . .” She uttered the last bit as her voice trailed off. I waited a few moments before asking Sabina if she was ready to continue with the interview.

“When you were in Class six or below, did your teachers ever talk about HIV or AIDS?” I asked this question in an attempt to steer the subject away from her painful past.

“They just used to talk about HIV, but I was young and I couldn’t understand,” she replied.

“Were you ever tested on facts about HIV/AIDS in school?” I inquired, trying to gauge the quality of her formal education experience. “Like knowledge about HIV/AIDS? Were you ever tested on that? On a written exam?”

She waited for the translation and took a moment to recall her experience. “Nothing like that because I stay up country, in village areas and there was nothing like that at all,” Sabina stated.

“How often did your teacher talk about HIV?” I asked, wondering if it was a one-off occasion or if it was integrated into a series of several conversations.

“That one time,” Sabina remarked. This could be an indicator that rural village settings, like the one in which Sabina resided, lacked sufficient curriculum materials to deliver information about the disease effectively. It may also have been the case that she was too young to interpret the health messages in a meaningful way. The latter was the reason Sabina believed was responsible for her incomprehension.

“Did you not understand the facts because they were too complicated?” I questioned.

“Yes. I think I was too young to understand the information, or maybe, I am not sure,” she said, shaking her head, as if she were still searching for reasons.

“Before you knew your positive status, who would or could you go to in order to ask questions about HIV/AIDS?” I asked, wondering if anyone in her village had ever discussed the topic with her.

“I would get information from a clinic. When I sent my child to the clinic, there was a Sister [from the church], who has been a friend to me. I used to see her before and she used to tell me all about HIV,” Sabina answered.

“Okay, and now?” I asked curiously. “Is that where you still go to get information?”

She shook her head and I knew she had understood my English. “Before, I used to live in a village that is when I used to get my information. Now I am in town [close to Mombasa city]. I have not asked questions, so I have not asked those questions,” Sabina said in reference to seeking AIDS-related information. When I asked about media as a source of knowledge, Sabina indicated that she had received some ideas about AIDS-related information from the television. “I watch it on television and I get information about HIV,” she stated.

“Is there a specific program?” I wondered.

“I have not seen a specific program but sometimes it [HIV information] used to show on TV breaks and I would get the information about HIV,” Sabina told me, referring to advertisements on television.

“What is it that they’re talking about?” I asked of the messages in the commercials. “I know they are talking about HIV/AIDS, but is it a program or like, the news?”



“Okay,” she said and looked up while putting on a thinking face. “It’s on KBC [Kenya television channel] and they are talking about a certain woman who was suffering from HIV. It was like an ad for a program, but I don’t know what, and that is where I get the information about HIV.”

“Do you remember any details about what you saw?” I asked, thinking there must be more to these advertisements if they were her only source of AIDS-related information now.

“I do not remember.” She let out a sigh and paused to think. “Just a woman?, suffering from HIV.” I decided to move on and ask about other sources of ideas about HIV/AIDS in her community.

“So I want to ask you some cultural ideas and about stigma. What do community members who are not HIV-positive, or do not know their status, think about people with HIV/AIDS?” I asked.

“Stigma is there,” Sabina said firmly. “At home, I face it, because when I discovered that I am HIV-positive, they isolated me. They separated things from me. They thought that I am going to spread the virus to them so I was left alone. But then I went to the hospital and got the information, I told them about it, they treated me equally, like themselves.”

Sabina communicated that this isolation went on for an extended period before she presented them with the information.

“So right now, who are you living with?” I asked, hurriedly adding, “if you don’t mind me asking?” realizing my question had been quite invasive.

“Right now, I am living with my sister,” Sabina said.

“Okay, and does she know your positive status?” I asked. Sabina nodded.

“Okay, and before she knew your status did she treat you differently?” I inquired.

“She has not cared with my status. The only difference is that the other women in the village, they are uncomfortable with me,” Sabina stated, later informing me that in addition to women in her community, this group included aunts and female cousins who were members of her extended family. “But my sister, she understands me completely.”

“Could you tell me what some of the women, the other women who are not okay with your status, who don’t know how to accept the disease? What are some of the things they say about people, or even you, who have HIV?” I inquired.

“Those women before they used to treat me badly, but when I started using drugs [ARV medication], and I gained my weight, and I was in good health, in a good position to walk on my own, to do anything—because before I was weak I couldn’t walk, I was bedridden, but when I started using the drugs and they saw me getting better each and every day, they started to treat me in a different way. Before they used to separate me from their kids and their homes. They are now giving me water with their cups, sharing food with me, and they treat me better. So I’m okay, but still they don’t know much about HIV. They think HIV people are not people to mingle with them.”

I wondered if perhaps these women in Sabina’s community thought that, because she had returned to her usual appearance, she might not have the virus anymore. I would never be sure. “So you said they share their food and their cups, and they let you by their families? Did they not let you do that before? Were they afraid to share food with you or be around you?” I realized after the interview I had repeated exactly what she had

already told me, but I was happy I had, as she elaborated further on her experience of their stigmatizing.

“Yeah, we are okay. I am okay with them because I shake hands with them, I drink with them, and I eat with them. Before they didn’t want to do anything with me because when I was at home, very sick on the bed, they’d come at our home, just stand by the door and say that I am going to die. But right now, I’m okay with them,” she said with a smile.

“Okay, that is good,” I stated, although I felt a little angry at the women for ever treating her badly at all. I had to constantly remind myself that not everyone has had the same exposure to AIDS-related information and to not let my overly emotional side get the best of me. “Okay, I just want to talk a little more about stigma; because I think what you’re saying is interesting.” She nodded. “Can you remember any specific comments they’ve ever said to you? For example, ‘don’t come near me’ or just anything that you can tell me about how you feel stigmatized, some specific examples I guess is what I am asking,” I said, hoping I hadn’t confused her or the translator by my roundabout question.

“Yes, those women they come where I was sleeping, eating my food when my sister was not there. When my sister was not with me, I could not eat anything or drink anything. What they used to tell me was, ‘if your mother died, you could also die, because we can’t look at you. Your sister is not here, unless you hire a maid to look after you, but we can’t look after you.’” She got this out before doubling over from her raging cough. She was not feeling the best and I hoped that retelling these stories was not making it worse, but she assured me she was fine to continue.

I looked at the last few questions on future changes concerning education. I tried to imagine what it would be like to have to fend for yourself at such a young age. After the interview, I found myself reading about children orphaned in Africa.

At the end of our time together, I asked Sabina what changes she thought could be made in Kenya in order to make a more supportive and safer environment for people growing up in the same situation. She told me that she thought AIDS-related education should begin at the age of 15. She feels youth are in a position to understand the issue at this time. Sabina also said, “I think people should get the information. Those who are infected should live positive-positively. And those who are not infected should know how to protect themselves from the virus so that each and every one should have the knowledge that HIV is there, and that they should take the precaution—protect themselves from HIV.”

Sabina had hoped to communicate her ideas more thoroughly in her photo-journal, in which she wrote diligently for over a month. However, in November she came to visit me at the NGO office, explaining through tears that it had been destroyed in the Mombasa rain we had in mid-October and that she didn’t know how to tell me. I assured her that it was not a problem and that she should not apologize, as this was just a creative process for her benefit designed to help her communicate ideas she could not find the words for during the interview. She seemed to feel better at the end of our conversation and I gave her another journal and camera, but explained that there would not be enough time to include it with the data collection and that if there was anything she wanted to add, she could tell me when we went over her transcripts.

Despite the isolation that Sabina often experiences with the rest of her family and community members, her sister's support gives her strength. She takes each day as it comes. On days when the effects of "Slim" (a nickname given to the wasting effects of the virus on the body) give her exterior a gaunt and fragile appearance, she endures stigma as community members call HIV/AIDS a death sentence and tell her it is her fault. On better days, she experiences periods of acceptance when the treatment works with her body to fight the infection, giving her renewed strength and a belief in a life that is as close to normal as she can imagine.

### **Stacy**

Stacy is a young woman who bore visible signs of the deleterious impacts of HIV on her body. Regardless of her small skeletal frame, watery, bloodshot eyes, and a cough that caused her to double over in the chair, Stacy had a beautiful wide smile. At the age of 24, Stacy's knowledge and understanding of AIDS-related information was limited, and the majority of her exposure to this knowledge occurred after her diagnosis. She understood the basics of transmission—sex, blood, and unsterilized objects—but did not fully comprehend how the process occurs. Wanting to know how Stacy had arrived here to share her story of living with HIV, I asked her to tell me what her life had been like before she found out her status.

"I used to work but when I got HIV, it was last year [2010] when I tested because I didn't know if I might have HIV because the man I had moved in with he started to react when I visited him." She later clarified that he had been sick when she would visit. "I tried to tell him about his life, and then he refused to talk to me about it. He didn't tell me he had HIV, but I knew he had." Stacy told me she was 19 when she learned of her

positive status, after convincing her partner to visit the clinic with her. He had reached a bedridden stage several times throughout the course of his sickness.

“At the moment we started it,” said Stacy, referring to the treatment, “we started healing. He was sick. I used to visit him, give him support—food and water. Then it—it was last year on October, I told him that he must visit the clinic, and then he said that we can go. We went to the clinic and he was tested. So I found that he had a HIV. He is HIV-positive but it was very high,” she said, shaking her head in sadness. When I asked her what was high, she explained that the viral load in his body was at a dangerous level, meaning he was already at an advanced stage of the illness.

“When we went to the hospital we had counseling and I was tested and he started treatment right away. Then, on December I went back to the clinic and they told me that I could not start the ARVs, I could start on the Septrin first because of my CD4 count.” I understood right away what she was telling me and I breathed a sigh of relief. Stacy had been diagnosed with the virus at an early stage, which meant she would have a better chance of the treatment being successful. “So I started on the Septrin, but the man I had, it was high, so he used the medicine,” Stacy continued. “I started using medicine, and it started on the spot,” she said of the medicine taking effect and working. “Nobody knew or knows up to now, that I am HIV-positive.”

“Okay, so people in the community are not aware of your HIV status?” I asked, making sure she had not left anyone out.

“No. In our area we are social with everybody, we communicate together, we sit together, everything we do together, and there is no separation.”

“So if they did know, would they treat you differently?” I wondered if this was why she had remarked earlier that her community does everything together. Stacy told me she didn’t think so, that everything would remain the same. If that was the case, I could not help but wonder if there were something she was not telling me. Perhaps she did not yet trust me, since she did not seem as open as the other women to sharing her thoughts.

Droplets of water leaked from the corner of Stacy’s eyes, but they were not tears. “An infection,” she explained, “that is worse because of the virus.” It was affecting her vision and making her eyes sensitive to anything from light to wind. I offered her a box of tissues from the desk and closed the curtains to block out the sunrays. “Asante [thank you],” she said, and I knew this had made it more comfortable for her, making me feel better about taking more time to learn about her life. I continued with my questions. “Where did you first learn about HIV/AIDS? Who first told you about it?” I asked, wondering how she had known that her partner’s symptoms were consistent with HIV.

“Mostly I heard on radios and listening to TV,” Stacy paused, thinking of other sources. “Oh, and counseling, counselors.”

“Counselors? Where were these counselors from?” I asked.

“Outreaches,” she stated, and I started to wonder how trained these counselors were. Stacy continued, “During outreaches, this group, [the partner NGO], they were coming to our areas to educate us, counsel us, and show us how to deal with people, yes.”

“Okay, and did you go to school when you were younger?” I inquired. She said she had but had not made it to secondary school. She did say, however, that her teachers had discussed HIV/AIDS in school in passing, but had not placed an emphasis on the

topic. This led me to believe that school was the first place she had heard of the disease.

“Before you knew your positive status, where would you go to ask a question about health?” I continued, trying to piece together her story of how she came to understand the disease.

“I went only to a doctor. The clinic I went to, they had counseling every Thursday so I used to go to it.” I was almost positive she had misunderstood what I had asked.

To clarify, I asked, “And this is before you had HIV?”

She shook her head to say no. “I had,” she answered.

“What about before?” I questioned.

“Nobody,” she said flatly.

“Nobody,” I repeated out loud and in my head a few times. I started to think to myself that this might have been a question that was of no relevance to her situation. Why would someone who knows very little about the disease search for information about it, especially if it was never really discussed in her home?

“Because I knew I am clean,” Stacy said, as though she had read my mind. When I asked if she had been curious or if there had been anyone she could have talked to if she had wanted, her answer to both questions was no. She also could not recall, at the time of the interview, many community ideas about HIV/AIDS.

“Some are talking that AIDS does not have a cure. They think if you have HIV you can die, you know, something like that . . .” She snapped her fingers and added “quickly.” The way she presented this to me, I thought that she was saying that the community was wrong, and that there was a cure for the disease. Before I could ask for clarification, she continued. “If you use ARVs you can live longer, stay longer,” she said



in reference to the medications helping a person stay alive longer. When asked in her second interview to clarify if she thought there was a cure, it was clear she fully understood that a treatment for HIV exists, but no cure. I tried for a few more minutes to get Stacy to share more of the ideas she had or that the people she knew had, but she divulged nothing else.

Despite not wanting to share much during our interview, I later read in her photo-journal some of her thoughts and feelings about issues the disease presented in her life.

In one caption she wrote:

The fear of people living with HIV/AIDS is that they're going to die very soon, but according to me if you are infected you can live for as long as you take your medicine properly. Most infected people are women, hence leaving [when they die] their kids without proper parental guidance just because they don't have anyone to look after them. But if there could be any group or organization, which can come up and take care of them it could be better because the children will be happy about their future.

This caption accompanied Stacy's untitled photo (see Figure 5) of children in her community. Stacy communicated during our second meeting that this photo was particularly significant in her life. "You see Laura? I was like these children. I lost them [parents] to AIDS, like they have lost." I felt sad for Stacy and these children as I realized she was talking about her growing up as an orphan, just as these children would.

This photo, I felt, helped put me in a position to understand her experience. I had struggled at many points during our conversation to understand what she was trying to tell

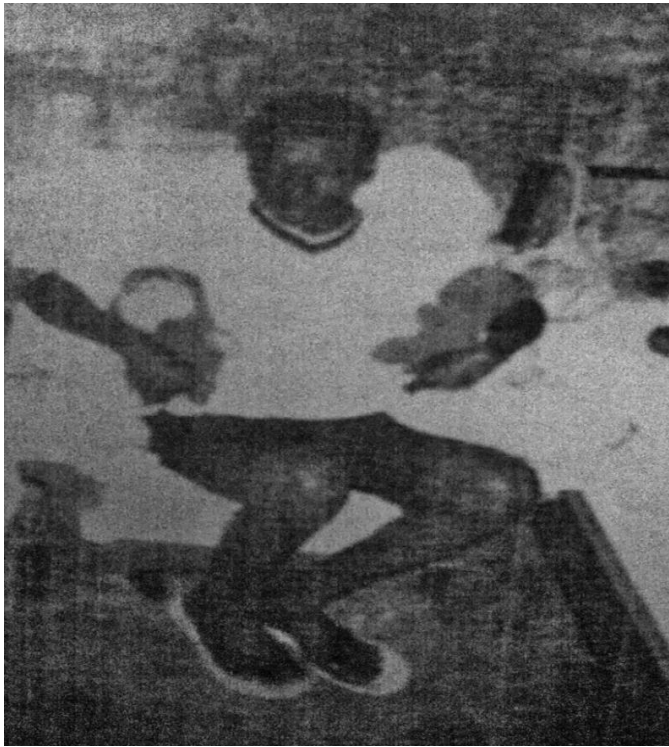


*Figure 5.* Untitled. Stacy. (October 2011).

me, because her stories were sometimes disjointed, with small details left out here and there. This may also have been the result of the translation process. The photo may be representative of Stacy's fear of what will happen to her family if she dies of the disease. Will someone take the children in and care for them as their own? Will they be educated? Will they be lonely? Stacy's description also signifies a message of hope that future institutional structures will be put in place to aid families affected by the virus. This would ensure that, once a parental figure has passed, the children would have a chance to avoid the same fate.

I was thankful that Stacy included the photograph and caption in her journal, as well as the next image she took and titled "Orphan" (See Figure 6). The image of a young girl, to whom Stacy assigned the pseudonym Teresia, is representative of what Stacy's life was like growing up as an orphaned child. Without the support of a family or parental figure, Stacy did not have access to the best education or, therefore, information to protect her against infection. Had Stacy grown up in a different environment, one that fostered support for her safety and development, she may have been in a better situation where she could have asserted her agency. Stacy told me that the image of the Teresia holding two teddy bears is her representation of how HIV/AIDS has penetrated the younger generation and will continue to do so unless orphaned youth are better supported within their communities. In the photograph's caption she wrote:

Teresia is a child who was born with HIV. She used to stay with her mother's sister when her mother died of AIDS. Her aunt gives her very good parental guidance, she also takes her for clinic every month to get



*Figure 6.* Orphan. Stacy. (October 2011).

treatment and medicine, which she is using to date and she is healthy up to now; and nobody can know that she lives with the virus while going to school.

“Teresia will be able to go further than most left behind,” Stacy said, as she gazed at the photograph (Figure 5). “How many will be as lucky as Teresia? Who will support those children who cannot support themselves and do not have the families to do so?” Stacy asked rhetorically. I thought that this question would be an extremely valid one to ask government policymakers, educational program officers, and health providers.

“What should people learn to help protect themselves and to educate, support, and be able to show tolerance for others?” I asked. Stacy suggested better education of youth, but explained that her hope for the future rests with the Kenyan government. She said, “They must do counseling and help the HIV infected because like us [those who have HIV] we don’t have any support from government or these groups [health organizations and NGOs]. But if there is a group like [the partner NGO] and us we are outside—we do not know about help they can give us. We, people who are HIV-positive, we must eat—we must do everything [the same as people who are not HIV-positive]. So if we can get support even if it is little support it would be good—the government helps those groups.”

Her frustrations regarding lack of access to information from these organizations as well as with the lack of advertising done by government agencies to advise people on where to seek out accurate information about HIV/AIDS were very evident. I thought this was a strong sentiment on which to end our interview for the day.

“Before ending our conversation today, is there anything else you would like to add that people should know or changes that can be made?” I asked, thinking she was finished. Stacy paused, and I realized she was formulating an answer. Perhaps there were many ideas running through her mind, but she chose to describe the importance of knowing one’s status and of being educated about testing at an early age. Stacy said, “Nowadays, even ten years and above education needs to begin because if it is a girl, who is ten, she at an age to understand. So we can educate them, yes.” She paused, then added, “They must educate the youth; they will be the ones here after us. If they can know early,” she said in reference to one’s status, “to test is important, and to know your partner, and the disease.” She took a deep breath before communicating her final thoughts for our conversation, “The youth they will be in a better place than me.”

### **Atoti**

Atoti was raised without a father and was cared for by her mother. Her mother was a small businesses owner, selling traditional brew. Traditional brew is a sub-standard form of alcohol that has been reported to cause severe sickness, loss of eyesight, and even death. It is more widely consumed in low-income areas where bottled beverages, imported from the global north, are not readily available to the majority of the population. By the time Atoti had advanced to class Five, her schooling was discontinued after her mother was arrested and detained in jail for selling the brew. Since her mother was the sole provider of her school fees, as well as the person taking her to and from school, Atoti was forced to stay home.

Recounting the details of her life that had led her to our meeting was not an easy task for Atoti. Mustering the courage to tell me how she had contracted the virus stirred

emotions deep within Atoti and these emotions came across in her words as she answered my question, “Can you tell how you came to find out you were HIV-positive?”

Atoti nodded. “I was sick. Then I went to the hospital; I was tested for TB. I found that I was HIV-positive. I went home and I told my fellows, but I was not happy with the results.” She stated how she isolated herself for a while before deciding she needed reconfirmation of her diagnosis. “Ah I went [clears throat] after staying alone for some time, I went to the doctor again.”

Atoti’s story of how she came to be HIV-positive was more complex than what she first offered. Not understanding the source of the virus in her case, I asked if she knew whether she had been born with it, or if it had been contracted in another way. Her voice broke as she walked me through the next part of her story. “I was raped, and after I was raped I came to realize that I was pregnant. By the time I went for the pregnancy test . . .” Her voice began to break. “When I was raped, that’s where I contracted HIV.”

“Okay.” I paused for a moment before asking “And you had the baby?” I sat trying to absorb the shock of what she had just disclosed to me.

“No,” she said sadly, shaking her head as tears began to stream down her face. In her photo-journal Atoti used animal symbolism, taking photos of an insect, a lion, and a leopard to show what the disease is in her life. To convey her thoughts and feelings about HIV/AIDS, she wrote:

The photo (see Figure 7) I have taken shows how the virus is like an insect. It enters and hides itself inside a person. It’s just the same as the insect biting the person and then hiding itself. To me, HIV is the insect that has given me a permanent mark.



*Figure 7.* The insect bite. Atoti. (September 2011).



This description accompanies the photo of the insect in the bowl (see Figure 6), which Atoti took in her home. “I was getting ready for dinner, to cook it, and there was the insect, it came out of nowhere, like HIV does,” she explained.

Atoti also took the next two photos, while watching a television program. The animals reminded her of the disease. The first picture she took was of a lion (See Figure 8). To her, the lion represented how people behaved once they came to know her status. Her caption reads:

Why have I taken a photo of this lion? Because most people do fear HIV, the way I fear the lion. With human beings when a person spots a lion he or she will usually collapse even before it comes near him or her. The same way people fear when they find out my status.

After looking at the lion photo and its caption, I was unsure if Atoti herself feared the disease or if this was how she portrayed the fears of others. This was clarified when I saw the next photo. In the third photo (See Figure 9), a picture of a leopard was taken from the television. Of the photo, she wrote, “Due to the photo I have taken of this leopard, it shows how I fear it, and that is why I have compared it to the disease.”

Despite the fears she conveyed in her journal, after disclosing her infection story during our conversation Atoti continued to tell me about how her mom made her less afraid. “My mother advised me. She gave me hope and told me that ‘HIV is something that is there, and you’re just going to live so long as you follow the doctor’s prescription. You’re just going to live.’” She began to sniffle and



*Figure 8.* Lion. Atoti. (September 2011).



*Figure 9.* Leopard. Atoti. (October 2011).

held back her tears. Without waiting for me to ask another question, Atoti continued. “I wanted to continue with the job but most of the people in my community were refusing to give me a job because they were stigmatizing me by saying, ‘you can’t work at my place because you are going to infect my kids, and you are going to infect people here, so I don’t want to take you as my worker.’”

“So they thought that just by you being around their children and other workers that you could infect them?” I restated what she had said to ensure that I had properly understood what she had meant.

“Mh mm,” she said, nodding.

“Okay, so now that people know, do they treat you differently?” I asked, wondering if she had experienced stigma outside of places of employment. She nodded. Atoti resides with her cousin who is also HIV-positive. Atoti disclosed that she does not always feel safe in this home environment. Her cousin’s husband verbally and physically abuses her as punishment based on his belief that Atoti transmitted the virus to his wife. “Do you really believe that is why he says mean things to you?” I asked of the verbal abuse she had disclosed.

“The husband he stigmatizes me because he doesn’t want his wife’s relatives staying with him. If people find out my status, they may know hers, so he treats me badly so I will leave,” she said softly.

“So it is hard to talk to people to make them aware of the disease?” I asked. She nodded in the affirmative.

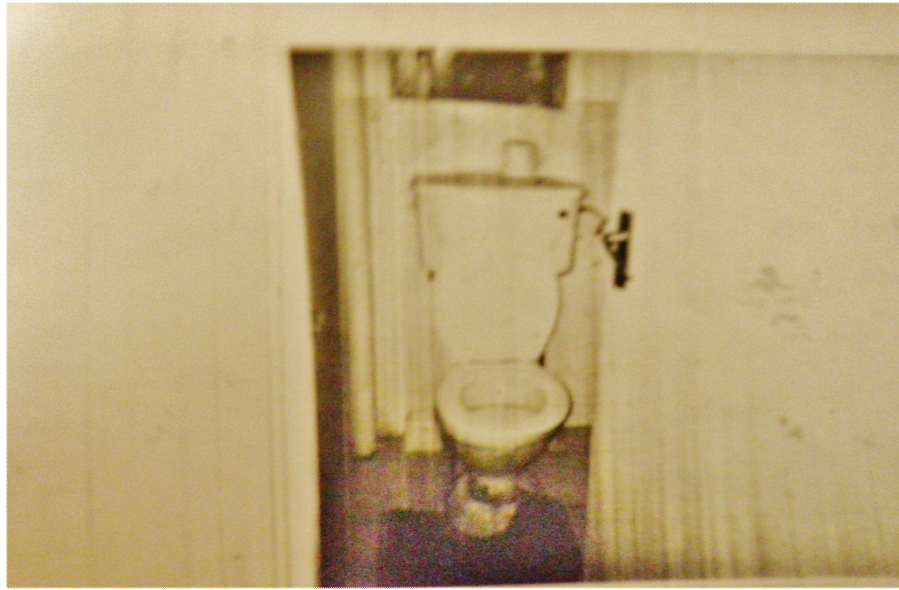
“When I was younger, I saw a girl who died of AIDS. She came from Nairobi, she was covered in nylon and buried,” Atoti explained, and a look went across her face hoping I understood.

“Okay.” I nodded. “Are there any other ideas in your community that you have heard people say about the disease or people with the virus, Atoti?”

After she thought for a moment, Atoti shook her head no. I told her that was okay and that if she could think of anything later, she could always write about it in her journal. That is exactly what she did. The picture (see Figure 10) taken by Atoti is not simply an image of a toilet.

Atoti explained that it represents households where family members have abandoned the HIV-positive women for fear of catching the virus from a toilet seat. In her journal, she wrote:

Why have I taken a photo of this toilet? Many people think when you share a toilet you can get the virus. Sharing the toilet cannot make you contract the virus. It is only when you are raped—having sex without a condom—or you get in an accident and you were sitting near a person who has the virus when his/her blood comes into contact with your open wound and yet you don’t have the virus. You might get infected with the virus [in these ways, you may not . . . referring to the toilet] so don’t fear sharing toilets.



*Figure 10.* The toilet in my home. Atoti. (October 2011).

Atoti also recorded other myths in her journal that existed in her community about how one could be infected with the virus. For these captions, Atoti also had accompanying photos. However, due to lighting quality, and perhaps how the camera was used, the photos did not develop correctly. Of the photos, she wrote:

- Some people think when you share soap with a person who has the virus you will also get infected.
- Some parents who are not infected will never allow their visitors who are infected to share with them the same towel, just because they think they will get the virus from touching the same towel.
- There is a parent I know who can never use a plate, which has been used by an infected person just because she believes she can contract the virus by sharing with an infected person, even though she really cannot.

Knowing she had no other ideas to offer about HIV that she had heard from friends, family peers, or members of her community, I decided to ask Atoti about support. “Where can you find information right now about access to treatment, support, and care?” I asked.

“I get the support, treatment, and care at the medical clinic. That is the place where I was first tested and realized that I was HIV-positive. I went to my homeland, but when I came back to Mombasa I continued taking my medicine at home.” She gave me a look to ensure I was still following and then continued to explain her experience of support. “I usually get the support and advices about HIV/AIDS from my fellow support

group members at the clinic, but nowadays we are getting our medicine from another district clinic, but we usually meet at the clinic just for the advices and to get the experiences about the fellow members of the support group. Because if you hear also somebody, somebody talking about herself, you feel at least you are better off with your own life.”

“You mean that you don’t feel as though you are the only person struggling with the disease?” I asked, wanting to make sure that I had understood her correctly.

“Yes, not so alone,” she replied.

The support and treatment Atoti received at her clinic acts both as a source of knowledge about the HIV/AIDS and its management and as a source of hope. In her journal, Atoti took a photo (see Figure 11) of a support group she attends. She took the photo herself during one of the support group sessions and did not give it a title. All of the members in the photo gave their consent for her to use the photo in the context of this research. In the caption, she wrote:

I have been enabled to share different things, which we [people who are HIV-positive] undergo. We share advices with each other on how to live positively, how we should take our medicine and how we can share our secrets. That is why I have decided to take a photo of all these people. I love you all. May God be with you.

To end our conversation, I asked Atoti what changes she would like to see in her community to make people more knowledgeable about HIV/AIDS. Atoti urged those who contract HIV to think positively about the disease and not dwell on dying. In addition, she touched on the importance of support for children who contract the virus





*Figure 11.* Support family. Atoti. (October 2011).

and need guidance to learn how to live positively with the virus. She took a deep breath and said, “I was raped 12/9/2008, from that date am taking medicine.”

I thought it was brave of her to repeat this again and could tell it had been difficult to do so. Atoti said, “I would say, I am pleading with you don’t leave your children just because they have the virus.” She spoke these words so sincerely that I could tell she truly believed that despite all the hardships and stigma they encounter, HIV-positive people can live positively if supported.

Atoti added, “What they can do to help is go door-to-door and advise people. Advise people now. After advising people, you know how people feel. You know when you go door-to-door you talk to somebody at her place where she is. He or she will feel this person,” she said, referring to a counselor, “has come to where they are at the home place so there is no need to refuse whatever information they want to tell me.” Atoti paused as she searched for the words to tell me how meaningful support in the home could be. “Somebody will feel very thankful for that person to come to where they are, to give advice about HIV. Now the people in the home will have the idea of getting tested and know her status. That will help everybody to know about HIV and understand more about HIV to protect themselves.”

At the age of 24 Atoti has had to endure a greater degree of emotional and physical suffering, at least from my Global North standpoint and experience, than most will experience in a lifetime. Her mother remains a strong source of emotional support and encourages her to follow the doctor’s prescriptions, saying she will live if she does so. Atoti’s ability to remain composed and hopeful in the face of adversity was another demonstration of her perseverance.

“A lot of women are infected though they fear going for clinic but the problem comes when they are pregnant and there is a need for the expected baby and mother to go for a checkup and get tested so as to know how to proceed. The woman becomes very worried after being tested and then finds that she is HIV-positive. But after that she is usually going to the clinic to get more treatment and information about the disease.” Perhaps Atoti was trying to make the point to me that she did not have to disclose to anyone, that it was only truly important to know her status and take the proper steps to maintain her health.

### **Jane**

Growing up in a rural village north of Mombasa without any formal education, Jane’s lack of community support and the outward disapproval of her positive status might have severely hindered her ability to think positively about managing her life with HIV. When she arrived at the NGO office to meet with me about the research in late August, I was unsure she would want to participate, but she surprised me. After I took a little over an hour to explain the process, the goals of the research, and who I was, she said that she would like to talk to me about her experience. She requested a translator and where this barrier had deterred other women from participating, to my pleasure it was not a problem for her. As a teenage girl, Jane moved away from her rural home to the city of Mombasa. After returning home to bury her father in the village, Jane fell extremely ill. A local doctor there informed Jane of her positive status at the age of 19.

“It’s now three years since I was tested and found the virus with AIDS, at that time I had my husband with me. My husband was first to be tested, outcome was

positive. I followed myself, and outcome was positive. By good luck, the baby was safe.”

“Before the age of nineteen were you living with your family or relatives?” I inquired.

“I was at my home with my parents,” she said.

“So did your parents ever talk about HIV/AIDS with you?” I probed, wondering if her parents had had any formal education and if they even knew about the disease.

“Yes,” she said, surprising me and reminding me that I should not be so quick to make assumptions.

“Yes,” I repeated, probably sounding surprised and hoping that the emotion was lost in translation. I did not want to come across as ignorant or all-knowing; I simply wanted to understand her experience. “What kinds of things did they tell you about the disease?” I queried. There was a long pause in our dialogue as the translator communicated the meaning of the question and then repeated Jane’s words back to me.

“My mother used to give me hope, she used to tell me, ‘don’t worry, you’re just going to live,’ but some people from outside they were telling me, ‘you’re not going to live, you’re just going to die because you have the HIV virus so you’re not going to live. If we share anything with you, for example utensils, we’re just going to die. You’re no longer going to live because you have the virus. You went to Mombasa and in Mombasa, you pretended you had a good life, but Mombasa is not a good place. Mombasa is where you contracted the disease and that is why you came here to our community and you’re not going to live.’” I asked the translator to clarify where this community was and she

made it clear that Jane had been speaking of returning home and of the people in the rural area.

“And that is what your rural community members think?” I asked, looking at Jane. She nodded and I knew she had understood. “So when they said things like that, how did it make you feel?” I asked. I wanted to understand the effects this cruelty by others had on Jane.

“I can respond in English,” Jane indicated. I smiled and she proceeded. “Okay, I felt very bad. Even I was just feeling like taking—so when you can take any poisons . . . so that I can die,” Jane said sadly as she gestured as though she was putting something in her mouth.

Knowing that at least some community members were aware of her status, I asked her to elaborate on how they treated her. Jane explained that her HIV had advanced quickly after she found out her diagnosis. She was soon bedridden to the point where she could not make her own way to the bathroom.

Jane explained, “People used to tell me ‘that is HIV and you’re just going to die.’ I used to know that I was not able to do anything by myself. Even I could urinate on the bed where I was sleeping because I couldn’t help myself to the toilet. That’s when people started saying ‘that’s HIV and you’re just going to die.’” When I thought she had finished with her story, Jane continued to speak to the translator in Kiswahili. “Before they knew I was HIV-positive, people were treating me very well, but after they came to realize that I was HIV-positive, people started treating me very badly, they were stigmatizing me badly.”

Accompanying the photos Jane took, which were not developed clearly (with the exception of the photo of the cup, Figure 12), Jane wrote this caption:

People around me discriminated me the most; they didn't want to share anything I am using—spoon, soap, and cup and toilet. People were scared to buy me tablets when I send them any tablets, painkiller or virus tablet thinking I will affect them with virus.

“So did the stigma ever stop you from wanting to go for treatment?” I asked Jane during our interview.

“I continued taking my medicine,” Jane said in English. “Because I was thinking about my kid and she is now three years old.” She told me this with a smile. “At the time, I was thinking about her and that is why I decided to take medicine.” Her love for the child was apparent in the way she spoke.

“Who did you get information about taking medicine from, to know to do so I mean?” I inquired.

“When I was tested at the hospital, they found I was HIV-positive. They got me the medicine there and I began taking treatment. I started to take Septrin but they told me to come back to see how I was going. They said, ‘before you go back to Mombasa, before you go back to your husband, we will test you again, so we can see how the medicine is responding to you, or give you another medicine and you can also join a support group. It’s right here, if you feel like, you can join the support group.’” She paused to cough and then continued. “I was unsure of the group,” she finished.

“Did they tell you how the support group could help? Or did they just tell you, ‘this is a support group for people with HIV, join if you want?’” I wanted to know



*Figure 12.* My cup. Jane. (October 2011).

whether or not the hospital had provided her with valuable information she could use to manage her HIV infection.

“When I was told about the support group at the hospital I went and talked to my step-mother. She is the one who explained to me about the support group. She gave me hope, telling me, ‘I’m HIV-positive and I am very okay because I’m still living and taking good care of my kids.’” Jane stopped; she looked to the translator and then to me and smiled. She wanted to see if I was correctly interpreting her words. I nodded and she finished her story. “‘Don’t worry you will also be okay, let’s just go to the hospital and join the support group because it will help you. You’re going to get a lot of advices about how to live positively,’ is what she told me,” Jane said, referring to her stepmother.

“Was there anyone else you would talk to besides your stepmother to get information about HIV?” in an attempt to find out if, regardless of those who had expressed their cruel sentiments about the disease, there were other sources of support or information in her life, and what ideas she had received about the disease.

“I usually get the information from the radio or from the television. I’ve heard advices from there.”

“What sort of things are being talked about?” I probed further.

“I hear things about condoms. The person talking with the men and women asking if they wear condoms or have live sex,” Jane said. I had heard the term *live sex* at some outreach events I attended around Mombasa; it means sex without condoms, and I was almost certain I had listened to the same radio show as Jane had, just two days earlier.



“Do they explain about safe sex practices at all?” I asked, remembering a few details of the program that I had heard featuring local radio hosts who spoke English. The same was true of the program Jane tuned in to.

“Most of the time they are just talking about experiences of stories they have heard about friends and the virus,” Jane explained.

“And do you learn anything from these stories?” I questioned, hoping she would tell me some of the take-away messages she had learned.

“Mostly I just listen. Sometimes we [referring to the television viewers] learn how to use condoms, or how to ask our partner to protect us.” Sensing that was all she had to say on the subject, I decided to move on and ask her about the changes she thought were necessary in Kenya, in terms of how people learn about HIV and access information, treatment, and support.

“The government should advise people, and also ask who is HIV-positive to try and get people to talk about HIV, because you can tell somebody to use a condom but when he or she goes to do sex they cannot choose it.”

“She can’t choose it?” I asked, wondering if that was what she had meant to say.

“People they can’t choose, because okay...” She paused to see how she could explain this without the help of the translator. “You may be a girl. Maybe your fiancé has told you to help him wear a condom, but here you help him wear the condom but maybe by the time you’re waiting for her to help he can decide to turn and he tears the condom so that he can, he can get, he wants to enjoy the sex. They’re [referring to males] saying doing sex with condom they will not enjoy. So they want to do sex without condom.” She raised her eyebrows, perhaps to see if I would react to this.

“The men?” I asked to confirm I had understood.

“Yeah,” she said, and continued to elaborate. “Somebody might tell you, your fiancé might say, ‘I am wearing a condom,’ but by the time maybe you are not looking at him, he removes the condom and throws it away without you seeing so that he can do sex with you, without a condom.”

“Okay, I understand, and you want to make people more aware about HIV to change their sex practices?” I asked, waiting for the translation.

“Yes,” she said, “and their ideas about people with HIV.”

With the support of her stepmother, who is also HIV-positive, Jane has found a voice of hope and encouragement to continue with her treatment and to seek the necessary support to ensure she understands how to best manage living with HIV.

### **Whitney**

“I am very happy because at 20 years I am healthy, my hemoglobin level is normal, and my pancreas, kidneys, and liver are all well,” Whitney said to me when she walked into the office for our interview and I asked how her day was going. As the youngest participant, she offered a unique story in terms of her upbringing and its influence on her ability to understand and better manage her positive status. Looking at and speaking with Whitney, an animated 20-year-old, one would never know she has lived her entire life with the HIV virus. She lost both her parents by the time she was twelve, but still managed to maintain her studies and is currently in training to be a Voluntary Counseling and Testing counselor.

It was her doctor who first came to her house to inform Whitney about the disease and her positive status. Whitney had watched her father become very sick, and two years

later her mother died after living through bouts of illness and going on and off an oxygen mask. At the time, she thought her mother had died of a broken heart. She will never forget the day her doctor showed up at her home and said, “Whitney do you know what your parents died from? Your mother was HIV-positive and so are you.” She had heard the terms HIV/AIDS on the news before, but she remembers asking the questions, “How does it [HIV] look like? How can I have HIV without a boyfriend?”

“Had you ever had conversations about it in school or with your parents?” I asked Whitney, after she had given me the abbreviated version of how she came to know her status.

“Sometimes,” she said, and continued to tell me more about the day she found out her status. “So after the death of my mum in May 2003, the doctor came to the house in the same year, in August, and told me about the disease and whatever. He told me ‘Whitney, you know, it’s been a secret now for a long time between your parents and me it’s good now that I can open up to you, tell you the truth, save your life, Whitney you can still be here. When I told your mum, your mum told your dad.’ This is what the doctor told me. ‘OK, do you know HIV means lower class to some people, HIV, is, what is it? So what is HIV?’ He asked me over and over before telling me, ‘You know HIV, how does it look like? How does the body act? HIV when HIV came to your parents, it came like a skeleton, very thin and he’s actually weighing less still he lived for a while.’ This is when he told me what killed my parents.” She said this all in what seemed like a single breath.

“How old were you when you found out?” I asked, immediately intrigued. How could you have such a serious condition for so long and not know? I thought to myself.

“12 years, I was just 12,” Whitney said.

“12 years,” I repeated, trying to remember my biggest ordeal at that age. “So your parents knew you were born with it and never told you?” Reflecting back, I asked this with a little too much judgment in my voice. Despite not being a parent, I understood the desire to protect others.

“Yeah,” she said softly. “I took vitamins everyday growing up, that is what I thought they were. These drugs kept me healthy and my immunity up.” Her parents probably took these measures to conceal her positive status to ensure Whitney was not subjected to labeling and stigmatization.

“So, for your mother then, did she contract it from your father or did he contract it from her? Do you know?” I inquired, trying to put pieces of her story together.

“I don’t know.” She paused for a moment and glanced toward the ceiling as though she were looking for an answer. “I don’t know.”

“That’s okay. So, when you found out what you had, did you cry, were you scared? What was your first reaction?” I realized I had sounded too eager as soon as the questions rolled off my tongue, but her story was already very different from the other women I had interviewed.

It took her only seconds to recall the emotions of that day. “I was very shocked, I cried a lot; I asked why, why, why, am I still alive? At 12 years old, my immunity was suppressed and I took different combinations of drugs like Kaletra, Neviraprine, Combirer, Zerit, Abacarir—you name it. The drugs used to have a lot of side effects for me: bloating, stomach pains, rashes on my body, and itching. I became very depressed

and most of the time I slept. I could not read or study well and thus my performance was affected.”

“So at the time where no one knew your status, did you talk about it a lot in school, or no?” I asked.

“It did exist in school, in fact the moment I was HIV-positive was in primary, I was going in and out, in and out, of school, because I realized I was having that disease. I would be sick, on and off.” I could hear the trials she had experienced in her tone.

“So you would leave school because you were sick?” I asked.

“Yeah.” She dragged out the syllable, knowing I had understood. “The medic that told the principal about my disease said, ‘This girl she is not feeling well she is having HIV that is why, she is shocked and she is in denial at the moment. You need to encourage her but don’t tell any of the other teachers about the disease, that she has HIV, because she is going to be pushed from school. The moment that she is feeling, it’s bad.’” Whitney paused and then added, “Yeah,” saying it to herself, as though she were remembering those early days of the disease when she was struggling to cope with her diagnosis.

“Okay, so when people did find out, when you decided to tell people your status, what, if you can remember, and I know this could be kind of painful to talk about, but are there any things they said about you besides that you’re just going to die? Were there any mean things they said? Or things about where they said you got the virus from?” I queried.

“Okay, before I started doing disclosure I used to be scared. When I go to school someone, follow me to school because I was scared. So when I would go to school I

would go home and people would see me and say ‘See that girl, she is HIV-positive’ so everybody knew that I was positive at that moment in our community, in our area. So I asked God, ‘God, if I am going to die, where will I go? I don’t want to go back to my family, back to work, back to my school.’ It took me some courage to talk to those people. So, it was a sad day for me because these were people close to my house, my neighbors, they patronize me. It was just my doctor on my side who told me I cannot infect them just by touch and that is what they thought.”

She continued, “Now I can talk to youths about my story. Because many people at the moment abuse people, they say, ‘they are HIV, HIV, positive!’ When they are HIV-positive they don’t care about their life, they commit suicide to kill themselves. What am I? I am a young positive girl. I am there to talk to people, to give them hope, to encourage them. HIV is a lot about the stigma. But you have to be strong when you have it, because people do say you—people talk about you, but it’s here. So you have to be strong and tell them, ‘Me I know my status, me I am plus, what about you?’” She said this with a bold tone.

“You obviously know how HIV can be transmitted; you seem very educated about the disease. Have you ever heard people talk about HIV and how it’s transmitted, but what they are saying is wrong?”

“People say that when you go to eat with those who are HIV-positive you will get infected. They think if you eat with them, you can pass it on. But it’s very wrong. But HIV comes through sex, give transfusion, sharp objects, and mother to child.”

“Yes,” I said, nodding to agree with these modes of infection.

“Yes, so if I sit with you and I am positive, how can I infect you today?” she asked, mocking those who actually believe these ideas. “People are so negative about HIV. They talk about HIV but do not know their status. They do not know what they are. The main problem.”

“So they don’t know their status and that is the main problem?” She nodded in the affirmative. “Okay, and then they come up with ideas that are wrong. Are there any positive experiences in your community where people support you?”

“Okay, now at the moment, my family they support me, especially my sister and my cousins at the moment. They support me, they take care of me, and they love me. So the first time I did disclosure was at the youth center in town.” She later explained that this was a clinic and youth center where she volunteered. “I was so scared, I used to cry. I would think if I just look at the youth and tell them I am positive, I would wonder, ‘how they are going to think about me?’ But they said, ‘Thank-you, Whitney, you are one of the million, it’s hard to talk about that, but we know you Whitney, we love you so much.’ So I was shocked. I was so shocked.” A smile spread from ear to ear as she told me what followed. “So I said, you love me? Well, me I love you too.” A tear ran down her face as she laughed.

I could not help but laugh with her, because I was happy that she’d had such a positive experience. “In that moment, they gave me much, they made me feel like I can do it, it changed my life, and it gave me hope,” Whitney said with a sigh of relief.

“They called me in June to come in for an appointment, the NYCC. My sister asked why they wanted to talk to me. They wanted me to do disclosure. The coordinator

asked me. I was scared. I said, ‘Why do you want me to talk to other people about my disease, why?’”

“So you didn’t understand why they wanted you to share your story?” I asked.

“Yeah, they would say ‘Whitney, tell me about you, what’s your story?’ I was scared at first, but I did it. They wanted me to go to Nairobi for a conference to talk to the youth about my courage. To give them hope. Now I am used to it,” Whitney said proudly.

I was proud of her too. “So you have really accepted it,” I said. She smiled. “You are really helping a lot of people.” She thought about this for a moment before agreeing with a nod. “Good for you!” I said, meaning it. As a voluntary counseling and testing counselor, Whitney uses the support group setting to inform other individuals about AIDS-related information. In her photo-journal, she wrote of this experience:

I do my talks by sharing with youth and to give them hope. My story has healing qualities to an individual and to myself. I always feel that weight has been taken off me and that I have had an impact on someone’s life. I have a support group, which we encourage other people to attend, and we recruit people by post testing.

The photograph (see Figure 13) entitled “Sharing Stories” accompanied Whitney’s journal statement and she said it represents the empowerment and personal healing she has experienced through sharing her story as a counselor and youth educator in the community center where she volunteers. The photo, titled by Whitney, was taken by a friend of Whitney’s at an outreach event where Whitney shared her story with hundreds of youth. It is her hope that others going through a similar experience will think more





*Figure 13.* Sharing Stories. Whitney. (October 2011).

positively about their future with HIV or AIDS as a result of hearing her personal account of living with the virus.

“When you were scared, or maybe when you first told people about your status, were you ever scared or deterred from seeking treatment? Or were you always willing to go get treatment?” I asked.

“I used to be scared, but the drugs had been working. But sometimes I used to jump. I would just eat and not take.”

“Oh, so sometimes you would take your medications and sometimes you wouldn’t?” I asked, hoping she would clarify.

“Yeah. I took many medications. But I was scared.”

“Why were you scared to take the medications? Did you think people would see you at the hospital?”

“I was scared people were talking about me, I was young, and I was so young.”

“So you were scared that they were thinking, how did this young girl get HIV?”

“Yeah.”

When I asked Whitney to whom she would go to ask a question about the disease before discovering her status, she replied, “My family, my dad, and my mum. He used to say, ‘If you have HIV it is not good. He [her father] said it is not good.’ I said, ‘Why?’ And he said, ‘Because HIV kills so fast, HIV causes death. Like that!’” She snapped her fingers and continued, “If you have you will last with HIV for little time.”

“You father said this to you?” I asked, a little shocked, and she said he had. “So he even said this to you knowing you had the disease, and he didn’t tell you?” I asked in disbelief.

“Yeah,” she said, as if realizing this for the first time. I was sad for her. I decided to move on.

“Okay, and now where can you find information about care, treatment, and support?” I inquired.

“At the moment I am taking my drugs in the hospital. I do discussions in many places. I do go to support groups to talk to the young people. I talk to the young people because they are in denial at the moment. I share my stories with them, talk to them about positive living, how I would not get through if I didn’t have support in my life. At the moment, I am good,” she said, indicating she understands enough information to manage the virus and live positively. “Information I get it from many places: NYCC, my family, my fellow members.”

“Your fellow members, as in, of the support group?”

“Yeah. Giving me hope.”

“When you do go to the hospital, is it a comfortable environment? Did they make you feel comfortable about taking your drugs? Or was it still scary?”

“They give me the love, the information, the ideas, because they knew I was HIV-positive, because of my mom and dad.”

“So you always felt comfortable?”

“Yeah.”

When I asked Whitney about the changes she would like to see occur for the future of the disease in her community she said, “I would like to see more people tested and to hear that people are disclosing their status while in relationships to give others the option to protect themselves. Information to be reach more people, and for schools,

ministries, and organizations to have conferences to educate people in these locations about the disease.”

Whitney had to struggle through the stages of acceptance throughout her teenage years. Without the support of her sister, doctor, and the counselors at clinics, Whitney believes she would not be in the position she is today. Whitney had to endure the stigmatization associated with the disease throughout her school years, and avoided certain normal situations a teenage girl would typically partake in. She also struggled with decisions related to whether or not she would disclose her status. In addition to all of these external issues, Whitney educated herself about all aspects of HIV/AIDS in order to survive the toll the virus took on her body. Whitney has successfully accepted and learned to manage HIV as something that is a part of her life, but which does not define it.

Open in her demeanor, and displaying a caring and positive attitude toward all people, Whitney has a desire to educate others about her experience with the virus, discuss how to manage it, and educate those not infected about safer behavioral practices. In her spare time, she volunteers at a community center in Mombasa city as a peer counselor, providing free testing to help individuals know their status. This position enables Whitney to help community members by counseling them before and after the test to make informed choices, whatever their test results are. Whitney has outstanding knowledge of both the physical and emotional implications of the disease. The gradual progression of her understanding of the virus through her developmental years has enabled Whitney to make more informed decisions while helping others do so, too. Her level of knowledge was apparent throughout Whitney’s interviews and photo-journal.

Her powerful story is one of survival and hope for all individuals, especially those of the younger generations, living with HIV.

Being this brave was not an easy feat for any of these women. Following the theory of social constructivism the women's ideas about HIV and how they have come to understand it in the past, present, and future, as conveyed in the previous narratives, have been shaped in many ways. These include the ideas the women have received from family, friends, and community members, as well as the information relayed through community organizations and institutions such as schools, clinics, support groups, and hospitals. Their narratives are also shaped by the fears the women have come to develop personally about the disease; the fears HIV-negative people and those with an unknown status have subconsciously used to stigmatize those whose status is known; and the relationship each woman has with her autonomy and agency over her decisions and her body.

### **Summary of Story-Telling**

Making the assumption that the stories shared with me would remain consistent across different contexts would be unrealistic. Narratives are built on dominant social discourses, and power relationships that inhibit or enhance the abilities of some and not others. Dominant social discourses will change, even if only slightly, with time (Riessman, 1997), thus, changing the way individuals construct their stories and the meanings they convey through the telling of their stories. These stories are also dependent on the audience to which they are being told (Soskolne, 2003). However, a narrative outlook distinguishes universal factors of storytelling do exist like the capability of stories to transform people's perspectives and the pursuit of humans to find meaning in

their individual experiences, and to have that meaning be revealed (Gergen & Gergen, 1997). Therefore, storytelling tries to advance studies focused on the creation of particular meanings for people in their individual contexts that can then be shifted onto new settings to put forth a framework for comprehending how individuals come to know and construct themselves and their stories (Durrheim, 1999).

The narratives of the eight women revealed their self-identity and degree of acceptance of their status. However, as a researcher I can only know as much about each woman's sense of identity as she divulged in the particular stories she shared with me. Five out of the eight women described having a relatively positive perception of their life living with the virus. The other women tended to frame the disease from a more negative position.

These women's narratives demonstrate that the environment in which they told their stories is filled with complexities. For example, an individual living in a household where she suffers from stigma may not feel safe in answering or rendering her experiences in a true sense. An individual's environment and the audience can lead to a different version of a story. The research I have conducted and the data I have gathered are dependent on the social environment and temporal space in which each woman told me her story, as well as how each woman felt on the days she met with me and completed her photo-journal. Stories then are always dynamic, changing over time with every new experience and new interpretation of that experience.

I further interpret and analyze the women's stories in the following section through themes that have arisen within the women's stories. Moving outside the chronology of the women's stories (past, present, and future experiences living and

learning about HIV/AIDS), I have used themes to provide a more detailed discussion of their stories. The process of unpacking these themes will hopefully provide deeper meanings to the stories (Huber & Whelan, 1999). Excerpts from interviews and passages from photo-journals of the participants have been integrated with my interpretations. I have discussed each of the themes in terms of the women's identities, and more specifically, how they embraced or concealed their HIV-positive status as part of those identities. How the women viewed their HIV-positive status was affected by stigma and the burdens of disease, as well as their empowerment or lack thereof and their ways of knowing HIV/AIDS.

## **Chapter 5**

### **Themes and Transformations**

While each story the women chose to share, reflected their individual experiences learning about and living with HIV, similar themes in their plotlines did arise. In the following chapter, I discuss the themes that emerged from the data. These themes represent the eight women's ways of knowing HIV/AIDS. These ways of knowing the disease are directly linked to how each woman negotiated her HIV-positive status as part of her identity. To conclude the chapter, I present a summary of the story-telling process to validate the power of sharing experiences in this way.

#### **Overview of the Findings**

As I came to understand how the HIV-positive women in my study conceptualized the disease, I gained a deeper appreciation for how these women interacted with the ideas of HIV/AIDS present in their social environments. These insights assisted me in recognizing how fear of infection resulted in concerns about isolation, exclusion, rejection, or abandonment. Setting borders for specific themes is a difficult task when dealing with narrative data. Since several stories can be representative of a single experience for one individual, an overlap of thematic ideas may appear in the telling of each story. This was present throughout each woman's narrative as fears of infection, burdens associated with the disease, and empowerment were all underscored by stigma and how to negotiate an HIV-positive identity.

As discussed in Chapter Three, I used thematic analysis as a main part of my analytic approach. I have grouped my findings into the following three themes and placed them in a thematic map as illustrated in Figure 13 below:



- 1) Fear of Infection: Infecting and Being Infected
- 2) Disease and Disempowerment: Ways of Knowing HIV/AIDS
- 3) Negotiating the Burdens of an HIV-Positive Status

Figure 14 illustrates the core themes and the subsequent sub-themes I identified as emerging from the data. Stigma underlies each theme and, as such, there is an interconnection between each theme represented by the black triangle in the center of the figure.

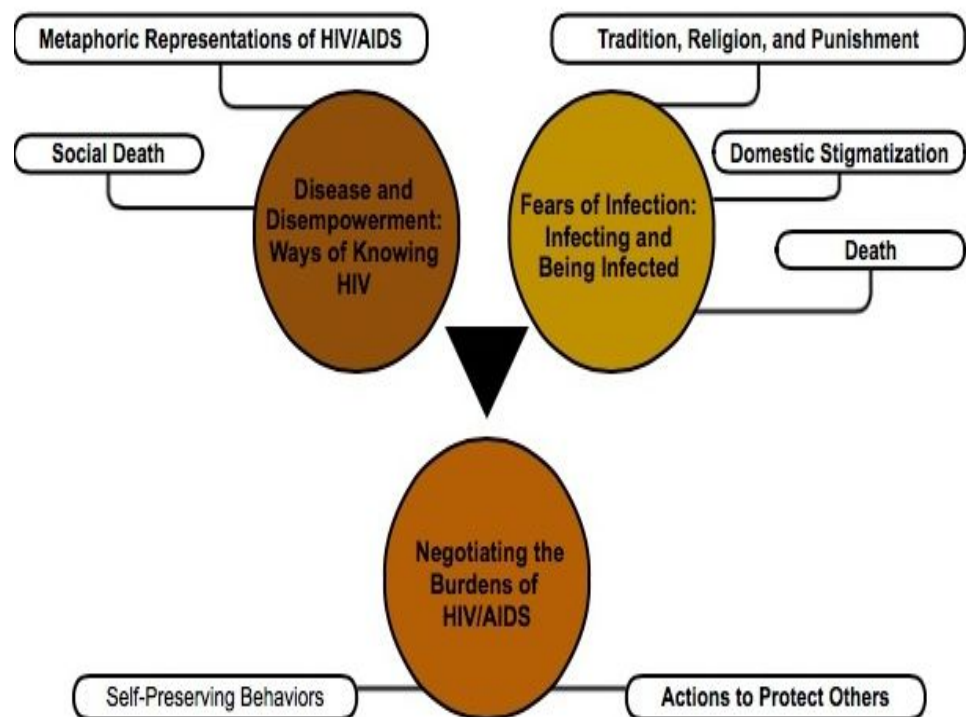


Figure 14. Thematic Map: Emergent Themes and Sub-Themes from Analysis.

The narratives presented in the first section of this chapter clearly answer the primary research question, “What are the experiences of young women living with HIV in Mombasa, Kenya?” These narratives demonstrate the complexities of growing up

underprivileged in a society that does not place high value on the education of women or emphasis on the discussion of HIV/AIDS. None of the women's perceptions have been shaped by a single influence. Social relationships, especially those with family members, partners, and social groups have influenced the women's beliefs about the disease, how the women chose to manage their condition, and whether or not the women decided to disclose their status to others. These beliefs and choices were heavily impacted by existing disease stigma. Stigma in the lives of these women was produced from lack of information and beliefs that were more entrenched because they have the weight of culture, religion, and social pressure behind, beneath, and all around them, as well as internalized by them. Hence, a belief may carry more weight if it is the result of years of connecting disease with contagion, and social deviance, rather than a person having the idea "I think you are contagious just because I do not know how the disease is transmitted." The weight of beliefs, and in turn stigma, is determined then by how stigma is constructed. In this study, strong meanings were constructed through ideas influenced by society, culture, religion, politics, whereas, weak meanings were constructed simply through ignorance.

Community cultural and traditional beliefs also contributed to what the women understood about the disease and in turn, their own identity. The undercurrent of stigma throughout the data are present in its two types, perceived stigma (e.g., fear of negative reactions from their communities/families, or isolation) and enacted stigma (e.g., rejection by partners, exclusion by family members), defined in Chapter Two of this thesis. The women experienced empowerment in the process of accepting their diagnosis and/or

disempowerment as their fears surrounding the disease increased. Both feelings were present as re-negotiation of an HIV-positive identity occurred often.

Answers to my question, “How do women with HIV from Mombasa, Kenya adopt a particular perception of HIV/AIDS in their lives and communities?” can be found both in data from the interview transcripts and from the women’s photo-journals. Each woman’s particular perception was ultimately shaped by her negotiation of fears (hers and others) surrounding the disease and the resulting stigma. Various factors shaped the nature of this negotiation for each woman: access to HIV/AIDS information from different sources, perceived and actual support, and length of time a woman had known her positive status. In the discussion around the theme entitled Fears of Infection: Infecting and Being Infected below, I address some of these negotiations focusing on fears of contagion, fears of death, and the view of disease as uncontrollable by the woman affected. This theme also encompasses fears of infection that stem from cultural traditions, religious beliefs, and/or religious practice.

All three themes are evident in the answers I found to the other question, “Does stigma impact the existing discourses that influence how the women form their perceptions of HIV/AIDS?” Stigma is a key determinant in how each woman perceives herself and is perceived by others. The existence of stigma has created an “us versus them” dichotomy between the women and those in the community who are HIV-negative or unaware of their status. For some of the women in my study, the combined effects of both enacted and perceived stigma have exacerbated their positions as the other. In some cases, the women have tolerated enacted stigma such as verbal abuse, unnecessary sanitation practices, and exclusion (by immediate family, extended kin, or community

members) in order to remain in their houses, to maintain their day-to-day lifestyle, and/or to remain part of the family unit.

Stigma thus has an obvious connection to fears of infection, but there are also clear relationships with my other two themes. The effects of stigma include the burden that the disease has on women and whether or not they choose to disclose (as well as what will happen if they do). In discussing burden of disease, I found that the women's beliefs and understandings about HIV/AIDS, including whether they felt a perceived stigma, were informed by family, peer, and community member relationships. Their understandings were also informed by society-level factors such as cultural practices and religious beliefs. There is also a clear connection between stigma and my third theme of disease and disempowerment. This theme focuses on how the women conveyed the meaning of HIV/AIDS in their lives through representing the diseased body with visual and literary imagery. Stigma comes up in these representations through metaphoric comparisons to nature, the use of animal symbolism to represent emotions surrounding the disease, disempowerment generated through social rejection, and reflections about the changing body once infected with HIV.

I explore the final question, "How have influences from social environments interacted throughout the process of acceptance, to shape women's attitudes about moving forward with an HIV-positive status?" Using data that focuses on support, improvements in education, and ultimately hope for the future. Again, this question connects with all three themes as the women envision their futures of living with HIV. The women answered this question through describing experiences that helped them to negotiate the concealment or acceptance of positive status as part of their identities.

In the rest of this section, I analyze the data I collected by focusing on how it touches the themes and sub-themes I identified as emerging from the data. I used a model I developed as a framework to locate women within the negotiation process of incorporating HIV-positive status into their public identities.

### **Arenas of Negotiation: Embracing, Negotiating, and Concealing the HIV-Positive Identity**

The most essential possessions amongst people as social beings are identities (Soskolne, 2003). Our identity to both others and ourselves defines the structure and the prospects we are offered or denied and determines the relationships we will have with others. Individual identities originate from both views and internal judgments (of both individuals and others) and by socially enforced characteristics (Soskolne, 2003). Goffman (1963) noted that identities are information, which allow others to make judgments of character and can be utilized by individuals to locate their own positions within social categories. Therefore, social identities are vital to our well-being (Tewksbury, 1994).

Past studies have explored the negotiation and incorporation of an HIV-positive status into part of one's self as a stigmatized or spoiled identity (Dozier, 1997; Flowers et al., 2006; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). In general, results from these studies defined the negotiation process by stages; shock, denial, battle with stigma, and eventually acceptance. Baumgartner (2007) identified each stage of negotiating an HIV-positive status to help counselors identify specific turning points with the disease in order to aide in the incorporation of that positive status as part of the overall self identity. This model along with models from other studies (Amiot, De la Sablonniere, Terry, & Smith,

2007; Stets & Burke, 2000) represents viable steps toward understanding negotiation of an HIV-positive status. However, I wanted to illustrate the dynamic nature of the negotiation process and that experiences cannot always fit in pre-defined categories as the possibility to evolve or shift negotiation is always present.

In an effort to illustrate how the women in this study have negotiated the decision to embrace or conceal their HIV-positive status as part of their public identity (identity as seen by others), I developed the Arenas of Negotiation Model (see Figure 15). I included three arenas in the model: 1) negotiating HIV-positive status, 2) embracing positive status as part of identity, and 3) undisclosed HIV-positive status. In moving between these three arenas of negotiation the women primarily perform two types of behavior: 1) actions to protect others and 2) self-preserving behaviors. These two types of behaviors will be discussed with the third theme later in this section.

Each separate arena represents the space where the women negotiated the burdens of the disease, and in turn, if they would accept being HIV-positive as part of their identity. These arenas are not equal—rather, a woman starts in the negotiating arena and ends up either in the embracing or not disclosing arena according to how she experiences ideas about HIV/AIDS and PLWHA. She might also re-experience the negotiation process later if she decides not to disclose, or imbalances in power (i.e., those created by stigma) inhibit her ability to choose her HIV-positive status as part of her identity. Each arena is defined by the ways a woman can come to know their HIV-positive status while inhabiting that space.

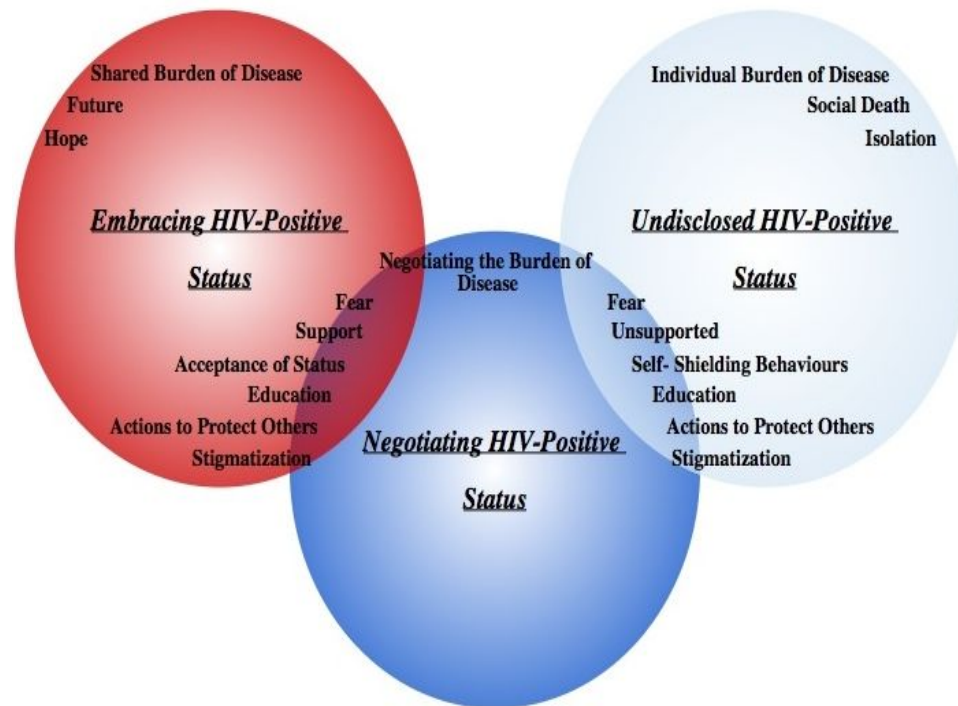


Figure 15. Arenas of Negotiation.

Figure 15 illustrates the overlapping factors associated with navigating an HIV-positive identity. These factors caused the women to move between different arenas of negotiation.

Each arena of the model helps locate the women in their stage of acceptance with HIV-positive status as part of their identity at different times in their narratives. The words on the outer edges of the arena of negotiation of HIV-positive status overlap the two additional arenas of negotiation. These words represent the experiences the women had while inhabiting this space. Some women experienced more than others. Fully occupying the arena of embracing HIV-positive status or the arena of undisclosed HIV-positive status (represented by the words on the outer edges of these two arenas) is characterized by the experiences a woman might have if she moves away from the

negotiation of HIV-positive status entirely (i.e., shared burden of disease, hope versus social death, individual burden of disease).

The first arena, negotiating HIV-positive status, represents a space where a woman weighs the risks and benefits of disclosure and decides whether or not to disclose. The second arena of the model, embracing HIV-positive status, represents a woman's arrival at self-acceptance with the diagnosis. In this space, the woman is willing to risk exposure to enacted stigma in sharing her status with others. Deciding to embrace her positive status, a woman occupying this arena of the model will consider her status part of her overall identity. Women in this arena have chosen to disclose and seek outside support. Disclosures from women in this arena were also more positively received on a larger scale. After disclosure occurred, some of the women in this arena indicated that they had increased hopes for a future with the virus.

The women who have embraced their positive status have sometimes been able to occupy a space where education can occur and where they can talk to others about their experiences with HIV. However, fear still plays a role in how these women conceptualizes their existence, in some cases leading them to perform actions to protect others against the risk of infection. In other cases, the women have enacted behaviors to protect themselves from co-infection (infection of more than one disease at the same time i.e., Hepatitis B, C, or Tuberculosis) and from stigmatization by others.

The third arena of the model, undisclosed HIV-positive status, represents a space where a woman's HIV-positive status remains undisclosed to others. All of the women I studied have acknowledged their HIV-positive status to themselves, but they have not all chosen to embrace it as a part of their identity. Those women who fully accept their own



status but choose not to share it with others exist in the undisclosed arena. This is a space where the women sometimes subscribe to others', and in some cases their own, misconceptions about the disease (i.e., casual contact with surfaces an infected individual had touched as a source of transmission) in order to refrain from being isolated or further excluded.

When these women were at the height of concealing their status, the undisclosed HIV-positive status arena became a space where they retreated into themselves. It was a space where they did not openly embrace HIV-positive status as part of their identities. In doing so, some of the women enacted self-preserving behaviors (i.e., avoiding intimate relationships) to conceal their status or decrease vulnerability to stigmatization. Consequently, concealing the status sometimes caused an increase in self-stigmatization, which may have been an effort to escape the social death that accompanies PLWHA. However, choosing to conceal part of an identity could also result in further isolation.

A woman's locations between the arenas was constantly varying and overlapping, making negotiation a continual process. In cases where a woman disclosed to some, but not all members of her community, this was particularly evident. Similar to models for identity negotiation in the Lesbian, Gay, Bisexual, Transgender community that distinguish stages in the coming-out process (Bilodeau & Renn, 2005), this model highlights some fluidity between arenas in a woman's life—she might experience some of the positive and negative effects of negotiating an HIV-positive status, simultaneously. This was apparent throughout the narratives of the women in my study.

I learned that stigma can be present in each arena of negotiation, and it played a role in how the women shifted embracing or concealing their HIV-positive identities. It

is important to remember that any agency the women may have had over choosing their identity was largely influenced by the risks and benefits of disclosure. However, it is also important to realize that as the women come to know HIV in different ways in the future (i.e., discovering more knowledge, receiving emotional support, experiencing greater stigmatization, developing increased sense of body agency), they may shift how their HIV-positive status fits into their overall identities. Thus, defining one's identity is dependent upon the moment, circumstance, environment, and social surroundings and experienced or perceived interactions. Figure 14 can be used as a framework to further understand the following three themes, and their subsequent divisions.

### **Fears of Infection: Infecting and Being Infected**

The experiences the women shared were saturated with the concept of infection. Each woman indicated that the way she understood HIV/AIDS was impacted by others' fears of being infected or her own fears of living with a diseased body. These fears affected how each woman negotiated her identity. As illustrated in Figure 14, there were three key sub-themes relating to the fears of infection surrounding HIV/AIDS that shaped how the women perceived their HIV-positive status:

- a) Domestic Stigmatization
- b) Tradition, Religion, and Punishment
- c) Death

These three sub-themes will be discussed in the following sections.

**Domestic Stigmatization.** Relationships with family members and their support (or lack thereof) are vital to consider in understanding these women's experiences with HIV and how they have formed their perceptions of disease. These interactions shaped

how the women perceived both the disease and themselves, in relation to others who do not have a known positive status. With the exception of Whitney, the women who participated in my study reported having been subjected to numerous acts of stigmatization in the home by immediate and extended family members. I have termed this stigma in the home *domestic stigmatization*. This category of stigma refers to any humiliation or segregation experienced within the domestic environment, as directed by immediate family members, a partner, or extended kin residing in the household.

Domestic stigmatization occurred primarily in three ways: 1) exclusion practices, 2) unnecessary sanitation practices, and 3) removal from or isolation within the household.

Exclusion practices included acts where those living in the household abstained from casual interaction, refused to share items such as utensils, and/or refrained from contact with the belongings of the women. Jane, in her photo-journal, described some of the exclusion practices she had observed because of others' stigmatized beliefs about HIV-positive individuals. Jane elaborates on stigma she has faced (See Figure 12) and in her caption, describes how her friends and peers feared becoming infected through casual contact with items she had used, such as the following:

- Soap: The soap I had been using to shower while ill; when people notice, they would neglect it and rather purchase brand new soap.
- Cup: When I had used a cup for water or tea, or porridge, then the cup will be blazed or thrown away.
- Saliva: Even if I spit, people think I want to infect others.

- Money: This money reminds me of moments I had been suffering when I was to give someone money, they would not want our hands to meet. Instead, the money would be placed on the table to avoid touching hands.
- Cloth: Many people discriminated my clothes and were scared of washing, or touching by hands, thinking they will be catching.

Tina shared similar sentiments in her photo-journal. She further described several fears surrounding infection that were present in her home and community. Here is a list of some incidents where stigmatizing beliefs about HIV/AIDS existed that Tina documented:

- Home utensils—like cups, plates, and spoons—they are separate and keep yours away.
- If you go to the toilet, people fear to use that toilet again.
- People fear to greet you.
- People think that they can get infected by using your clothes.
- People [who are not positive] cannot eat with you . . .
- People fear to wash your clothes.
- People fear to use a basin or a soap, which has been used by you.

These fears represent common misconceptions of what people without the disease in their homes perceive to be true about contagion and individuals with a positive status. These ways of knowing HIV-positive people as a vector of infection through casual contact

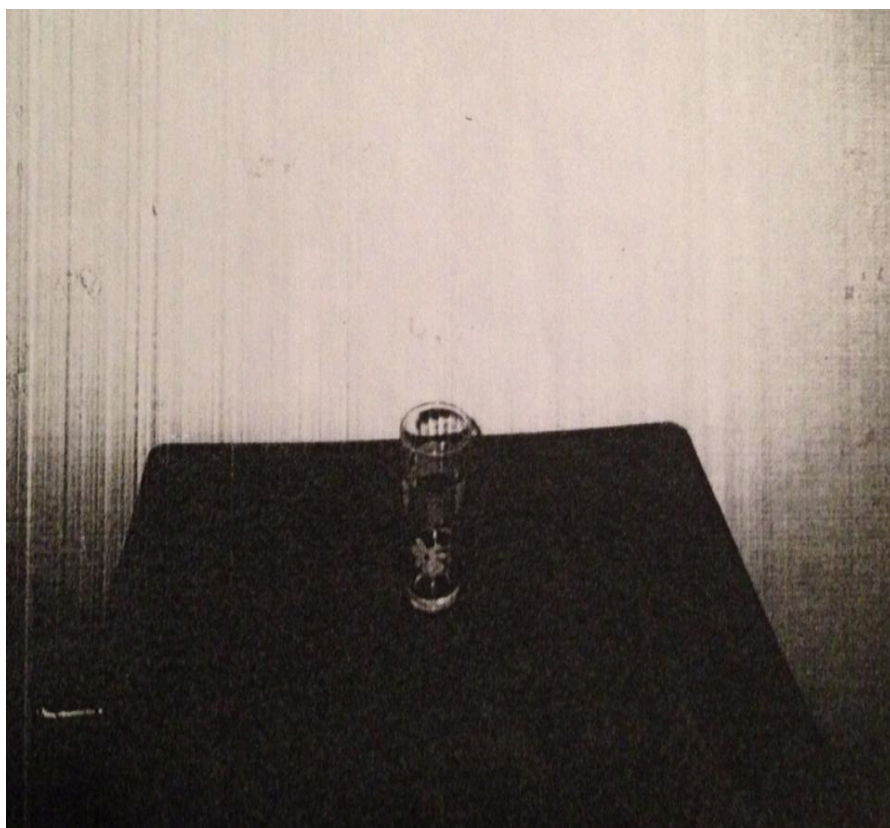
exemplify received knowledge, where understanding is based on and validated by existing beliefs within the community.

Atoti wrote the following list of captions in her photo-journal, which represented the exclusion practices she encountered in her household with her cousin's stigmatizing husband, as well as ideas she noted as being held by some members of her community.

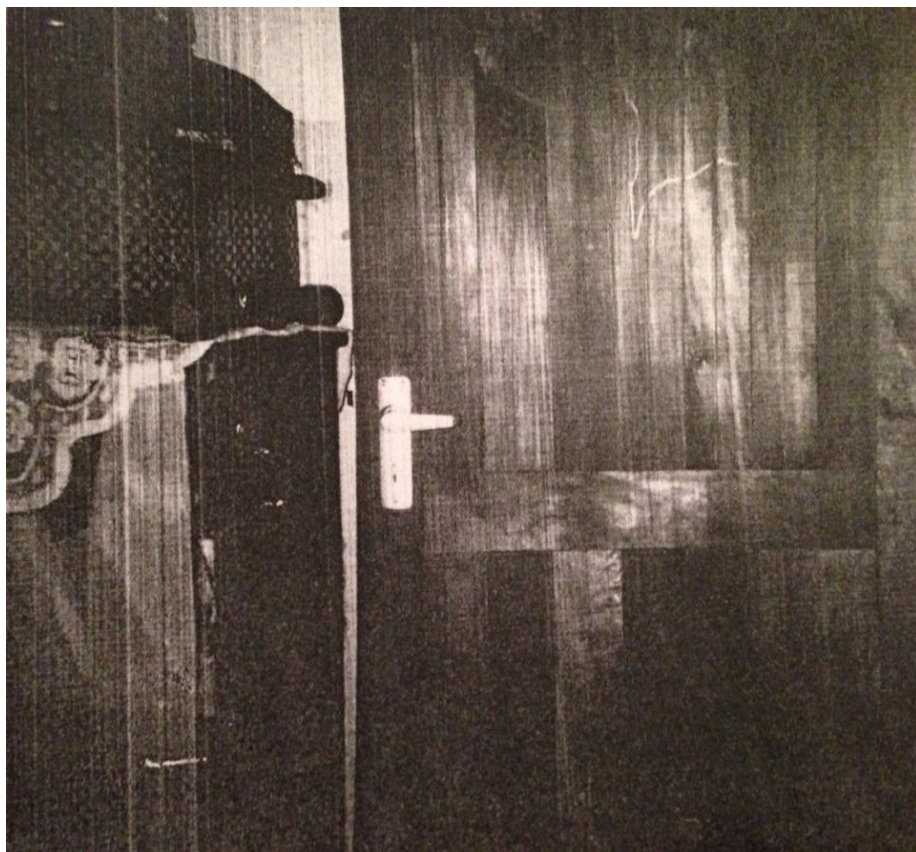
- I have taken the photo of this bed; it shows that some people in the home and my community think that you can get the virus by sharing a bed with a person who has the virus. No. The virus is not spread through sharing beds with infected people, so don't fear sharing anything with your fellow just because you might get the virus. [See Figure 16]
- I took this photo of this glass, it shows that some think you can contract the virus by sharing glass with an infected person. [See Figure 17]
- Why have I decided to take a photo of this door? Because people have entered where I live, who are not infected and they think that they can get the virus even by touching a door, which has been touched by an infected person. [See Figure 18]
- Some people think when you share soap in the home with a person who has the virus you will also get infected. Nobody can get the virus



*Figure 16.* Bed. Atoti. (October 2011).



*Figure 17.* Glass. Atoti. (October 2011).



*Figure 18.* Door. Atoti. (October 2011



by sharing soaps. That's why I decided to take a photo of this soap. [See Figure 19]

Similarly, Atoti's photograph of the toilet (see Figure 10), combined with references to isolation and sanitation practices within the home, serves to highlight the stigma associated with HIV/AIDS as well as the multiple identities it creates for women with a positive status. The association of bathrooms with dirtiness generates stigma because of the associations between chronic illness, infection and uncleanness framing PLWHA as vectors of infection. The spaces HIV-positive individuals occupy are also deemed unclean. These misconceptions undermine the women's capacity to be integral household members.

Atoti's documentation of domestic stigmatization further highlights the misinformation surrounding HIV/AIDS in the household and raises the following questions:

- How can members of households be reached and informed about accurate AIDS-related health information?
- How can steps be taken to provide information in culturally relevant ways?
- Is accurate information about HIV transmission the answer to reducing domestic stigmatization of HIV-positive women?
- What else needs to be addressed in the household to reduce stigmatization of HIV-positive individuals?



*Figure 19.* Soap. Atoti. (October 2011).

Although Whitney was well-supported after being made aware of her status at the age of 12, she encountered examples of domestic stigmatization during her counseling training. In her photo-journal, she documented some of the effects of this stigma that others experience while living in their homes:

- Isolation
- Lack of love
- Separation from relatives
- The people affected end up getting into drug abuse like cocaine
- Because of the stigma, the people refuse to go to medical care.

I heard further evidence of domestic stigmatization in the interviews when some of the women reported that removal from, or isolation within the household, had occurred since they were diagnosed. The women described isolating practices where family members would maintain distance, separate their belongings, or leave the home altogether while the women were suffering bouts of illness with the virus. Sabina recalled some of the initial reactions her family members had when they learned of her positive status:

Stigma is there at home, I face it because when they discovered I am HIV-positive they isolated me because they separated things from me. They thought I was going to spread the virus to them, so I was left alone. I went to the hospital and got the information. I told them about it, and now they treat me equally, like themselves.

Once Sabina sought out health information and educated her family about the disease, their treatment of her became more positive and inclusive. This change in how

Sabina's family treated her, after learning more about how the virus transmits, is cause for hope that with education, domestic stigmatization can be lessened or eliminated altogether. Sabina's experience suggests that stigma is ultimately a result of misinformed or insufficient information, that is not enacted with the intent of othering PLWHA. Sabina's experience is representative of how understandings of the disease are socially constructed. Her family members were able to re-construct their perception of HIV based on the experience of viewing change in someone with a HIV-positive status, and through receiving and validating information given to them.

Tina also suffered from domestic stigmatization. Tina stated that her partner was unwilling to test and did not accept her diagnosis. He verbally abused her and then ended the relationship. He demanded that she leave their home. Tina's experience of domestic stigmatization placed her in a position of increased vulnerability and powerlessness. She had no agency in choosing to stay or leave her home. Additionally, she was automatically framed as the other when her husband refused to test, discuss the disease with her, or have an association with her HIV-positive status. Atoti experienced similar treatment in the house where she resided:

It's only the husband of my cousin who is stigmatizing me because he doesn't want the relatives of his wife [Atoti's cousin] to live with them there. That is why he's stigmatizing me and the people in the community are not stigmatizing me because they do not know my status . . . I wish one day somebody will come and help me got to college, and get a job so that I can be able to sustain myself and take care of myself.

Atoti's desire to be self-sufficient is evident. However, her cousin's husband has made it difficult for her to live at their home, a place where she feels supported because she is with her cousin who is also HIV-positive. His stigmatization reduces her power as an individual because she is trapped by her reliance on her cousin's emotional support. If Atoti were to leave, she feels she would have no support emotionally or financially, which leaves her with no option but to remain in the house.

In extreme cases, partners of the women ended their relationships after learning of the women's status. In Sabina's case, her partner never returned to their home after she revealed her status during a phone call. In her interview, she stated:

I can't recall how I got the disease because I am not sure if it is my boyfriend or who else because my boyfriend is not around and I was suffering with illness and I tested. I called him; I tell him that I am, that I am on drugs. He told me he will be back, but second day he didn't show up. I don't know . . .

The experiences of these women suggest that availability of and access to AIDS-related information by every member of the household is vital to decrease domestic stigmatization and give the women an increased sense of agency in their life decisions.

Three decades into the AIDS pandemic, infection fears continue to exist. This finding suggests that communities highly vulnerable to HIV need to be evaluated in terms of household access to, and understanding of, AIDS-related education. The presence of direct domestic stigmatization in the lives of some of these women, as well as indirectly, through ideas they have encountered in their communities, has influenced their perceptions of HIV/AIDS. The strong effect of stigma has reduced women's agency in

choosing how they wish to exist in their homes. The stigma has also served to frame the women as different or other, creating a divide between the women and their families. Domestic stigma focuses behavior on segregation and ultimately, sometimes without malicious intent, magnifies the us versus them dichotomy between individuals seen as diseased versus healthy. This creation of the diseased body versus the healthy body will be explored further in the second theme, Disease and Disempowerment: Ways of Knowing HIV.

The next sub-division of the Fears of Infection: Infecting and Being Infected theme places emphasis on the influence of religion, powerlessness, and punishment. This theme considers the effects these factors have on shaping the women's perceptions of HIV/AIDS. In this section, I will discuss the stigma that affects how people cope with HIV infection, ideas about why people become infected, and how God and religious references have been a source of both hope and stigma for the women.

**Tradition, Punishment, and Religion.** References to God and ideas related to religious practice were apparent throughout the data. I did not account for these relationships in my initial analysis, as the questions in my interview guide did not specifically focus on religion and its influences. However, some of the women did relate their fears of infection to religious elements. These fears indicated stigma inherent in cultural traditions, fatalism (or the belief that one is powerless to create change), and a lack of agency over the disease.

Atoti described the stigma inherent in certain cultural practices as a result of the fear generated by the idea that causal contact with HIV-positive individuals can cause infection:

We used to talk about HIV with my friends maybe we were telling stories then somebody started talking about HIV. We could share and talk but if we just talk about if somebody died of HIV we saw her she was [pause] she was she was buried. Like, if you come near her you are going to get infected also. So she was covered very, she was covered so that nobody-nobody could see her or him, and if she dies today she could be buried today so that nobody can get infected with the virus. Her coffin could even be covered with nylon.

In Atoti's community, covering the coffin with nylon was a common burial practice for those who died from the disease. This practice relates to longstanding traditional beliefs about death and HIV in Kenya. Conversely, bodies without HIV, or not yet known to have it, are buried without a cloth cover. This implies a fear of those who are HIV-positive and connects the infected body to the unsanitary or dirty body. It positions those who die from HIV/AIDS in a different location than those who die of causes unrelated to the disease. This act serves to further segregate HIV-positive persons and increase the fear of death surrounding the disease. In turn, these negative ideas about HIV have worked to shape the women's perceptions of the disease. In Atoti's case, these ideas influenced how she negotiated her HIV-positive status as part of her identity. Before contracting the virus, she came to know the disease as an attribute that indicated a decreased value of life for HIV-positive individuals, marking them as contagious and outcasts from the community.

In addition to creating misconceptions about the transmission of HIV, the women suggested that perceiving infection as a punishment frames those with the disease as

deviant members of society. This perception creates a conception that individuals are powerless against infection. As an example of this, P. Diddy recorded in her photo-journal that being punished by contracting the virus could also be a curse by God for unknown reasons. Her caption reads, “Before you become sick you look healthy and cute, but when infected, you start to look weak. Is this a curse given by the Lord? What is so bad that we have done?”

It could be considered ironic that one participant (P. Diddy) perceived God as responsible for delivering a curse or punishment based on ideas that existed in her community, yet some of the other women in the study relied on God as a source of hope. In this quote, P. Diddy struggled to find an explanation for how she (and others) could be deserving of a lifetime of battling a chronic illness. She wondered what they could have done that was so bad. In resolution of this question, she framed contracting HIV as an extremely harsh punishment. Despite the presence of clinics nearby (that provide HIV/AIDS information and treatment), HIV as a curse or punishment is still an idea about the disease that persists in P. Diddy’s community.

Similarly, people in Sabina’s community told her that she was being punished for the sin of separating from her husband.

Sabina: Before I was married. Then I separated from my husband. So when I was sick, those in the community used to come at home, talk a lot, say that maybe I am the one who contracted the HIV or it is my husband who contracted HIV, and I am now suffering because I am separated.

Laura: So they [community members] thought it was a punishment?



Sabina: Yes, that is what they are thinking.

Framing the disease as a punishment for making certain choices that are undesirable in the eyes of others is problematic. It could generate unnecessary fears of those living with the HIV and also could increase fatalistic beliefs about their futures being HIV-positive. As a result of these beliefs, Sabina was deemed punishable for being passive and for her failure to keep her husband satisfied. While Sabina had friends who were knowledgeable about HIV, community and cultural ideas remained dominant. For a woman to leave her partner and break the sacrament of marriage is frowned upon in Kenya according to both traditional and contemporary societal beliefs and cultural values. Blaming a HIV-positive status on separation or divorce may indicate that cultural ideas are still more powerful than medical facts in communities where access to accurate information is inadequate. This would result in the cyclical perpetuation of stigmatizing beliefs about the disease.

As an engaged woman, P. Diddy was aware of the stigma associated with being divorced. She had to negotiate the fear that comes with being infected and how she would let the stigma affect her life with the HIV if she chose to leave her relationship in the future, as shown in this quote:

She [her friend] says “go to talk to your friends, and your fiancé” and then maybe if he refuse to go to the clinic together, I can decide for myself to leave him because it’s my life.

P. Diddy debated whether or not to disclose her positive status with her fiancé because revealing her positive status could mean loss of the relationship. She might also be blamed for ruining the partnership, and assumptions could be made about infidelity and her moral character. This was a negotiation of her power in the relationship.

The connection between religious ideas and HIV-positive status seemed to stem more from community and societal influences than from the women's individual beliefs. For Whitney, belief in God provided her with a means to overcome fears of infection, rather than cementing stigma:

Whitney: I used to count some days. My doctor said it will be up to God when I die, but he told me ten years, you live ten years. Therefore, I gave until through high school until I was eighteen, then I think me die. Some days I would think I will just die, I would ask myself, why am I not dying?

Laura: So you were counting down the months?

Whitney: Yeah, WHY, WHY, WHY, am I not dying? But this was a stupid question. You have to die. I have to die me [chuckles]. I was in denial. After eighteen years, I realize, if I have not died at this moment, then God has a purpose for me, to live.

Where beliefs about God or religion related to HIV status have characteristically been negative, belief in God often gave Whitney a purpose for life and God was the entity she looked to for hope and health in the future. Whitney, compared to the other women in this study, exhibited a more refined sense of control over the HIV infection, but in the aforementioned quotation she gives some of this agency to religion, or more specifically to God. This contradicts traditional religious schema around HIV/AIDS. Where Whitney places her trust in a belief that having HIV is part of God's plan, HIV-positive individuals are usually placed in a negative space with relation to God and the moral spaces claimed by religion.

The connections and associations made in the previous section about HIV and religious beliefs warrant further exploration in future research. Had I accounted for each woman's religious background in the interview guide or probed deeper into their references to religion, I might have discovered a more profound explanation for how religion and faith affect fears and negotiations of stigma surrounding HIV. Although these concepts were mentioned by a few of the women in the study, the others did not indicate religion as an influence over how they negotiated fears surrounding the disease.

**Death.** All of the women mentioned death and I have included the most representative quotations in this analysis. It was evident that the association of HIV with death contributed to how these women negotiated fears of infection and formed their perceptions of the disease. The women reported certain discourses and labels that they and their families, friends, and communities used in making a connection between HIV and death including “death sentence,” “kill me quick,” “widow,” “widower,” and “deadly-monster.” In using words such as “monster,” the women highlighted the fear that an HIV-positive diagnosis is an immediate death sentence for a woman and anyone who comes into close contact with her.

Stacy commented in our first interview on the pace at which people believe the disease takes over the body, saying, “Some are talking AIDS does not have a cure. They think if you have HIV you can die, you know, something like that [snaps fingers] . . . quickly.” Because HIV is seen as a death sentence by some, coming into close contact with an HIV-positive person is considered the same as placing oneself in death's path. These common associations of HIV with death are problematic, and are responsible for diminishing hope for survival as well as for feelings of powerlessness against the virus.

This persistent misconception also dismantles the capacity of an HIV-positive person to gather support in the non-positive community by creating a fear among potential sources of support of being infected.

Tina's dialogue in both her interview and photo-journal placed a heavy emphasis on the fear of death. She had encountered ideas of stigma from the community that reflected fatalistic attitudes about living life with the HIV:

People take this disease as a very bad disease, they take it as death.

[Thoughts of] death can make you to not walk. This can also make you feel like not going for treatment or you refuse to go and pick your medicine or to take the medicine. Sometimes it's because of how people think. I am still taking my medicine but there are people who are of that type. There is a person who when he hears that when you take the medicine you are going to die—he turns the medicine down but am still giving myself hope for living. When my time for taking medicine reaches, I take my medicine. At first, I was afraid because when you are started on drugs you dream of bad things like grave or of a person dead but now I am used to it, and I am not afraid anymore.

When discussing this type of stigma in her journal, Tina wrote, “When people realize your status, they start thinking that you will die very soon.” This belief of immediate death, or the focus on a looming death, provides little comfort for PLWHA and makes it very difficult to visualize a future. As Tina noted, once she moved past the idea of dying immediately and was eventually able to believe in the possibility of a life with

medication, she was able to overcome the fear. Community members who share these rumors propagate fear of the HIV/AIDS and fear of individuals living with it.

Atoti urged those who contract HIV to think positively about the disease and not to dwell on the fear of dying. “Please don’t have any thoughts [of death] because thoughts can finish you very quickly,” she warned. Again, Atoti’s statements are a reflection of the need to understand HIV infection and one’s capacity to live with it in order to disable the misconceptions about death and the disease.

Ultimately, these women’s fear of death in relation to HIV highlights the misconceptions prevalent in their communities. These misunderstandings of the disease have created a direct challenge to the women’s ability to perceive themselves as full community members rather than deviant or amoral people existing on the outskirts of their communities. The perception of these women as dying created power imbalances between them and their healthy counterparts. This sometimes resulted in the women tolerating stigma in order to feel some sense of membership in their homes and communities. Additional instances of disempowerment the women experienced as a result of their positive status will be discussed in the next theme, Disease and Disempowerment: Ways of Knowing HIV.

### **Disease and Disempowerment: Ways of Knowing HIV**

Disempowerment occurred in a variety of interactions the women had in their environment. However, disempowerment was most heavily dependent on existing societal beliefs the women encountered in their relationships with community members, family, and friends. These beliefs framed persons with HIV/AIDS as vessels of physical and moral pollution, thus spoiling the identities of HIV-positive individuals trying to exist

in the social sphere. As I explored how the women in this study came to know the disease, two sub-themes emerged in relation to disease and disempowerment:

- a) Social Death
- b) Metaphoric Representations of HIV/AIDS

These two sub-themes will be discussed in the following sections.

**Social Death.** For these women, a positive diagnosis (laden with stigma due to current societal beliefs) was associated with both literal death (i.e. dying from the AIDS) and social death. Social death, as used here, includes the women's feelings of non-acceptance, loss of opportunity, discrimination related to capability and appearance, and exclusion or rejection from the community or society to which they lived in but to which they did not always belong. An example of social death in one of the participant's own words was recorded in Tina's photo-journal under a section entitled, "Stigma Surrounding HIV/AIDS." Tina wrote of some of the stigma-laden beliefs she encountered in her community:

- If you are a teacher when parents get to know your status they take their kids out of that school and they transfer them.
- If you are not married, or you are not going to marry, people [a partner] will fear to approach you.
- People will talk about you when you walk.
- If you are doing a business [business owner], when people come to realize your status they will never buy whatever you are selling.

Other women in the study also recorded that members of their communities considered types of interaction including hugging, being in the same room, taking care of children, sitting next to a fellow student with a positive status, caring for a person who is infected, and greeting a person who is infected to be potential ways of transmitting the virus. These ideas resulted in community members isolating HIV-positive women or limiting their opportunities, thereby enacting social death.

The women were framed as vectors of infection for two main reasons: 1) assumptions of deviance (e.g., promiscuity, evil, and sinner, unclean); 2) fears of becoming infected. The women often communicated feeling discouraged by these assumptions and fears about an HIV-positive status.

Several of the women reported being subjected to assumptions of deviance. In our interview about her photo-journal, Tina described being openly stigmatized by community members who knew her status and saw her diseased body as a carrier of death:

Laura: You said people talk about you when you walk so what do you mean? What do they say?

Tina: For example, somebody has known my status, is a person who knows me very well. I can pass somewhere and you will hear people saying eeh ... that one she has it, she has it, and she is going to die very soon. That is why I decided to write it here [in reference to her journal]. When you walk people spread rumors about you and fear you carry death.

This disempowering treatment of Tina exemplifies the act of othering persons living with HIV by defining them on the basis of their HIV-positive status. By framing the diagnosis as an automatic death sentence, Tina's community members showed their disregard for her ability to survive and have a fulfilling life in spite of the disease. This is a form of social rejection (i.e., social death) whereby Tina is forced to negotiate two identities of undesirable social existence. The first identity is that of the chronically ill individual who must respond appropriately to maintain a standard of functional health. The second identity is that of the HIV-positive individual. The HIV-positive identity is one that is socially stigmatized and moralized. Altogether it is an emotional battle for the infected. Disrespect and devaluation of HIV-positive persons perpetuates a belief that these individuals' lives are insignificant. This frames PLWHA ultimately as bad people, encouraging them to live in silence, concealing their status; their thoughts, feelings and knowledge about the disease; and ultimately their identity.

Experiencing social death influenced how the women negotiated disempowerment, which in turn shaped their perceptions of living with the virus. Social death was connected to an increase in enacted stigma toward the women in this study. Women in Sabina's village, for example, were uncomfortable with her presence and made assumptions about her capacity to regain health, which limited her opportunities to socialize:

The only difference after telling my family was that the other women who are in the village they are uncomfortable with me, but my sister she understands me [her life with the virus] completely. Those women before they used to treat me badly, but when I started using drugs [antiretroviral



therapy] and I gained my weight, and I was in good health, in a good position to walk on my own, to do anything, because before I was weak—I couldn't walk. I was bedridden. But when I started using the drugs and they saw me getting better each and every day, they started to treat me in a different way. Before they used to separate me from their kids, their homes, they're now giving me water with their cups, sharing food with me, they treat me better. So I am okay, but they still don't know much about HIV. They think HIV people [at least when they look ill], are not people to mingle with them.

The assumptions Sabina's community made about individuals living with HIV reinforced practices of social exclusion. In the passage above, Sabina explained the changes in how she was treated by members of her community after physical transformations (due to treatment medications) occurred. The experience of being viewed as a walking infection could have created disempowerment, spoiling Sabina's identity through self-stigmatization and reducing her desire to live. However, when Sabina regained a healthy appearance the enacted stigma she experienced was reduced. While many of the women in Sabina's community did not have formal education about HIV/AIDS, they were able to learn through observing Sabina's rebound from the severe stage of the illness to her healthy self. This turnaround in the thinking of Sabina's community members indicates that a dominant practice of reading bodies' health based on their external appearance occurred. These women were able to re-configure their construction of the HIV-infected body, even if only slightly, after seeing the physical changes in Sabina.

Jane's experiences with isolation from community members echoed Sabina's. "When I was found with the disease at that time, my work ceased and friends run away, but my family was firm with me until I regained my good condition and went back to work as usual," she recounted. Both women were lucky in the sense that their community members responded in a positive way after they regained health. However, had they not, Sabina and Jane might still be facing isolation from their social networks. The background assumption is that Jane and Sabina, because they are HIV-positive, should look unhealthy. When they were experiencing visible illness, each woman was stigmatized based upon her physical appearance. When this background assumption was not fulfilled, because Jane and Sabina were on treatment and managing their illness effectively, perceptions about the disease and the women began to shift. The experiences of Sabina and Jane highlight the fact that perceptions of PLWHA in their wider communities have been socially constructed based on the communities' experience of witnessing those whose bodies have deteriorated as a result of the virus. It also illustrates that the social death faced by HIV-positive individuals can be decreased when communities are given the opportunity to re-conceptualize the disease with more information and exposure.

The fear of being infected by Atoti was too much for her employer and it resulted in the loss of Atoti's job:

I wanted to continue with the job, but most of the people were refusing to take me for the job because they were saying that—they were stigmatizing me saying, "You can't work at my home place because you are going to infect my kids; you are going to infect people here."

The employer for whom Atoti cleaned, cooked, and looked after the children was misinformed when it came to the pathways of HIV transmission. Fears of being infected by a positive individual through casual contact reduced Atoti's ability to act as a full member of society. This is not an uncommon misconception, as this fear was also shared by people in Tina's, Sabina's, Jane's, and Whitney's communities. All of the women were vividly aware of how many people perceived the illness, and in turn, the women in this way. This made the negotiation of to whom to disclose extremely important to avoid an increase in experiences of isolation, exclusion, and discrimination.

Misinformed beliefs that perpetuate stigma, such as the ones the women reported above, can inhibit desire to seek treatment or confide in others for support. These beliefs can ultimately encourage HIV-positive people to conceal their illness in order to maintain a façade of healthiness, thereby avoiding social death. These ideas illustrate that the communities in which the women live need increased opportunities for HIV/AIDS education and access to more accurate AIDS-related information.

**Metaphoric Representations of HIV/AIDS.** The women in my study used descriptive imagery, visual imagery, and animal symbolism to better demonstrate how they understood HIV/AIDS in their lives and in their communities. These ideas further depicted how the women negotiated the disempowerment associated with the disease and developed their particular perceptions of HIV/AIDS. The following two sections, 1) Rapid contamination, danger, and ability to defend the body and 2) the diseased body, taken together illustrate that the women's perceptions have been influenced by stigma in relation to contamination, perceived danger of the infected individual, and the internalized fears of living a life fighting an infection.

***Rapid contamination, danger, and ability to defend the body.*** Fire, the insect, and the lion were all metaphors developed by the women that depicted the dangers of being uneducated about HIV/AIDS, the rapidness with which virus can infect the body, and one's ability to defend the body against complete breakdown. All of these ideas contribute to how the women conceptualized the disease and negotiated its role in their identities.

*Fire.* In her journal, P. Diddy used the importance of handling fire with care as a comparison to the consequences a person can face when engaging in risk behaviors at a young age or when they do not have sufficient preparation for sexual encounters. "Getting into a fire by yourself" can have multiple meanings here. Reflecting back on P. Diddy's reluctance to disclose her status to those closest to her, I believe that this statement may be a reference to the self-isolation, fear of stigma, and the intense, often debilitating, emotions a person with HIV can experience. P. Diddy, newly diagnosed at the time of our first interview, was experiencing many of these intense emotions. In her description of HIV as fire, P. Diddy once again highlighted the fears associated with the disease.

In saying, "Everyone must be afraid of fire; even if it's a spark you can be harmed," she alluded to the fact that something small that you underestimate can harm you and should not be taken lightly. Protecting yourself from contracting HIV does not mean devaluing those who have the virus but taking the right precautions and practicing safer health behaviors. Like the sparks of a fire that may or may not cause harm, one may or may not contract the virus when having unsafe sexual encounters, not exercising the right precautions during a pregnancy, or not using sanitary practices. In using the

analogy, “[It] is the same as getting into a fire by yourself,” P. Diddy may also be addressing the pain one can experience and even the loneliness or isolation that may be felt by the HIV-positive individual. This could be a result of stigmatization and the shame with which the virus is associated.

*The Insect.* In her narrative, Atoti used the metaphoric insect and its bite to represent how one comes into contact with the virus and its subsequent takeover. She compared the virus to a permanent parasitic insect—once inside you, it latches on and you cannot get rid of it. This metaphor might be a reflection of the lack of control Atoti had over contracting the virus, as she was a victim of rape. It also represents the shock of the initial diagnosis when an individual is unaware of how she contracted the virus. This leads to a “permanent mark” or an internal scar which, unlike the venom of an insect bite, resides in the body for the remainder of one’s life.

*The Lion.* As discussed in her narrative, Atoti used the metaphoric lion to demonstrate the existence of fear in her community and about the stigma around PLWHA. This metaphor illustrates Atoti’s fear that if someone discovers her status they will become distant, wish to avoid contact, and enact her social death. Atoti compares people’s fears of the lion to their fears of HIV and being associated in any capacity with the disease. This is a disempowering action as it frames the HIV-positive individual as a polluted body capable of contaminating others.

**The Diseased Body.** Some of the women made vivid comparisons between their bodies and objects such as a mango, a mobile phone, clothes, or a crow. These comparisons illustrate women’s own ideas and the ideas they have received from their

communities about the body and HIV/AIDS. In discussing perceptions of the body, Kirk (2002) stated:

Like a script, bodies tell a story about the person they embody. The physical appearance of bodies conveys ideas and values. Like scripts, bodies are read. Each of us, in the course of our everyday lives interprets the signs they emit. (p. 82)

The women referenced the physical appearance of the HIV-infected body with symbols in several of the following descriptions. To some of the women, the HIV-positive body is something to conceal, or something that requires constant upkeep to maintain an appearance of normality. The following metaphorical representations highlight the ways in which these women subjectively experience living with HIV..

*The mango.* P. Diddy used the mango to discuss changes in her body due to HIV infection, comparing the virus in the body to a maggot in the mango (see Figure 20). Her caption reads:

A mango is a fruit which you can eat raw or ripe. When on a tree you see it as attractive, but inside where you cannot see, it has the maggot. This is to compare the body to the mango. At the time when the virus goes inside your body people will not know until they see changes in your body. Just as they will not know the maggot is inside of the mango until it is destroyed by the maggot, when its skin and surface changes. (P. Diddy)

In this metaphor, P. Diddy addresses issues of disclosure and privacy around the disease, as well as its deteriorating effects. P. Diddy describes the virus hidden in her body as a maggot beneath the mango's skin, speaking to the disclosure decisions an HIV-



*Figure 20.* The body, the mango. Diddy, P. (September 2011).

positive person must make. Despite their own awareness of an immune system battle occurring beneath their skin, HIV-positive people do not always outwardly show illness. Thus, from a physical point of view, it is not always apparent that one is infected at the time of initial diagnosis. At this stage, a person can choose not to disclose their positive status and be perceived as healthy based on appearance. The body's degeneration due to the virus occurs over time and starts from the inside out. Awareness of the virus' eventual effects on the body can be disempowering because the HIV-positive woman knows that she will ultimately be unable to perform as well as a non-ill body. Negotiating an HIV-positive identity became more difficult when there was a deterioration of the appearance of health, as judged by other. In order to remain positive about their futures, the women had to negotiate the fear of knowing that HIV was eating away at their bodies regardless of their efforts to maintain health. Despite treatment that can sustain the body in a state of functionality, the women had to face their fears of inevitable degeneration in order to ultimately remain positive about their futures. For some of the women, this was done through disclosure, which enabled shared burden of disease and ability to embrace the HIV-positive status as part of their identities. For others, the perceived stigma of disclosure was so great at the time of the interview that a future with the disease was better envisioned bearing the burden alone.

*Mobile phone.* In her photo-journal, P. Diddy also used the mobile phone as a metaphor to explain the importance of protecting her body:

The phone is a small thing, but do not be mistaken, it is of great value because it allows you to get messages to others in time. You must take care of it, or it will break every time like the disease when it gets inside the



body and wears slowly. You can decide to bring it [the phone] to a repairer man but these days this repair will finish your money. This disease you can compare with the phone. Without you taking care of yourself, you can be infected without knowing it and in time, you will know, but it will be too late. The disease will already be finishing you. In the same way, you treat the phone badly, eventually it is irreparable and you will not be able to send the message.

Money here might equate to the weakening of the body due to the effects of the virus. It might also reference the decision to spend money on treatment for the HIV infection versus saving money to put food on the table. Although treatment is free in Mombasa, the time it takes for P. Diddy to get to the clinic and the cost of transport takes away time from her work day and reduces her earnings. The burden of choosing whether to seek treatment or maintain overall financial survival is an aspect of treatment delivery that needs to be further confronted in communities like P. Diddy's. The Hobson's choice between treatment and earning income limits a woman's ability to effectively manage and have control over the virus.

In using this metaphor P. Diddy expressed that every cautionary measure should be taken when a person is vulnerable to HIV infection. Protecting the phone, a valuable material possession, is like protecting one's own body. If the body is infected with HIV it cannot be repaired, only maintained. Even maintenance can seem almost impossible as money poses a barrier to adhering to successful treatment. Thus while P. Diddy's advice to protect the HIV-positive body is warranted, it may not be realistic for many women.

*Clothes.* P. Diddy used clothes as a metaphor for deterioration, masking the body, contamination, and exposure. This metaphor highlights the burden P. Diddy feels living with a diseased body and is an example of how physical appearance is widely used as a standard for judging the character or abilities of a person (Kirk, 2002). Clothes to P. Diddy are both a literal form of masking visible effects of the virus and a metaphor for how a healthy body infected with the virus deteriorates over time. The infected individual, like the fading and tearing of clothes with wear, will eventually break down:

Clothes when new, look smart. As you wear them, they get dirty and you must wash it. While you continue wearing and washing, it fades and tears. This is to say HIV is like clothes. No one will know that you have the virus but as time passes they will see the difference in your body and will notice that you are infected.

Clothes represent a makeshift barrier against enacted stigma, but this mask cannot last forever. P. Diddy compares wearing clothes that get dirty over time to bouts of illness that make the body weaker. Such a comparison points to the literal contamination of the body as well as socially constructed perceptions about what health looks like, framing the diseased body as “dirty.”

Washing clothes might be compared to treatment regimen adherence. The clean clothes are similar to the refreshed body that has recovered from a bout of illness. The reference to washing might also point to how the HIV-positive body can maintain an appearance of health, since social constructed ideas of disease frame a body that is not visibly ill as “clean” and healthy. Of course, such treatment and masking HIV infection is not always possible. Over time, just as the washing and wearing of clothes breaks

down their fibers, the virus deteriorates the immune system and renders it incapable of fighting the virus and other co-infections. A woman at this stage may not be able to mask the signs of her HIV-positive status and can fall victim to the social constructs of “clean” and “healthy” versus “diseased” and “dirty,” experiencing stigma. For HIV-positive women, the eventual “wear” on the body is inescapable, leading to a constant struggle to maintain a socially accepted identity.

*The crow.* Jane used the crow, despised in her community, to describe how she was stigmatized while she was ill, explaining, “With us [her community], the crow is a despised bird. Firstly, its black color is ugly and its blood is not edible. So when I was sick many despised me like the crow.” Jane explained, during our second interview, that this drawing (see Figure 21) represented how the people in her community treated her when she became ill. The stigmatization and lack of support has been a constant struggle in Jane’s life. The ugliness Jane assigned the crow’s color can be compared to the transition from a healthy body to a deteriorating diseased body. The crow’s inedible blood is similar to the virus in the human bloodstream and the risk of spreading infection through blood contact.

Despite the delay in progression of the disease that treatment affords, the HIV-positive woman is inevitably unable to escape her fate. Weitz (1991) reiterated this fact, explaining that after an individual reaches a certain stage of this disease, they can no longer recover and their efforts to conceal are in vain. Thus, disempowerment might be experienced by the HIV-positive individual facing this inevitability who desires a new body.



*Figure 21.* The crow. Jane. (October 2011).

Symbols have value because they allow different contextual meanings to emerge from a single idea. Thus, how one person understands a symbol depends on their social location and experiences or pre-received ideas about that symbol, which may differ for another individual (Cunningham, 1992). The women used the aforementioned symbols to incorporate local ways of knowing into their constructions of HIV/AIDS. Four very different symbols—the mango as a context-specific food, the mobile phone as an everyday item, clothes as relevant to all the women, and the crow as a culturally despised bird—were each used to convey the same experience of a diseased body.

### **Negotiating the Burdens of an HIV-Positive Status**

An individual's identity is constantly shaped by the interplay between existing belief systems, others in her environment, and her own individual interpretations. Identity and belonging were synonymous in the narratives of the eight women who took part in this study. This is evident through the burdens of disease these women conveyed including living with stigma, avoiding stigma, maintaining health through treatment regimens and hygienic routines, preserving relationships, and deciding whether to disclose. These burdens created complex issues of negotiation for the women when choosing whether to embrace or conceal their HIV-positive identities.

For the women who chose to take on the status as part of their identities, stigma was still an issue despite support, causing the women to begin re-negotiating the burden of the illness. Thus, sharing one's HIV-positive status had two outcomes: increased support from family, friends, or community members and increased stigmatization. Understanding that these outcomes might occur, sometimes simultaneously, a sense of duty to protect others and in some cases themselves emerged. The women also noted that

education, in some cases including hearing about the experiences of others, helped them to want to share their status, and begin determining how best to embrace the HIV-positive status as part of their complete identities. However, for some women in the study, concealment of the HIV-positive identity was a more bearable space in which to exist.

This negotiation of identity for the HIV-positive women resulted in the development of two patterns:

- a) Actions to protect others
- b) Self-preserving behaviors

**Actions to protect others.** Adhering to treatment and strict daily cleaning regimens were actions the women took to protect themselves and others across all arenas of negotiation of their HIV-positive status. In addition, the women discussed the necessity of explaining risks and necessary precautions before engaging in any behavior that might place another individual at risk to infection.

In our interview, Jane discussed how she took actions to maintain her health in order to protect her daughter. Jane takes the medicine because she does not want to die from AIDS and leave her child orphaned. For Jane, her reason for adhering to treatment is to ensure that her daughter grows up with a mother. It would be a burden on others if Jane were to die, knowing there are no other options for her child. In addition, taking her medication also lessens the chances of passing on the infection, thereby protecting others. In adhering to treatment, Jane expresses her hope for the future and seeing her daughter grow up, despite her illness. Thus, those in Jane's situation may be able to embrace positive status as part of their identity because of the desire to protect others.

Both Jane and Mariam feel a duty to shield children from the devastating effects that can occur with HIV infection. In Mariam's case, she advocates for HIV-positive people who are potential parents to be educated about the implications of the HIV and AIDS:

I'm in a pity situation because parents are dying and leaving children behind [orphans]. Children are left in society/village begging for help. Some are being left in orphanage centers. I will be pleased if we help each other and unite so that we can help them [the children] and they don't feel so lonely. We should have to talk sweet words to those orphans. I would like to learn anything about this disease so that I can be able to educate others who don't have any information about HIV. I am willing to volunteer with my whole heart and I will be glad to do so.

Such conversations could enable women who are HIV-positive with children to understand the importance of a treatment regimen. In this excerpt from her interview, Mariam demonstrated a sense of responsibility for ensuring that children are not orphaned as she was and do not grow up with the same vulnerability to HIV infection. Education might place individuals living with HIV in a better position to embrace their HIV-positive identities, and those affected by it in a better position to embrace the identities of the HIV-positive people in their lives.

In contrast, the desire to protect her community and family members was a frustrating experience for Atoti:

So I think talking to them about HIV, it's just, it's useless because if maybe you want to talk to someone about HIV happens, you want to

advise someone about HIV and that person is telling you ‘ah oh ah I—I can’t, I can’t go and get tested. HIV is there [away from me] and I don’t want to go and get tested. I know my status; I know I’m okay, so there is no need of me going to the hospital to get tested.’ So I want to tell them about the importance of taking ARVs but they’re ignorant. That’s why I don’t feel like sharing the knowledge I have on HIV.

Her sense of duty to protect others is apparent through her example of trying to initiate conversations about the disease. However, Atoti’s ability to educate was frustrated by her community member’s unwillingness to be associated with the disease. Members of her community who subdue conversations about HIV detract from Atoti’s agency in her social environment and impair her ability to fully accept her positive status as part of her identity, encouraging her to instead suppress this part of herself. Atoti is thus left in a limbo where she can only partially embrace her positive status, waiting for a supportive space to open up where she can fully integrate her HIV-positive status into her identity without having to fear stigmatization.

Where Jane and Mariam discussed the need to protect themselves through maintenance of health and increased education, Whitney shared a similar desire to protect herself in her home. Whitney used a large amount of space in her photo-journal to describe cleanliness practices that she and her family execute on a daily basis to prevent co-infections as well as transmission of the virus. In her caption, she wrote:

I live with my family members and the most important thing we do is to keep our environments clean and our house too. Our sitting room is well ventilated for proper ventilation of air to prevent any airborne disease like



TB. My bedroom is well ventilated and clean. Also, my beddings are clean. This helps in prevention of any skin diseases. The toilets are washed daily to prevent any form of urinary tract infection like candidiasis, vaginitis and several diseases that can gather on top of the toilet seats. Proper disposal of dirt to prevent inbreeding of insects which are health hazards like rats, cockroaches, lizards.

This excerpt from Whitney's journal details how much of her time is occupied with ensuring the environments in which she lives are clean. This was not the only example of cleaning practices in her photo-journal. To Whitney, sanitation means safety from transmitting the virus to others or from contracting a co-infection. In the section of her photo-journal entitled, "A Day in the life of Whitney" where this particular excerpt is found, she explains the routines she subscribes to each day, without fail. Perhaps Whitney takes these actions because of the great sense of responsibility she feels to shield others from HIV infection. Whitney's training as a counselor has equipped her with the knowledge necessary to understand the importance of sanitation practices in reducing exposure to potential secondary infections that would increase the severity of the illness, as well as understanding the actions that risk exposing others to HIV infection. When Whitney embraced her positive status she felt accepted, had hope in her future, and ultimately felt supported in her life with the disease, making her identity as a person living with HIV as vibrant as an identity of an individual living without illness.

**Self-preserving behaviors.** Any behavior enacted by a woman to protect herself is, for the purpose of this analysis, defined as a self-preserving behavior. The women enacted these behaviors when they needed to make difficult decisions related to self-

preservation in their households, communities, or in social relationships. The women often found themselves making these decisions in the arena of negotiating their HIV-positive status, trying to discover the best way to preserve some semblance of “normal” identity whether embracing their HIV-positive status or not.

In addition to not wanting to infect others, Whitney has avoided intimate relationships, out of a fear of complicating her condition, in order to protect herself: I live a life of abstinence because I am still not ready for relationship and Mama, I don’t want to spread HIV to other people because I could also get other strains of the virus, thus making me sick, lowering my immunity.

Whitney’s desire to protect herself and others is a common feeling among women living with HIV or AIDS (Doyal & Anderson, 2005). This desire caused Whitney to isolate herself in some situations in the past while initially negotiating her positive status as part of her identity. When she was younger, her fears of rejection and stigma also caused her to isolate herself from her peers. Thus, as a younger woman Whitney chose to conceal her status from everyone except her sister and doctor. In deciding to avoid intimate relationships due to her HIV-positive status, Whitney justified this as a protection mechanism against heightening the negative effects of the virus on her own body. Now, however, she embraces her status as part of her identity and as a result self-preserving behaviors are less frequent.

P. Diddy gives advice to always take precautions when engaging in relationships with others: “In this world you cannot trust anyone. Even if he is a brother or friend. It is best to take care before anything bad happens.” This statement is important because P. Diddy highlights the possibility of stigma here, even from those closest to her. Protecting

herself means shielding herself from stigma associated with HIV. This forces P. Diddy to conceal part of her identity to guard against further negative experiences that would complicate her already difficult situation of living with a chronic illness.

Stacy also commented on the importance of maintaining the body, however, her reasons varied slightly from those of P. Diddy:

A person who has the virus is supposed to eat a lot of different fruits and a well-balanced diet so that she can have enough energy and keep her blood good. She is also not supposed to think about anything concerning her life in bad way. If she does this, nobody will know her status, because she will look healthy like somebody who is not infected.

This quote is a reference to behaviors that shield the women from stigma. To Stacy, looking healthy means others will be unaware of her HIV-positive status. Though the purpose of following a health regime is typically to maintain physical wellness, for Stacy it was also to maintain emotional wellness by protecting herself from stigma. Stacy negotiated that concealing the HIV-positive part of her identity was better than exposing herself to enacted stigma.

In terms of disclosure of status, a few of the women alluded to the fact that non-disclosure was sometimes a form of protection. Stacy also feared that if she disclosed her status, she would burden her family and friends:

I don't want to tell them. Because even if I told them [her friends and family] there is nothing they will help me with. I don't know if they would give me support or what because I myself—I know how to support myself, because I am the one who is young.

Common stories from similar studies regarding women living with HIV/AIDS, who had been excommunicated from home, been isolated, treated viciously, framed as contagious or a victim, augmented concern on confession in a way that the stories of the community are tangled with individual story lines. Thus, making the decision to tell or not to tell complex (Soskolne, 2003).

Non-disclosure of status served as a protection mechanism for P. Diddy as well. When I asked her directly if she was scared to disclose her status to family or friends because she feared negative treatment, she responded yes. P. Diddy's disclosure to a close friend resulted in the friend encouraging her to tell her family, particularly her fiancé. Her friend warned P. Diddy that she could not live with the virus without anyone knowing. While this was positive support, P. Diddy was still occupying the arena of negotiation at the time of our interview. For both her and Stacy, the arena of negotiation presented similar issues. Both women were resistant to the idea of disclosure. The negotiation of burden of disease for these women determined whether they chose to isolate themselves completely or continue to debate disclosure. Both were not yet ready to move to a space of full acceptance where they would wholly embrace HIV-positive status as one part of their identity.

### **Chapter Summary**

The findings suggest that the experiences of the women are complex. The undercurrent of stigma in the lives of these women is very apparent. Their narratives indicate that this stigma can be intentional on the part of those enacting it where dominant beliefs have been shaped by misconceptions or have connections to religious or traditional ideas that associate HIV/AIDS with deviance or contagion. The women also

experienced enacted stigma in the form of isolation due to others' fears of being associated with the negative assumptions that surround the disease. In other cases, those enacting stigma did not seem to have malicious intent but were acting in accordance with inaccurate information about the disease. Ultimately, stigma, whether intentional or not, was a result of misinformed information about HIV/AIDS, either from religious, cultural, or social constructions related to AIDS in the community.

Faced with burdens such as stigma, the desire to preserve relationships, and the need to maintain health affected how the women embraced or denied HIV-positive status as part of their identities. The women had different experiences of negotiating internalization of stigma and other burdens. Working through these negotiations often placed women in a liminal space between acceptance and concealment of the new identity, as well as being accepted or not by others.

In the final chapter, I will further describe experiences of how the eight HIV-positive women in my study formulated perceptions about the disease. I will relate their experiences as presented in this chapter to the existing literature. In addition, I will reflect on my growth as a researcher, the strengths and limitations of this study, as well as my recommendations for future research working with HIV-positive women in Kenya.

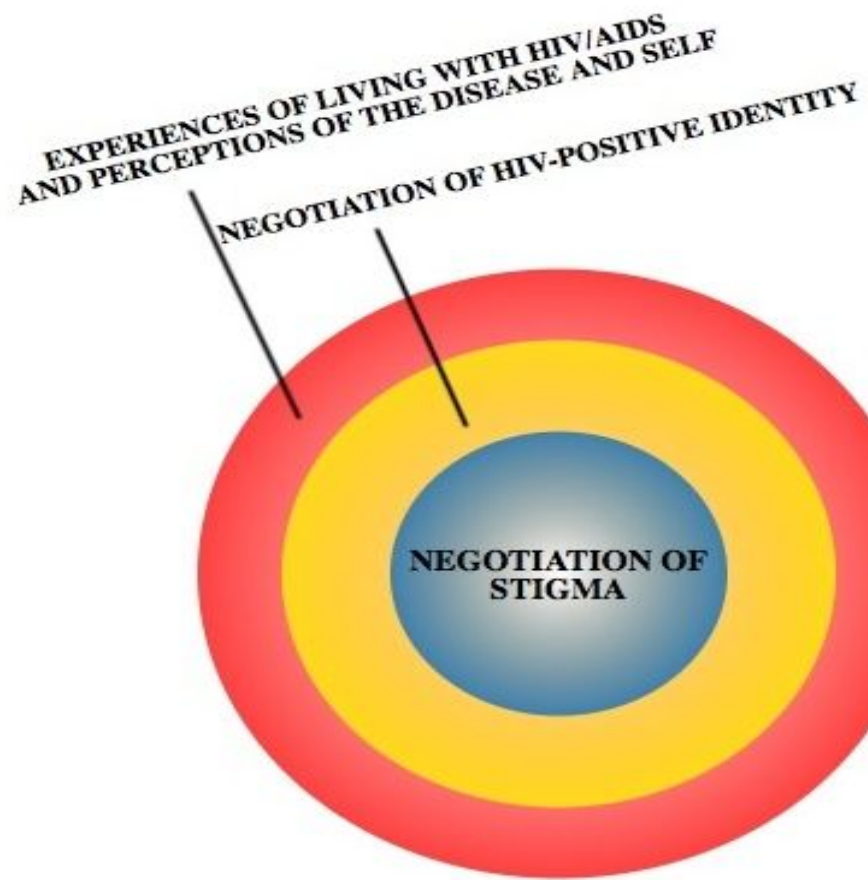
## **Chapter 6**

### **Discussion and Final Thoughts**

#### **Synthesis of Results**

Reality is individually constructed, thereby making reactions to specific situations or ideas different (Peterson & Willis, 2011). In this study, each woman had interesting experiences to share. How the women embraced or avoided incorporating their positive status into their overall public identities was dictated by their beliefs about where HIV/AIDS comes from, how others in their communities perceive the disease, their level of knowledge about it, and the amount of support they predicted would exist if they did embrace their status. The stories of these women are stories about stigma and, ultimately, the negotiation processes involved in embracing or concealing the HIV-positive status as part of their identities. In turn, how they each conducted these negotiations in the face of stigma led to the women's different ways of knowing HIV/AIDS that shaped their lived experiences with the virus.

The first three sections of this chapter are a synthesis of the results illustrated in Figure 22. First, the formations of these women's perceptions of HIV/AIDS cannot be understood without highlighting stigma. It is also important to recognize the use of stigma to other those living with HIV, thereby disempowering them and making difficult the process of negotiating a positive HIV status. Finally, the identities of these women were further shaped by their ability to arrive at a narrative turn in the experience of illness, represented by their capacities to think positively about a future of being positive.



*Figure 22.* Formation of Disease Perceptions and Self-Identity as an HIV-Positive Individual.

I have divided my discussion into sections based on these three topics to summarize and explore some aspects of the women's experiences which were particularly significant in how they constructed perceptions of the disease and, in turn, negotiated their HIV-positive status as part of their identities. The three sections are as follows:

- a) Power Relations, Othering, and Defining Categories of Stigma
- b) Negotiation of HIV-Positive Status
- c) Thinking Positively About A Future of being Positive

In the final section, I reflect on my journey and how I have personally and academically grown as a researcher throughout this process. I then explain the strengths and limitations of the study and follow these with recommendations for future research about and with HIV-positive women. Finally, I present a way forward and my final thoughts.

### **Power Relations, Othering, and Defining Categories of Stigma**

The women in my study expressed that their family and community members indicated a lack of understanding of the HIV/AIDS and its modes of transmission, preserving stigmatizing discourses that disempower those living with HIV. The othering of HIV-positive women when individuals perceive the virus to be associated with deviance, uncleanness, and contagion perpetuates the us versus them dichotomy between the healthy and the diseased (Deacon et al., 2005; Grove & Zwi, 2006). Fay (1996) wrote, “There is no self-understanding without other-understanding” (p. 201). This quote illuminates how PLWHA are disempowered when individuals without HIV/AIDS (or those unaware of their status) construct diseased identities in relation to healthy identities, stigmatizing PLWHA and thereby refusing to understand their full selves. By segregating those seen as “diseased,” PLWHA are othered based on perceived difference (Grove & Zwi, 2006). Stigma creates power imbalances through this process as the stigmatizer gains perceived superiority (Holzemer et al., 2007).

Throughout my study, the women referenced acts that constituted the othering process. One such example was the toilet as a space that could not be shared with a person with HIV, unless it was thoroughly cleaned after each use. PLWHA in other studies used symbols such as the toilet, representing infection and uncleanness, to report



connections between disease and uncleanness as a potential source of stigma in the past (Bond & Nyblade, 2006; Warf & Arias, 2008). Othering involves marking the HIV-positive individual as differing from social norms. Taking unnecessary preventative measures because of fears of transmission, has framed some of the spaces the women inhabited, and the objects they used as dirty and diseased. Molotch and Norén (2010) stated:

Dirt is an “offense against order”, against the categories that promote social stability. It is, therefore, that which society feels it needs to eliminate, conceal, or purify in order to preserve order. Sounds, smells, sights, objects, or even people that cross boundaries threaten the purity of social categories and are causes of psychological and social unease. The body has a special symbolic role in this social ordering, since it is “a source of symbols for other complex structures” and “a reliably constant source of pollution”. (p. 25)

Thus the ways of knowing the disease referenced by the women in my study (i.e., social death, deviance, uncleanness, fear) was fraught with notions of othering. Equating disease with dirtiness, and the women with HIV as impure.

Practices of othering were extremely apparent in the home. These included burning cutlery and dishes to sanitize surfaces, separation of the HIV-positive women's belongings in the household, limiting sharing of spaces such as the bathroom to only after they had been cleaned, and disposing of items used by the HIV-positive women. I defined these acts of stigmatizing by any member living in or entering the home space as domestic stigmatization. Lekas et al. (2006) labeled forms of stigma around maintaining

clean environments such as unnecessary sanitation practices as “hygienic degradation acts” (p. 1180). This concept illuminates fears of being infected through casual contact. When Lekas et al. (2006) interviewed an HIV-positive Puerto Rican woman residing in the United States about the hygienic degradation acts she had experienced, the woman’s narrative echoed those of the women experiencing domestic stigmatization in my study:

She [R’s aunt] would bleach everything down. Ah, I had my fork, my spoon, my knife, my plate, everything put to the side. My own glass . . . [I felt] very uncomfortable. I remember at one time thinking, ah, “Damn, man, I wonder if this is the same way lepers in the olden days felt?” You know, everybody used to push them aside . . . She made me feel like a leper, you know? She made me feel like if I had all these types of stuff growing out of my body, you know? She made me feel alienated. She made me feel like I was a nobody, you know? (p. 1180)

Another woman from the same study shared a similar narrative about her family’s fear of contracting the virus through casual contact:

People rejecting me, my father, my mother rejecting me. My brothers, my daughter, even though she doesn’t know, to this day she still don’t know that I’m sick. But, those are the main problems that I was scared of. You know, about them touching me, or they don’t touch the same glass I’m drinking, you know. Or the same plate, you know. At one time my little sister she like, she didn’t know nothing. You know, she had my own plate, my own cup separate, you know. I said, “What do you got this separate if you know,” and those are you, you know, you have, and I said, “Don’t do

that, because you don't get it like that," so now she don't do it no more.

Because I gave her pamphlets, books, and all that. She read about it.

(Lekas et al., 2006, p. 1181)

The similar experiences of the women in my study and those in Lekas et al. (2006) clearly illustrate fears of infection through casual contact in the household, in addition to misunderstandings of how the virus is transmitted. This domestic stigmatization further relates to discrimination and abuse that individuals living with HIV/AIDS continue to encounter into the fourth decade of the epidemic (Ouma & Kalipeni, 2009). A number of studies have explored similar fears of infection through casual contact (Bogart et al., 2008; Campbell, Foulis, Maimane, & Sibiya, 2005).

**A new category of stigma.** Domestic stigmatization, as a type of stigma, has always existed but has never been formally defined or categorized in the literature. Several studies, consistent with the women in the current study, report experiences of stigma in the household (Bogart et al., 2008; Campbell et al., 2005; Cao, Sullivan, Xu, & Wu, 2006; Carr & Grambling, 2004; De Souza 2010; Lekas et al., 2006; Tang, 2008; Yebei et al., 2008). In order to effectively design initiatives that disable the influences of stigma, I propose that types of stigma such as domestic stigma be defined within the context being explored. Researchers and program designers can then categorize and rank types of stigma according to the degree of negative impact on communities under study.

Several studies do reference categories of stigma, but definitions vary from study to study (Airhihenbuwa & Webster, 2004; Berger, Ferrans, & Lashley, 2001; Bogart et al., 2008; González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007; Holzemer et al., 2007). Holzemer et al. (2007) created a conceptual model to understand

the complexities of stigma surrounding HIV/AIDS. Data collection for their study was extensive and spanned across five African countries. The researchers defined three key types of stigma—received, internal, and associated—and described several examples of each type using examples from their participants. They proposed that the model is transferrable and may be used to inform future stigma-reduction strategies in similar contexts.

I agree with the usefulness of their model in the specific contexts in which it was created and for the exploration of HIV stigma. However, I argue that for purposes of program design, categories of stigma must be distinguished based on type of stigmatized condition and the given country and cultural context and must be based on local knowledge specific to the community where change is being implemented. Therefore, the model must be adapted depending on the context of a particular study. An adapted version of the model could then be useful at the grassroots level to dismantle stigma from the bottom up, starting with individuals in the community.

A new means of deconstructing long-held stigmatized notions of HIV/AIDS might be to develop a research project where data collection focuses on each category of stigma that exists in each community with high HIV prevalence or a large vulnerable population. By measuring the effect of each category of stigma in these communities on a scale of severity, researchers might be able to pinpoint the areas of greatest challenge. Researchers, program officers, and community members could then work together using this scale to design initiatives focused on disabling the most prominent categories of stigma in a particular population.

### **Negotiation of HIV-Positive Status**

The construction of social identity is concerned with other things apart from common abstracts of “I versus the other” or hierarchies (i.e., sex, race, ethnicity) (Kraus, 2006). Instead identity encompasses interactions (experienced or imagined) with communities, groups, other individuals, and institutions. Therefore, a person has a wide range of attachments in relation to others; and this makes it necessary to understand how to manage these relationships in order to maintain a position of belonging. Developing an identity is a way for the individual to position themselves relative to others and for others to define the individual (Kraus, 2006). Therefore, people do not just gain affiliations on their own; people are positioned according to how others in society categorize them. An individual also needs to affirm their associations to others and either be accepted or rejected. Meaning that belonging is qualified time and again in order to fit a particular situation and it must be tested, negotiated, rejected or accepted (Kraus, 2006). This was the case for each of the women in this study, who at times, felt rejected or accepted based on their perceived identities living with HIV.

In reviewing literature on the effect of chronic illness such as HIV on a person’s identity, themes involving transition, loss and living with illness were better captured than the effect of illness on self-identity. Being seen by others as a diseased body, or dependent body, was one of the principal losses experienced by individuals living with a chronic illness (Baumgartner, 2007). In response to loss of identity, goals were changed. While some individuals held onto their identities of mother, wife, teacher etc., others shaped their new identities through aspiration building, intellectual challenges, and planning for the life ahead (Charmaz, 1995). Individuals who were chronically ill created

new identities after understanding how to live with the chronic illness. This approach was important to living a more fulfilling life (Adams, Pill, & Jones, 1997; Michael, 1996). Other people denied their identity with chronic illness while some adopted ways of limiting the effect of living with the illness (Adams et al., 1997; Baumgartner, 2007; Goldman & Maclean, 1998). Each of these experiences of living with illness and negotiating identity, are similar to the experiences of the eight women living with HIV who participated in my study. In line with other studies concerning chronic illness, this study demonstrates that identity negotiation with illness, such as HIV, is a dynamic process affected by how individuals are perceived, how individuals perceive others, and how individuals view themselves.

Two ontologies related to living with physical deficits such as disease are the foundationalist and anti-foundationalist perspectives. According to Turner (1992), the foundationalist perspective assumes that the individual is passive and that their identity is constructed via external influences such as social norms. In contrast, the anti-foundationalist perspective frames individuals as active participants in the construction of their own identities. According to this perspective individuals actively engage with ideas at each level of their environment (Turner, 1992). These perspectives are useful in understanding the complexities involved in negotiating HIV-positive status as part of the embodied self.

The women in my study were, at times, highly active participants in the self-construction of their identities related to HIV-positive status. From an anti-foundationalist perspective, the women actively engaged with ideas from their communities and attitudes of their family members, partners, and friends; thought about

societal discourse surrounding the disease; and negotiated how each of these influences would affect their perceptions of HIV and their own identities. In other instances, the women remained passive, not always by choice, in the face of challenges created by stigma. Hence, resilience to stigma came in both active and passive forms. Sometimes a choice to ignore or conceal their status, remain isolated, or subscribe to incorrect notions of cleanliness was a means of resilience in order to stay within their households. These different positions of negotiation were similar to the experiences of participants in a South African study (Gaudge, Ngoma, Manderson, & Schneider, 2009).

Soskolne, Stein, and Gibson (2003) investigated stigma and identity from the South African context by working with 12 HIV-positive women. The researchers uncovered how people with an HIV-positive status endured stigma and searched for ways to form more encouraging identities despite their illness. The authors argued that in order to place PLWHA in a more positive position in the social sphere, programs must acknowledge both the positive and negative aspects of being diagnosed with HIV/AIDS. This would ensure that the complexities and consequences of the disease are understood, while recognizing that HIV-positive individuals have the capacity to continue living and have hope for the future in spite of the disease.

Consistent with Soskolne's (2003) findings, I was struck by the tendency of the women in my study to describe positive experiences of support they had with HIV. These positive accounts were stories of transformation, highlighting the positive aspects of their lives. As the women spoke about their hopes for the future and conveyed their desires to gain more support through educating others and sharing their stories, I observed the narrative turns in each woman's life. At the very least, each woman envisioned a future,

and some had even arrived at a turning point where they embraced their HIV-positive status as a part of their embodied identity, running full speed ahead from that point.

**Stigma and the negotiation of identity with an HIV-positive status.** It is important to recognize that despite gains, roadblocks (i.e., stigma) continue to exist and can affect how HIV-positive individuals perceive themselves at any point. However, acknowledgement of capacity to maintain a good quality of life with disease can make the process of enduring stigma and coming to embrace a positive status as part of one's new identity less difficult (Soskolne et al., 2003). Openly discussing challenges with stigma may encourage further attempts to spread awareness, accurately educate communities, and develop prevention efforts, limiting the effects of stigma. Other researchers agree with these conclusions and stress that gaining control over HIV infection involves constructing a new identity where self-esteem can be maintained and individuals can find meaning in their lives (Charmaz, 1991; Frank, 1995; Kralik, Kock, Price, & Howard, 2004).

My findings support the conclusion that the negotiation of an HIV-positive status will remain a complex process as long as the current social discourses that stigmatize individuals with HIV persist. Borrowing from Soskolne et al. (2003), it is not enough to ignore the destructive capacity of illness and focus only on an identity shaped by notions of positive health. This would restrict the space to discuss the distress, the complications, and the struggle, both physically and emotionally, of living with the virus.

My findings, when combined with the previous literature, illustrate that moving between arenas of negotiation, as well as comfort level when existing in each of these



spaces, is dependent upon how individuals are enabled to manage AIDS-related stigma. The influence of stigma was present for women in my study whether they were embracing, concealing, or negotiating how their HIV-positive status fit into their identities. This suggests a need for work around changing perceptions of the disease, with particular attention to how stigmas surrounding HIV are formed, enacted, and sustained. Ultimately, PLWHA should not have to negotiate between three undesirable options of social existence (internalizing, enduring, or ignoring stigma).

Spaces where women (and all individuals) living with HIV can be supported and feel safe are needed. While the disclosure process for some women in my study proved positive and rewarding, this was not always the case. Gilbert and Walker (2010) note some reasons why HIV-positive individuals choose not to disclose “PLWHA are confronted by many factors that discourage disclosure such as: moral judgment and blame; ostracism by household or community; relationship termination; verbal and/or physical abuse as well as discrimination” (p. 141). In addition to these possible outcomes, once disclosure occurs reactions may differ depending on who is receiving the information (e.g., spouse, child, support group, employer, parent, extended family members, friends, neighbors) and ultimately the process is individualized (Carlson, O’Campo, Farden, & Eke, 1997; Greeff et al., 2008; Smith, Rossetto, & Peterson, 2008; Visser, Neufeld, Villiers, Makin, & Forsyth, 2008). Therefore, while disclosure may be therapeutic for some, for others it is impossible or considered unnecessary to move forward with life. The high risks of disclosure may be why some choose to bear the burden of their HIV-positive status alone.

From a theoretical standpoint, eradicating stigma requires that the social constructions of the disease be re-conceptualized.

### **Thinking Positively About a Future of Being HIV-Positive**

Similar to other studies (Paxton, 2002; Sosklone, 2003), the idea of envisioning a positive future while living with a chronic illness such as HIV was something each of the women in this study conveyed throughout their narratives. Some of the women indicated that their HIV-positive status provided a sense of purpose in life, while other women saw it as an opportunity to communicate educational ideas about the disease to their family, friends, and communities. Thinking about living with a lifelong illness was also made more bearable by the notion of sharing the experience with others.

Lack of support for individuals with HIV infection has been noted to hinder their ability to seek treatment and to adhere to it (Rohleder, Swartz, Kalichman, & Simbayi, 2009). Increased access to information and informative educational initiatives have helped to displace discriminatory notions about HIV/AIDS while in turn creating more support for women living with HIV (UNAIDS, 2006). Thus, it is not surprising that women in this study felt more positively about living with the virus and more supported in that challenge when they, their family, and their peers had greater knowledge of the disease.

At the community level, the women described clinics and support groups in their narratives as spaces where they felt supported. Esplen (2007) found that when battling a chronic illness (such as HIV), learning that others were having similar struggles and/or successes managing HIV could be encouraging, leading to better adherence to treatment regimens. The women I studied who attended support groups and heard the stories of

others noted feeling more positive about their futures and less powerless in the face of the disease. This has positive implications for those on treatment, as positive hopes for a future gained from such a supportive environment lead to greater adherence (Campbell, Nair, & Maimane, 2007; Esplen 2007).

In addition to the fact that individuals have to take responsibility for knowing their status, researchers have noted that safe spaces void of stigma are necessary for HIV-positive individuals to experience positive attitudes toward managing the virus (De Cock, Mbori-Ngacha, & Marum, 2002). This was the case for Atoti and Whitney who found discussing living with HIV in support group settings was particularly helpful in the emotional management of the virus. Studies conducted early in the pandemic had similar findings—those who receive support from their social networks are less likely to experience feelings of depression and powerlessness (Bor, Miller, & Goldman, 1993; Zich & Temoshok, 1987).

Some of these women might have avoided infection had they been able to access adequate education with the opportunity to take tests on and question knowledge of the disease. All the women in my study agreed that education at a younger age would be helpful in prevention efforts and should be a necessary part of institutional, government, and community program goals for education. The Kenya Institute for Education (KIE) completed the AIDS Education Project, a baseline assessment of the needs of youth in and out of school, in 1994. Since then they have produced health materials such as handbooks, magazines, and additions to school curricula. Unfortunately, this material is still not universally available at all educational institutions across Kenya, despite a new curriculum being mandated by the Ministry of Education in 2000. The KIE developed

this new curriculum, which expected teachers to integrate health messages across various subjects (*Analysis of HIV/AIDS Policy Formulation in Kenya*, 2007), but lack of teacher training means that teachers have a limited ability to actually use the KIE materials to communicate health information.

AIDS-related education was not a strong focus of schooling for the women in this study, although they did mention hearing about HIV/AIDS in this setting. The women hope to witness increased dissemination of health materials in rural and urban centers in the future. They also call for increased involvement of governments and institutions when providing equal access and opportunity for education at a younger age. This is important to create a better understanding of health that will allow young people to identify sexual risks as they grow older. Such efforts could enable the women's children's generation to be better informed about sex and safer health practices. Sallar (2009) supported the sentiments of these women in noting that increased health knowledge may reduce sexual health risk, thereby decreasing risk of infection. Similarly, Onah et al. (2004) suggested that having health knowledge is not always a guarantee that healthier and safer practices will happen, but that without health literacy, change cannot occur.

By caring for others, joining support groups, holding onto meaningful lives, and telling different stories about HIV/AIDS (stories of eventual acceptance and extended opportunities) the women were capable of altering restraining, socially built selves to challenge dynamic selves. Through non-acceptance of the damaging and limiting ideas about PLWHA voiced by their communities, these women fashioned alternate story lines, which allowed them to enlarge their story potentials and to revive hope for the future.

Conversely, most of the women still spoke of their lives as filled with difficulties—poverty, concern about the futures of their children, surviving through sickness and struggling to maintain work when ill. Moving towards an arena where their HIV-positive status could be embraced did not mean denying the actualities of life being hard, but the women were able to harness hope and voice stories that were significant to them.

Similarly, while AIDS is often designed as a death sentence in social talk, and its identity is viewed fundamentally negative (Soskolne, 2003), the women who tried placing themselves in readiness for disagreement with these discussions, or at least acknowledging how their HIV-positive status has changed preconceived notions about HIV/AIDS in their communities and households, helped some of the women build positive narratives around their status. Thinking positively about being positive allowed the women to voice stories about HIV, which undermined prevailing discourses.

Regardless of each woman's story of how her life has been affected by the virus and how she has learned or is slowly learning to come to terms with and manage the virus in her own ways, these eight women collectively exemplify characteristics of bravery both in deciding to share their stories and in taking steps to think positively about being positive.

### **Reflections, Recommendations, and Concluding Remarks**

**Reflections.** I consider myself extremely privileged that these eight women gave me a window into their experiences of living with HIV and I am humbled that it was me with whom they chose to share their stories and their time. These women taught me about their daily lives, what their lives were like before they were diagnosed, and their hopes for the future. I am forever grateful to have been welcomed into their communities

to listen to the deeply personal and often sensitive accounts of both the struggles and successes these women have had, thus far, living with HIV. However, their stories are only brief glimpses into who they are as Kenyans, as women, and as people with HIV.

It is difficult as a researcher to convey the value of this study without sounding somewhat arrogant. However, the stories of these eight women might never have been told had I not conducted this research. Using interviews and photo-journals, my research created a safer space than previously provided in their communities, where the women could openly discuss and reflect upon how they perceived the disease in their lives. The narratives, while deeply personal accounts, are only compilations of those stories the women chose to tell. It would take many other stories to construct a fully comprehensive narrative of being HIV-positive in Kenya. But each woman's story does help to bring researchers and readers alike closer to how individuals experience life with HIV/AIDS. In his book, *Truth About Stories*, Aboriginal Scholar Thomas King (2003) stated:

Take it. It's yours. Do with it what you will. Cry over it. Get angry.  
 Forget it. But don't say in the years to come that you would have lived  
 your life differently if only you had heard this story. You've heard it now.  
 (p. 119)

I quoted Thomas King because I thought he better explained why, even if this research contributes nothing to the academic world, the stories told are still important. King (2003) noted that he does not tell his stories with the belief that they will change the world, but he is always hopeful that they have the power to do so. I share a similar optimism that the women's stories I have helped share in my research will foster a greater understanding of the disease in vulnerable communities around Mombasa.

I am aware that multiple stages of editing took place during our time together and apart. Throughout the interview process the women had the power to select the stories they decided to share, as well as the perspective from which each was told. As the researcher, I also influenced how the story was conveyed through framing and restructuring the research questions, making interpretations, and choosing to focus on particular stories in retelling each narrative. Each stage of the sharing process unveiled a chance to refashion and fine-tune how best to present every experience. Through this process the stories have become ours—mine and the eight women's. Clandinin & Connelly (1994) further described this progression to co-authorship:

Stories are the closest we can come to experience as we and others tell our experience. A story has a sense of being full, a sense of coming out of a personal and social history. . . . Experience . . . is the stories people live. People live stories and in the telling of them reaffirm them, modify them, and create new ones. (p. 415)

In sharing their stories, these women entrusted me with retelling their experiences. Mindful of the power this placed in my hands, I have done my best to refrain from making generalizations from their personal understandings of the disease to a national and global context. Instead I would like to emphasize that each of the women had diverse and important perspectives to offer about life with HIV in Mombasa.

Ideas about health, in particular about HIV, are generated and shared through a variety of social contexts in all countries, reiterating the importance of uncovering the narratives of HIV-positive living. By choosing to study women in a Global South context, I opened myself to exploring the experiences of women living with and learning

about HIV/AIDS in a culture different from my own. My whiteness separated me immediately. Inherent in my skin color were my Global North cultural ways of knowing about HIV, which tend to generalize the experience of all individuals. Narratives such as these teach us about ourselves by leading us to acknowledge our privilege, our positions of power, and the locations we inhabit during our interactions.

These stories relate to how we know and understand HIV/AIDS from Global North perspectives by enabling us to interact with actual accounts of HIV-positive life in a Global South community and thereby to sort through the assumptions and claims we make about cultural ways of knowing. Finally, these stories illustrate that the human spirit is resilient. Despite accounts of sexual violence, verbal abuse, discouragement to live, domestic stigmatization, exclusion, and lifelong struggle with a chronic illness, these women remain hopeful. They are hopeful both for their own futures and for changing environments around how people in their communities come to know and understand HIV/AIDS and PLWHA.

**Growth as a researcher.** Reflecting back on my research journey I am overwhelmed with emotion in recalling my initial interest in HIV-positive women's experiences learning about and living with the disease. It was during my volunteer summer in Tanzania working with HIV-positive youth and adults that I came to recognize the lack of education I had about AIDS-related information and exposure to discussions of sexual health. The men and women I worked with looked to me for answers and framed me as the expert in health knowledge. Each day in Tanzania I read articles and books and accessed other learning resources to advance my knowledge of the subject, but knowing the medical facts about transmission and treatment did little to increase my



understanding of what it meant to be HIV-positive. As an outsider with little knowledge of the belief systems underscoring the tribal and traditional cultures with which I interacted, I was often quick to make assumptions about how these people had arrived at their locations in life. This was especially true of how my Global North biases influenced my perceptions of gender relationships, in particular the treatment of women by men and women's feelings about their own agency.

Since that time and throughout the process of my current research, I have come to learn just as much about the lived experiences of the HIV-positive women I interviewed as I have about myself and conducting qualitative research. I believe I have gained an in-depth understanding of myself as a researcher as well as experiencing the rewarding, but often taxing process inherent in carrying out qualitative research. Exposure to literature, cross-cultural living experiences, face-to-face interaction with the women in this study, and the experience of retelling their stories have enabled me to recognize the importance of being aware of the multiple positions I occupy as an individual. I have become increasingly cognizant of how these locations can place me in a position of authority or powerlessness depending on the context.

In addition, I feel like less of an outsider within the SSA context and have become comfortable residing in the area between researcher and participant. In this space I was given a chance to hear the stories of HIV-positive women, search for deeper understandings and descriptions of their experiences, and ultimately co-construct a narrative of how they have come to perceive ideas about HIV/AIDS. Corbin Dwyer and Buckle (2009, p. 60) discussed the idea of "the space between." As a researcher this refers to the gap between being considered an insider and being considered an outsider to

the group being studied. Both positions have associated risks. As an insider, the researcher may share and understand the cultural norms and expectations, but may not be able to probe deeper without crossing cultural boundaries and disrespecting the participant. An outsider, on the other hand, has a greater ability to ask these probing questions. I am not suggesting unethical practice here, but rather the ability to cross conversational barriers and cultural margins because I am not bound by the same terms of knowing and behaving (Kanuha, 2000). Outsiders, on the other hand, risk the implications of power associated with their outsider location (e.g., higher standards of education, greater socio-economic status, and misunderstanding of cultural nuances). Striving to maintain professionalism as a researcher may instigate an us versus them dichotomy where the researcher is viewed as the expert or position of authority, changing the way participants choose to disclose their experiences (Corbin Dwyer & Buckle, 2009).

Our lives are complex by social construction, and it is important to note that we are never entirely the same nor entirely different from any other person. No matter our positionality, we both share common characteristics and must acknowledge the diverse qualities that make each experience an individual one. This allows us to embrace difference and understand that there are multiple ways to know a topic or a single experience so that we can highlight the best ways to engage with these experiences. To this end I believe the women in my study understood, or at the very least felt from the outset, that their experiences were important to me and to the goals of my research. Otherwise they would not have chosen to share their stories. Simply put, this research has taught me the value of being a reflexive researcher.

**Strengths of the Study.** Past research has shown that, in cases where opportunities to talk about sex and HIV/AIDS are limited, inadequate access to health resources for information and treatment as well as widespread stigmatization of those linked to the disease can occur (Zhou, 2008). This literature speaks to my research and why I might have been able to get the women to share their stories without too much hesitation—there are limited chances to do so and I presented these eight women with such an opportunity.

The findings also present a unique perspective of hope for women living with a positive status. However, it is still necessary to address the ideas that the women in my study offered for better education, treatment, and support, and a more extensive study with that specific focus would be warranted.

Photo-journals proved to be a crucial part of my study and are an aspect I would urge researchers to use in order to complement their narrative work. In addition to enhancing the depth of each woman's narrative, the photo-journals also prompted a partnership and mutual respect between each woman and me. Combined with narratives, photographs can help to build a greater understanding of women's HIV-positive experiences or be used to illustrate brief glimpses of their lives with HIV. Prospective research studies should further engage with photographs as a tool to initiate conversations about HIV/AIDS. As I combined my interpretations as the researcher with the written descriptions and verbal explanations the women gave, the photographs provided an alternate window into the women's experiences of living with HIV.

An additional strength within my research was leaving the option open for the women to speak in either English or their first language, Kiswahili. In doing so, some

health knowledge perceptions the women may not have been able to fully convey in English were preserved, rather than lost. In addition, offering these options made it easier to recruit participants for my study as most of the women I met with initially felt more comfortable speaking in Kiswahili.

Finally, as my study employed qualitative methods, the perspectives of the women presented are open to discussion and different interpretations. Therefore, I welcome other researchers to decipher my conclusions further and to imitate or challenge the methods I used or the findings at which I arrived.

**Limitations of the study.** Whilst the findings of this study give a deeper perspective into some the individual experiences of women living with HIV in Kenya, there were limitations to the research. Although the option to speak in the language of the participant's choice was a benefit, speaking in Kiswahili may have also been a limitation because of the translation process. The nature of translation required time in between a conversational exchange and the next question, interrupting flow and fragmenting the interview. In addition, details such as pauses in conversation or tone of voice used by the participant may have sometimes been lost in translation, thereby erasing certain context to the women's experiences.

My subjective position and the biases inherent in my Global North ways of knowing determined the lenses through which I analyzed and processed the stories of each woman. Speaking Kiswahili at a learner's level meant that the interviews, photo-journals, and their subsequent analyses required several layers of interpretation. However, these limitations are inherent to the method and thus, reasonable.

Amount of funding and time allocated for data collection placed limitations on this study. Lack of funding limited the capacity I had as a researcher to spend time in country and in turn, on each process of data collection (e.g., assimilation in to the local culture, language training, time spent with each woman, number/length of interviews, and time spent on analysis while in country).

Thinking over the limitations to the study, I had to revisit my argument in chapter one about the insider versus outsider researcher position. While I claim my outsider status compared to the women, which makes sense, the obvious question is whether someone so removed from the women's experience is necessarily the ideal researcher. The outsider argument might be a good one, for example, a black African researcher from outside Kenya, or even a black researcher from another continent, but I think I have to acknowledge that my white privilege and Global North privilege do affect my findings. It might a good idea for future scholars to compare my research and other white researchers' work in Kenya with research done by black and/or African researchers to explore what the effects of certain privileges seem to be.

**Future research with, by, and about HIV-positive women in Mombasa.** It is my hope that the recommendations I have provided are useful in the study of and with HIV-positive women. Each woman's narrative had interesting and salient aspects, and further studies including more time with each woman and focus groups with family members and peers would be beneficial in gaining further insights into how AIDS-related information is translated and interpreted. Further inquiry into the women's social and cultural contexts, including religious and cultural-historical influences, might also

generate greater understanding of how ideas about HIV are integrated into these women's understanding and identities.

In AIDS research, the academic community is moving toward a connection between biomedical and social disciplines to build a more holistic approach to the management of this global pandemic. My findings suggest that policymakers, educators and their institutions, national and international government organizations, and NGOs need to connect with the people directly affected or infected. In addition, the findings suggest that social institutions and community organizations should work to translate the research findings into action. Change must strive to conserve the sexual agency of women while empowering, educating, and making women more aware of their fundamental human rights (Andreeff, 2001). Conducting research without producing action contributes to the growing body of knowledge around the disease and helps in the development of new approaches to research, but it does little to combat the devastating effects of the pandemic.

In order to reduce gender oppression or difference in terms of access to education surrounding HIV/AIDS and how such education is perceived and taken up in communities, both men and women must be present in learning about and understanding the disease. In addition, if this disease and the surrounding issues of sex and stigma are to become a less taboo discussion topic, both men and women must feel comfortable openly sharing their ideas with each other. In order for this to happen in countries with a patriarchal history, it is not enough for women to have or even understand knowledge if they have no authority over their bodies. While fighting patriarchy is obviously a positive aim, it may not be that simply having men and women openly discussing sex with each

other is the best approach. Thus, for HIV-positive women who prefer a safe, woman-only environment for support, open discussions involving men may not be desired. An intermediate step would be to educate men about gender equity, domestic violence, HIV/AIDS, and sexual agency separately, before bringing members of both the sexes together to discuss the topics.

Future research involving an HIV-positive woman's entire family collective may help to disassemble the long-standing stigmatized beliefs by starting in the home. Researchers can try to accomplish this through use of participatory action research, in which participants are involved at each stage of the research process. Research can help us understand the relationships occurring in the home environment surrounding HIV and may aide in the design of education programs or interventions that will assist in disassembling stigma associated with HIV/AIDS in the home. Projects that enquire further into domestic stigmatization will hopefully grow to engage members of the community and eventually foster individuals who are competent in terms of AIDS-related knowledge, sexual behaviors, and most importantly, sexual agency. While stigma is a huge problem, as it continues to contribute to the mistreatment of women and all HIV-positive individuals, it is part of a bigger picture. Participatory Action Research may act as a catalyst to acknowledge the injustices in the ways women are being treated—particularly sexually. To discuss issues of sex and disease, the entire collective needs to be engaged in education and safe spaces must be available.

AIDS researchers will also need to further investigate to gain a deeper understanding of how stigmatized perceptions of the disease at an early age may inhibit one's ability to ask questions and seek sexual and disease-related advice, thus limiting

understanding of the facts about and effects of HIV/AIDS. A better understanding at an early age might have prevented these women from having misconceptions about the disease. However, educating women at an earlier age will not help the situation unless they can use this education to exert more control over their own bodies and lives. Future research and prevention programs should address general bodily agency at an early age, where discussions about sex are not taboo, to ensure that vulnerable populations, both male and female, are reached.

It is essential that future research recognize the importance of situated knowledge—or what one knows based on the experiences they have had. Research must take into account the situated knowledge of the researcher but also that of the participants. Global North strategies are missing their mark because they are not designed for the Global South and thus do not work for the risk groups where they are implemented (De Cock, Mbori-Ngacha, & Marum, 2002). Less privileged women in communities and their unique experiences with HIV or AIDS provide an indispensable perspective for future research around women and HIV/AIDS. HIV-positive women simultaneously experience inequality through gender, lacking access to resources, economic status, and social positioning, as well as their positive status. To borrow from feminist theorist Marilyn Frye, “Oppression is multifaceted and intersectional and unless we accept this fact, change is impossible” (Frye, 1983). Acknowledging this reality to a greater extent will provide researchers in the field with a greater scope from which to begin inquiry.

In my future research, I hope use Participatory Action Research to not only learn more about HIV/AIDS in Mombasa but to enact change. New research should not be solely an academic exercise but should involve PLWHA throughout the writing and



analysis of the research, as well as the development of a community action plan for change. The elite cannot create sustainable change alone; rather, participants must take responsibility for their own understanding and future disease management. Those who occupy spaces of privilege can cooperate with those more vulnerable to foster individual capacity-building around exerting and understanding sexual agency. This is not just an education, resource access, or interpretation issue—a much larger societal change needs to take place. Change facilitation must come from HIV-positive participants themselves, their families, community members, and persons involved in policy creation to be successful. A change implemented from within the community will be more effective and long-lasting one implemented by external players.

A person's behavior can only be understood in the context in which it occurs (Clarke, McLellan, & Hoffman-Goetz, 2006). However, individual behaviors are also relative to all other experiences that occur simultaneously in their specific contexts. Thus, risk behavior cannot be separated from its context including co-occurring behaviors (Trickett, 2002). Future research will need to take into consideration what or who influences how individuals are exposed to educational information about HIV/AIDS and also how individuals construct and interpret this information. It is important to examine the positions of those who receive knowledge as well as their current capacity to protect themselves and use the knowledge. Exercising contextually relevant and comprehensible techniques of knowledge distribution can only do so much if the power dynamics that control how information can be used are not addressed.

## Conclusions

Many of the findings of this study are consistent with previous studies on HIV/AIDS related information in SSA communities. These findings indicate that power imbalances exist in relationships the women have with family, friends, and peers, creating stigma and causing women to self-stigmatize in response to fears of infecting others, isolation, and social death. How women felt empowered or disempowered also played a role in how they negotiated their positive status as a component of their identities. Education systems, prevention programs, and healthcare systems were not referenced by the women in this study as being major influences on shaping their perceptions about HIV/AIDS. However, the women did hope that in the future societal-level influences could more effectively reach all members of their communities. They expressed hope that an increased literacy surrounding the disease might dismantle the us versus them dichotomy produced through stigmatizing processes that other HIV-positive individuals in relation to those living without an illness. Disease literacy is just one part of the range of inconsistencies that must be addressed in future delivery of AIDS awareness, prevention, treatment, and education.

At the individual level, my findings suggest that the women construct their perceptions in relation to their own fears of dying and how they have come to see others live with or be affected by the disease. The women in my study continue to endure stigma and have inaccurate cultural ideas—either by nature of how they were received or how the women interpret the information—about where HIV originated and how it is transmitted. Ultimately, ideas of stigma persist within the home and out in the community, constructing HIV as a moral problem that the women have to negotiate. Not

always having a choice, the women have sometimes been forced to conceal their positive status to maintain a sense of normality in their daily interactions. This means that we need to look at how findings of previous research have been used to enact change. Three questions come to mind:

- 1) How have these previous findings been considered by the policymakers, educational leaders, and NGO activists whose role it is to reach all members of the public with the most up-to-date and accurate information about health in order to prevent or delay the burden of disease?
- 2) What are the problems with existing educational and intervention programs that do take a more holistic approach to HIV/AIDS education by accounting for cultural, social, environmental, organizational, and medical factors?
- 3) Do current prevention, treatment, and education programs take into consideration the local power structures that create imbalanced power relationships between men and women, as well as marginalized and privileged populations?

In order to create a more representative picture of what continues to generate misinformation about the disease, stakeholders must ask questions and use an approach that integrates various fields. Researchers, policymakers, and activists alike must get to know—really know—those individuals infected and affected by this disease. We must concentrate on a number of key questions. How do these individuals live day-to-day? What it was like for them growing up? How efficient and valuable was their education?

Are individuals able to evaluate the programs governments have put in place? Do they have access to information to do so? How do they put food on the table? Who cares for the sick, elderly, and young, and how readily accessible are resources? How do individuals in communities affected by HIV collectively gather? How are educational, medical, social, and economic resources managed and distributed? How did these individuals become infected? And most importantly, how are power imbalances continuing to contribute to the epidemic? Finding these answers and getting to the root of how people live will enable the creation of stronger methods to begin making societal changes.

A number of initiatives need to be employed before education about HIV/AIDS can be improved in an effort to reduce fear and stigma. AIDS educational programs need to be monitored more closely for the quality, accessibility, and outreach of their initiatives. This will help to ensure that initiatives are targeting and reaching the most vulnerable groups of the population. Continuous evaluation must occur to maintain effectiveness and recommend improvements. How a person arrives at their understanding of HIV/AIDS and behaves according to this interpretation determines the extent of widespread catastrophic effects the disease can have. It is imperative to examine in particular whether this HIV/AIDS-related education changes the way men behave towards women so that the alarming statistics for women with HIV/AIDS can be changed. Part of the education in this area needs to acknowledge that women do not have the control or agency necessary to completely prevent infection, so they need to know what to do if they suspect they may be positive. Finally, any effective educational

program must communicate information about HIV/AIDS using local content, respecting local beliefs, and enacting a culturally sensitive approach.

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## Appendix A

### Interview Guide

#### Questions:

##### Introduction

1. Tell your “life story” prior to acquiring HIV and your thoughts on how those experiences influenced your risk for HIV infection.
2. If you are comfortable sharing and you are able to answer, could you tell me the story of how you got HIV? When and from whom did you first learn about HIV/AIDS?

##### Cultural Ideas & Stigma

3. What do community members who are not HIV positive or whose status is unknown think about HIV and the people who are infected?
4. Are people in the community aware of your HIV Status?
  - a. If so, how do you feel they treat you?
  - b. Were you treated differently before they knew your status?
  - c. Do your family and friends know about your positive status? If so, do they treat you any different than before they knew?
5. What are some ideas you have heard about the origins of HIV/AIDS?
  - a. Where do you think it comes from?
  - b. What are some ways you know that the HIV virus can be transmitted?
  - c. What are some ideas about how HIV can be transmitted that you have heard others talk about?
  - d. When discussing HIV/AIDS many individuals associate the disease with death. What are some existing ideas about death or fear of death surrounding AIDS that you have heard from people in your community?
  - e. What positive community approaches to supporting people and families living with HIV/AIDS have you encountered?

6. How do these community ideas affect your willingness to seek out treatment and further information about HIV/AIDS?

##### Sources of Knowledge

7. Before you knew your positive status, who would you go to ask a question about HIV/AIDS? Whom would you go to now?
8. Where can you find information about access to treatment, support and care?
9. Have you ever received any knowledge from television, radio, magazine articles, newspapers, or the internet?
10. With whom have you discussed HIV/AIDS?

**11.** What changes do you feel could be made either to the education system, health organizations or to community to make knowledge about HIV/AIDS more easily available?



## **Appendix B**

### **Information Requested in Interview Guide**

Participants will each be given a paper requesting the following information:

Name:

Pseudonym:

Email Contact:

Email will be used to inform participants, individually, of the themes arising from the analysis.

## Appendix C

### Letter of Support from Partner NGO

Program Manager  
Partner NGO  
Mombasa, Kenya

17 January, 2011

Dear African Initiative Graduate Research Grant Committee:

I am writing this letter in support of the graduate researcher, Laura Chubb, and her proposed study *The Health Knowledge Perceptions of HIV-Positive Women in Kenya*. Specifically, [Partner NGO] is committed to the success of this study and believes that gaining more knowledge of how women have come to their understandings of health will benefit the community and endorse the goal of the organization to increase education and awareness in various areas, in particular Health and HIV/AIDS.

[Partner NGO] is familiar with the plans for this study and wants to support this effort by assisting the researcher in making contact with female participants. As well, I will aid in discussing the study with potential participants, provide viable contacts for a translator to assist in the study and provide an area in [Partner NGO] offices where interviews can be held in privacy.

In conclusion, [Partner NGO] is fully committed to the sustained success of the proposed study in collaboration with the researcher, Laura Chubb, and the School of Human Kinetics & Recreation at Memorial University of Newfoundland & Labrador. Thank you for your consideration and we look forward to working with Laura Chubb to ensure her study is carried out successfully.

Sincerely,

Program Officer,  
[Partner NGO]

## Appendix D

### Letter of Information



### Letter of Information

Dear Participants,

I am a graduate student in the School of Human Kinetics and Recreation (HKR) at Memorial University of Newfoundland (MUN). As part of a requirement for the completion of a Master's in Kinesiology conducting a research study is mandatory. You are receiving this letter because as part of my research study I am looking to speak with women between the ages 20-25, living with HIV or AIDS to learn about the everyday health conditions you experience. You are invited to share your relationships with health: the types of health promotion you have experienced, what you think about this health messaging, how you practice health, how people in your life enhanced or hindered your health practices. I am looking to learn more about the prevention and sharing of information for women related to HIV/AIDS.

Participation in this discussion is voluntary. You will be asked to take part in two face-to-face interviews. After the initial interview you will be given a blank journal and a disposable camera. You will be asked to create a photo-journal, which represents your thoughts, feelings, ideas and ultimately your understanding of HIV/AIDS and health. Your identity in the face-to-face interviews and photo-journals will be kept confidential. If you choose to become involved, you will have to sign a consent form along with this information letter. Signing a consent form states your willingness to participate in the face-to-face interviews, create a photo-journal about what HIV/AIDS means to you, as well as your willingness to be audio recorded. You will also be given the option to sign an interview release consent form and a photo-journal consent release form stating that the researcher has the right to use the information contained within both documents in the manner in which she so chooses. If you decide to withdraw from the research study, you can do so at any time. In addition, you can contact the researcher at any time, if you have any questions or concerns at the address provided below.

Participating in this study will create no physical harm, and have no impact on your relationship with either of the partner organizations, [Partner NGO]. In addition, there is no compensation for this study- meaning no money, no food, or no gift reward will be exchanged for your participation.

All information obtained from you as a participant is considered completely confidential and will be safely stored in a locked filing cabinet. Every attempt will be made to keep

your information confidential, however, I cannot guarantee confidentiality. Some steps put in place to increase the confidentiality of the research include: Consent forms being stored in a cabinet at the office headquarters of [Partner NGO], a secure location away from any of the information obtained during data collection; Only the researcher and academic supervisor of the research project will have access to the audio recorded information in addition to the photocopied replicas of the photo-journals of each participants; Data will be stored upon return to Memorial University in a locked cabinet in the academic supervisor's office; Participants will be addressed from the minute they agree to participation in the study (both verbally and in text) as a made up name; Immediately following the completion of the interviews, photos will be coded according to these pseudonyms as well. While I, the researcher, have the right to use the information obtained in the study for academic purposes there will be no identifying information associated with the journals or interview data. All data collected throughout the study will be destroyed in the next five years.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics Review in Human Research (ICHER) and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant) you may contact the Chairperson of ICHER at [icher@mun.ca](mailto:icher@mun.ca) or by telephone at 1-709- 864- 2861. The [Partner NGO] program manager will act as a local contact through which you can contact the researcher, Laura Chubb, or her academic supervisor, TA Loeffler, or the ICHER with any of your concerns.

I look forward to speaking with you and thank you in advance for your assistance in this project. I hope that the results arrived at from listening to your experiences can be used to inform education programs and government policy to change women's lives and their health.

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

- Laura Chubb                      Phone: 709-689-4671                      Email: [f29lac@mun.ca](mailto:f29lac@mun.ca)
- Dr. TA Loeffler                      Phone: 709-864-8670                      Email: [tloeffle@mun.ca](mailto:tloeffle@mun.ca)

Yours Truly,  
Laura Chubb

## **Appendix E**

### **Instructions for Creating Photo-Journal**

1. Get organized. Plan how you want your journal to look. Since the provided disposable camera takes 27 pictures you must decide how often you want to place entry into your photo-journal between the date you receive your camera and blank journal, and your second interview with the researcher.
2. The photos are meant to depict how you personally feel about the topic you are writing about on that day.
3. Each photo you take must include a written description in your journal so that when the photos are developed with the researcher an explanation is included.
4. You may write the written description in the language of your choice.
5. Date your journal for each day you write.
6. Entries can be made in the journals that do not have to include photos- you may write as often as you feel like sharing your ideas about how you understand HIV/AIDS. Topics you can choose to discuss in your photo-journals include but are not limited to:
  - 1) Contracting HIV
  - 2) HIV/AIDS Prevention
  - 3) HIV Treatment
  - 4) HIV/AIDS Awareness
  - 5) Places that offer information about HIV/AIDS
  - 6) Where HIV/AIDS Exists
  - 7) Family Ideas about HIV/AIDS
  - 8) Community Ideas about HIV/AIDS
  - 9) Feelings about living with HIV/AIDS
  - 10) How you maintain your health
  - 11) Health Practices
  - 12) Stigma surrounding HIV/AIDS
7. In your second interview with the researcher you will develop the photos together.
8. Once photos have been placed in the appropriate space in your journal, according to the day you took the picture you, will add captions to your photo that describe your feelings or explain any special parts of your photo.
9. Decorate your photo-journal however you wish- on days where photos are not taken, you could, if you wish, draw a picture instead to capture what you are writing about.

**Appendix F****Photo-Journal Release Form****PHOTO-JOURNAL RELEASE FORM FOR PARTICIPANTS**

Project name:

---

Date: 

---

Interviewer:

---

Interview number: 

---

Name of person(s) interviewed:

---

Address:

---

Telephone number: 

---

Date of birth: 

---

By signing the form below, you give your permission for any copies of documents including written work or photographs made during this project to be used by researchers and the public for educational purposes including publications, exhibitions, World Wide Web, and presentations. By giving your permission, you do not give up any copyright or performance rights that you may hold.

I agree to the uses of these materials described above, except for any restrictions, noted below.

Name (please print):

---

Signature:

---

Date: 

---

Researcher's signature:

---

Date: 

---

Restriction description:

---

## Appendix G

### Permission to Use Photographs



#### PHOTOGRAPH RELEASE FORM

##### IMAGE(S):

##### Photo location(s):

The **photographer** warrants that the rights and permissions\* to use the above image are held by the photographer (attach documentation), and the photographer grants use to Memorial University of Newfoundland and the Researcher, Laura Chubb, to use for research and educational purposes, including publication in journals, manuscripts, and presentations. For any uses of the above image in other resources, the researcher will obtain photographer permission.

Name (PRINT NEATLY):

Address:

Date:

Signature:

I, \_\_\_\_\_ give my permission to the Researcher, Laura Chubb, to use the above image(s) of myself or my underage child(ren) for the purpose stated above.






\*NOTE: Permission must be secured (and attached here) for photos of people other than yourself, and of children (whose legal guardians must sign) other than your own. Permission must be cleared for photos of artworks (including sculptures) not belonging to the photographer. In the case of stained glass windows, ask the congregation whether you need the artist's permission; attach the congregation's response to this form. If the congregation says you need the artist's permission, obtain it and attach it to this form. Artists' names/credit lines must be clearly indicated with their permission for use of their work in a bulletin photo. Photos that do not have all permissions cleared and accompanied by hard-copy proof will not be used. If you sent permissions with your original submission form, please note that here.

Date:

Signature:

**Appendix H**  
**Initial Category Codes**

Initial category codes were identified in copies of the transcripts in the color corresponding the category name provided below:

<b>Contagion</b>	
<b>Stigma:</b>	
<b>Knowledge:</b>	
<b>Fear</b>	
<b>Support</b>	



## Appendix I

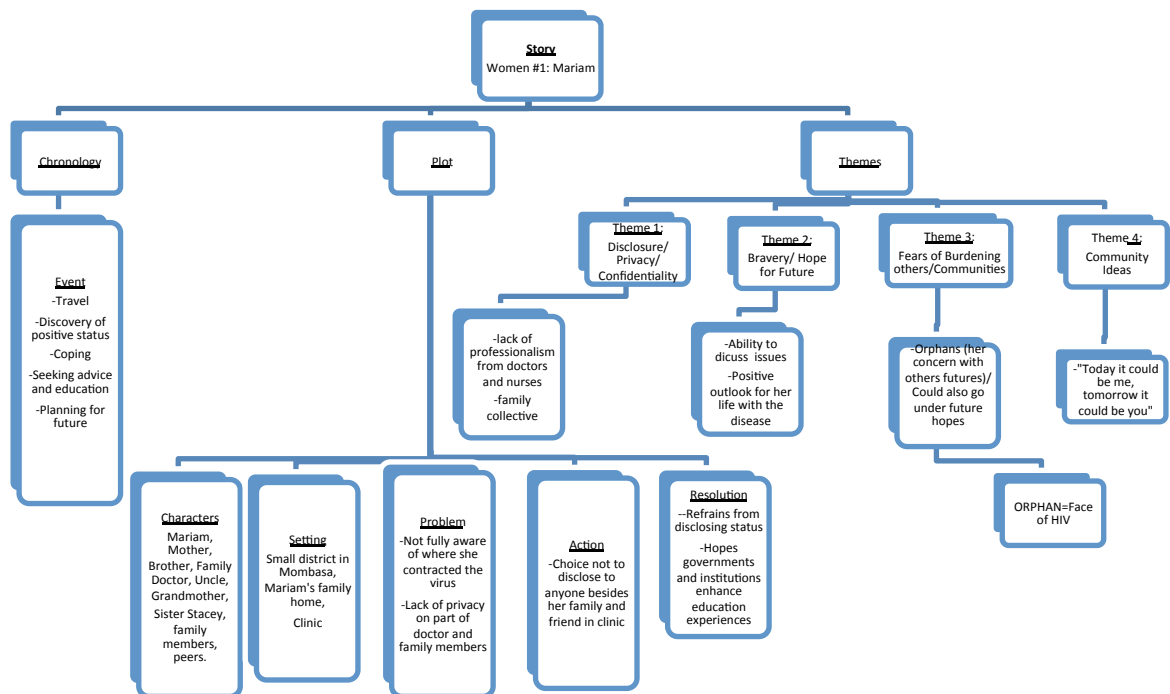
### Examples of Category Codes

**Table 1: Category Codes**

<u>Category</u>	<u>Sub-cat 1.</u>	<u>Sub-cat 2.</u>	<u>Sub-cat 3.</u>	<u>Sub-cat 4.</u>
<b>Fear: F</b>	<b>Infection: FI</b>	<b>Infecting Others: FIO</b>	<b>Acceptance: FA</b>	<b>Death: FD</b>
<b>Knowledge: K</b>	<b>Education: KE</b>	<b>Sources of Information : KSOA</b>	<b>Knowledge&amp; Education: KE</b>	<b>Incorrect Knowledge&amp; Education: KEI</b>
<b>Faces of HIV: HIV-</b>	<b>Fire: HIV-F</b>	<b>Death: HIV- D</b>	<b>Deviant Body: HIV-DB</b>	<b>Orphan: HIV-O</b>
<b>Agency: A</b>				
<b>Stigma: S</b>				

## Appendix J

### Coding Chart Example



## **Appendix K**

### **Cumulative Listing of Emergent Categories**

**(November 2011-April 2012)**

#### **Privacy**

- The confidentiality of test results being told to other members of the immediate family or members of the community, instead of the individual and the lack of such confidential information is quite intense. This confidential practice could have been more thorough especially in an environment of professionals (doctors/nurses).
- Lack of privacy can result in an individual's status being revealed without them having the choice, or being able to do this in their own time. This could result in social and domestic stigma, and a negative aspect of how the disease is perceived before the HIV-positive individual is ready.

#### **Bravery**

- An individual's ability to talk about the disease, from another family member to a large community group, and discuss their positive status without the fear associated with the virus.
- Provides the individual with a positive outlook on the future with the disease.

#### **Testing**

- A common occurrence in the interviews conducted was the women promoting the testing for the virus and having the power to go themselves.
- Ability to assess the disease and begin negotiating their status and decide on a future path.

#### **Education**

- Some women are willing to speak publicly about their status and the disease in order to promote knowledge and correct information regarding the disease.
- Better education, also in regards to beginning HIV/AIDS awareness at a younger age, is a common theme throughout the interviews.
- Better education will lead to the prevention of contraction, very important to begin this in the school environment, with high dropout rates, this should be done as early as possible but at an age the children can still understand. Some of the women in this study do not remember being taught about HIV/AIDS where some mentioned it was briefly covered, others have had it discussed at length.
- Better access to disease information, especially factual information on how to contract the disease and knowledge of symptoms and care needs to be implemented.

### **Media**

- AIDS-related advertising on T.V. commercials provide images and information, however, these are not frequent. The images of the adverts are remembered by some of the interviewed women, but the message behind the campaign is not.
- This is a good media to share the experiences and stories of other people.

### **Strength in Groups**

- Community groups and some social contexts provide a safe space for positive-status individuals to openly discuss the disease. This space also provides information for everyone, positive and non-positive, about the disease and factors of the disease.
- Removes the feeling of being a social outcast from a community.
- Builds self-esteem and provides positive reinforcement and hope for the future.

### **Fear**

- Metaphors used in the interviews by some of the women to represent the fear of the disease. (Lion/Insect/Leopard)
- Stigmatization in the social, community, and domestic environments, do not provide a positive area for an individual to negotiate the disease.
- Domestic stigmatization provides added burdens, abuse in the home, both physical and verbal, on a positive-status individual. This could also be the case if the individual has not divulged their status, and is in the process of negotiating the disease.
- Social stigma (Social Death), and exclusion from the community may prevent the disclosure of positive-status and result in staying in a state of negotiation with no outcome to move forward.
- Fear of infecting others, also fears of becoming infected from a HIV-positive status individual also provides fear surrounding the disease.

### **Sources of Knowledge**

- School (Elementary)/Clinics/Television/Radio/Community Groups/Support Groups/Professionals (Doctors/Nurses)/Organisations.

### **Disclosure**

- In some cases, community stigma reduced once treatment started and a more 'normal' looking body began to return.
- Discovery of positive status has resulted in stigma from family and community members in some cases with individuals being isolated, removed from common areas of the house, not being able to use household items, unable to work or take care of children, not allowed in work places and blamed for breakdowns in relationships.

- Some women chose not to disclose their identity for various reasons. Verbal/Physical abuse, reaction from other individuals in their lives, the belief of bringing shame to the family, tensions within relationships, and some women feel content with just the immediate family knowing and not the greater community.

## Appendix L

### Ethics Approval



Interdisciplinary Committee on  
Ethics in Human Research (ICEHR)

Office of Research  
St. John's, NL Canada A1C 5S7  
Tel: 709 737 8368 Fax: 709 737 4612  
www.mun.ca

ICEHR Number:	2010/11-117-HK
Approval Period:	June 15, 2011 – June 30, 2012
Sponsor:	N/A
Responsible Faculty:	Dr. T.A. Loeffler School of Human Kinetics and Recreation
Title of Project:	<i>Are women's understandings of health affecting the impact of HIV/AIDS on the global health climate?</i>

June 15, 2011

Ms. Laura Chubb  
School of Human Kinetics and Recreation  
Memorial University of Newfoundland

Dear Ms. Chubb:

Thank you for your email correspondence of June 13, 2011 addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) concerning the above-named research project.

The ICEHR has re-examined the proposal with the clarification and revisions submitted and is satisfied that concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, the project has been granted *full ethics clearance* for one year from the date of this letter.

Please note that we have noted your change of supervisor in our files.

If you intend to make changes during the course of the project which may give rise to ethical concerns, please forward a description of these changes to Mrs. Brenda Lye at [blye@mun.ca](mailto:blye@mun.ca) for the Committee's consideration.

The *TCPS2* requires that you submit an annual status report on your project to the ICEHR, should the research carry on beyond June 2012. Also to comply with the *TCPS2*, please notify us upon completion on your project.

We wish you success with your research.

Yours sincerely,

Lawrence F. Felt, Ph.D.  
Chair, Interdisciplinary Committee on  
Ethics in Human Research

LF/en

copy: Supervisor – Dr. T.A. Loeffler, School of Human Kinetics and Recreation

## Appendix M

### Free and Informed Consent

***Project Title: The Health Knowledge Perceptions of HIV-Positive Women in Kenya***

***Investigator: Laura Chubb, (M.Sc. student, Graduate School of Human Kinetics and Recreation, Memorial University of Newfoundland)***

***Supervisor: Dr. TA Loeffler (Professor, School of Human Kinetics & Recreation)***

I, \_\_\_\_\_, agree to take part in the study examining how women living with HIV/AIDS in Mombasa, Kenya and surrounding communities practice and understand health and its messages. As a volunteer for this study, I recognize that the information letter details the interview process and handling of research data. I also recognize that any questions I have asked have been answered satisfactorily and that I have received contact information if I have any concerns or questions arising subsequent to the interview process.

I understand the interview will take approximately 60 minutes. I understand I may refuse to participate in the entire study or in any part of the study. I have the right to not answer questions I do not feel comfortable answering and can stop the interview without any negative consequences. I understand that data will be collected using an audio recording device and that permission to use these devices is assumed upon the signature to my consent. In addition, I understand that by agreeing to participate in the interview I am agreeing to create the photo-journal project assigned by the researcher. I understand that I will be given a typed copy of the interview so that I may further add to or make clear any information provided during the interview, if I so desire. I understand that privacy and confidentiality issues will be followed at all times, but cannot be guaranteed and that only the researcher and the supervisor will have access to the research data. Once the data are collected, I understand that any personal identification will be removed and my identity will be protected as much as possible. Any comments I make that may lead to my identification will also be disguised to prevent my personal identity from being known.

I understand what this study involves and agree to participate. I have been given a copy of this consent form and an information letter.

Signature \_\_\_\_\_ Date \_\_\_\_\_

## Appendix N

### Confidentiality Agreement for Translators/Transcribers

This form may be used for individuals hired to conduct specific research tasks, e.g., recording or editing, transcribing, interpreting, translating, entering data, destroying data.

**Project title:** \_\_\_\_\_

**I,** \_\_\_\_\_, **the** \_\_\_\_\_

**(specific job description, e.g., interpreter/translator) have been hired to** \_\_\_\_\_

**I agree to:**

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., external hard drive, audio recordings, transcripts, journals, photographs) with anyone other than the *Researcher(s)*.
2. Keep all research information in any form or format (e.g., external hard drive, audio recordings, transcripts, journals, photographs) secure while it is in my possession.
3. Return all research information in any form or format (e.g., external hard drive, audio recordings, transcripts, journals, photographs) to the *Researcher* when I have completed the research tasks.
4. After consulting with the *Researcher*, erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher* (e.g., information stored on computer hard drive).
5. Refrain from discussing details of the research in any capacity with persons not involved in the study, and outside the offices where the research will be conducted.

*Employee*

\_\_\_\_\_  
(Print Name)

\_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(Date)

*Researcher*

\_\_\_\_\_  
(Print Name)

\_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(Date)

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by The Interdisciplinary Committee on Ethics Review in Human Research at Memorial University of Newfoundland. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.