

Women Living in Kibera, Kenya: Stories of being HIV+.

by

Samaya VanTyler  
B.Ed., University of Victoria, 1985  
M.A., University of Victoria, 2003

A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

DOCTOR OF PHILOSOPHY

in Interdisciplinary Studies

© Samaya VanTyler, 2012  
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy  
or other means, without the permission of the author.

## **Supervisory Committee**

Women Living in Kibera, Kenya: Stories of being HIV+.

by

Samaya VanTyler

B.Ed., University of Victoria, 1985

M.A., University of Victoria, 2003

### **Supervisory Committee**

Dr. Laurene Shields, School of Nursing, University of Victoria  
**Co-Supervisor**

Dr. Robert Dalton, Department of Curriculum and Instruction in the Faculty of  
Education, University of Victoria  
**Co-Supervisor**

Dr. Darlene Clover, Department of Educational Psychology in the Faculty of Education,  
University of Victoria  
**Departmental Member**

Dr. Francis Adu-Febiri, Department of Social Sciences, Camosun College  
**Additional Member**

## Abstract

### **Supervisory Committee**

Dr. Laurene Sheilds, School of Nursing, University of Victoria

**Co-Supervisor**

Dr. Robert Dalton, Department of Curriculum and Instruction in the Faculty of Education, University of Victoria

**Co-Supervisor**

Dr. Darlene Clover, Department of Educational Psychology in the Faculty of Education, University of Victoria

**Departmental Member**

Dr. Francis Adu-Febiri, Department of Social Sciences, Camosun College

**Additional Member**

There is an abundance of biomedical and social science research relating to HIV/AIDS which has focused on understanding the disease from a medical crisis. The research has attended to matters of prevention and clinical treatment. This study is a naturalistic study which explores the socio-economic and political-cultural aspects of the disease in and on the lives of nine women living in one of the world's mega slums, Kibera in Kenya.

The study is based on the assumption that the HIV/AIDS pandemic has brought about social disruption and profound changes to the micro contexts of community and family life. Cultural norms, practices and values that historically sustained the fabric of African life are slowly being stripped away as those infected with HIV and their families cope with the impact of the chronic illness. Living as HIV+ women is yet one more challenge that these women face every day. They struggle to provide self-care and a healthy life for those they are responsible for within an environment that lacks so many social determinants of health.

Using a methodological convergence of narrative, feminist and Indigenous methodologies within a post-colonial paradigm, I have explored how nine HIV+ African women story/experience their daily lives and participate in community activities.

Consideration of the reality of the day to day experiences of HIV+ women living in an African slum settlement may offer insights for government, policy makers, and community-based and non-government organizations to better support and promote quality of life for those living with HIV/AIDS.

## Table of Contents

|                                                         |      |
|---------------------------------------------------------|------|
| Supervisory Committee .....                             | ii   |
| Abstract .....                                          | iii  |
| Table of Contents .....                                 | iv   |
| Definition of Terms .....                               | viii |
| List of Tables.....                                     | x    |
| Acknowledgments .....                                   | xi   |
| Dedication .....                                        | xiii |
| Chapter 1: Introduction.....                            | 1    |
| Study interest to researcher .....                      | 1    |
| Background for the study.....                           | 5    |
| Significance of the study.....                          | 6    |
| Purpose of the study.....                               | 8    |
| My role as researcher .....                             | 9    |
| Overview of the study.....                              | 13   |
| Chapter 2: Literature Review .....                      | 15   |
| Poverty, health and HIV/AIDS in Kenya .....             | 16   |
| Definitions of poverty .....                            | 16   |
| Poverty in Kenya .....                                  | 19   |
| Disparities in geographical poverty concentration ..... | 21   |
| Women and poverty .....                                 | 23   |
| Female-headed households (FHHs).....                    | 25   |
| Poverty linked to health .....                          | 26   |
| HIV/AIDS within a global context .....                  | 31   |
| Linking poverty, health and HIV/AIDS.....               | 32   |
| HIV/AIDS in Kenya .....                                 | 33   |
| Pre-requisites of health.....                           | 36   |
| Health literacy .....                                   | 39   |
| Gender and the feminization of HIV/AIDS .....           | 40   |
| Brief overview of HIV/AIDS .....                        | 40   |
| Gender .....                                            | 42   |
| Stigma .....                                            | 45   |
| Colonization and its influence .....                    | 50   |
| Past meta-narratives of the colonizers .....            | 52   |
| Separating land and people .....                        | 54   |
| A genealogy of Kibera .....                             | 55   |
| Administrative change and land disputes.....            | 56   |
| Thwarted attempts to develop Kibera .....               | 58   |
| Chapter 3: Methodologies and Research Methods.....      | 61   |
| Story.....                                              | 62   |
| Narrative.....                                          | 63   |
| Narrative methodology .....                             | 64   |

|                                                                           |     |
|---------------------------------------------------------------------------|-----|
| A narrative researcher .....                                              | 65  |
| Narrative use and narrative research.....                                 | 65  |
| Feminist methodology .....                                                | 66  |
| Difference.....                                                           | 68  |
| Multi-methods .....                                                       | 68  |
| Indigenous methodology.....                                               | 69  |
| A decolonizing agenda.....                                                | 70  |
| Authenticity .....                                                        | 71  |
| Networking .....                                                          | 71  |
| Difference.....                                                           | 72  |
| Relational interdependence .....                                          | 73  |
| A methodological convergence .....                                        | 74  |
| Research methods .....                                                    | 77  |
| An international site for research.....                                   | 77  |
| Ethical considerations .....                                              | 78  |
| Entry into the research field: Community contact in Kibera .....          | 80  |
| Participant selection.....                                                | 81  |
| Participant recruitment.....                                              | 81  |
| Meeting up with my community contact .....                                | 83  |
| To tell their stories .....                                               | 84  |
| Participant observation.....                                              | 87  |
| Other meetings.....                                                       | 88  |
| Storyed conversations in homes .....                                      | 88  |
| Storyed conversations in the compound .....                               | 89  |
| Reporting of findings .....                                               | 89  |
| Data analysis.....                                                        | 90  |
| Anonymity and confidentiality.....                                        | 93  |
| Reciprocity .....                                                         | 94  |
| Trustworthiness and validity .....                                        | 94  |
| Reflexivity.....                                                          | 95  |
| Liberties taken .....                                                     | 96  |
| Chapter 4: Understanding the Research Context and Meeting the Women ..... | 98  |
| The basics of life in Kibera .....                                        | 100 |
| Water.....                                                                | 100 |
| Electricity .....                                                         | 101 |
| Garbage and drainage .....                                                | 101 |
| Health facilities.....                                                    | 102 |
| Housing .....                                                             | 103 |
| Fear of eviction.....                                                     | 104 |
| Mobility.....                                                             | 106 |
| Political and community life .....                                        | 107 |
| Changing traditions.....                                                  | 109 |
| Language .....                                                            | 111 |
| Education.....                                                            | 112 |
| Employment .....                                                          | 112 |
| Donor support.....                                                        | 114 |

|                                                    |     |
|----------------------------------------------------|-----|
| My community contact: Winnie Manga Mwarcharo.....  | 114 |
| Meeting the women .....                            | 118 |
| Amina Abdul .....                                  | 118 |
| Amina Bashir .....                                 | 121 |
| Loise Anyango Mango.....                           | 123 |
| Lucy Njeri .....                                   | 124 |
| Mama May .....                                     | 125 |
| Penninah Ngina.....                                | 127 |
| Sarah Chelangt.....                                | 128 |
| Zakia Yusufu .....                                 | 130 |
| Zuhura Odhiambo .....                              | 131 |
| Summary of the research participants.....          | 133 |
| Chapter 5: Interpretative Findings.....            | 137 |
| Beginning the day .....                            | 138 |
| Waking up to start the day.....                    | 138 |
| A busy day.....                                    | 139 |
| A different busy day.....                          | 141 |
| An African woman .....                             | 141 |
| Learnings from the past.....                       | 142 |
| Boys and girls become men and women.....           | 143 |
| Left alone with the baby.....                      | 144 |
| Women support women .....                          | 144 |
| A witch to blame.....                              | 146 |
| Keeping his secret.....                            | 146 |
| After telling her secret.....                      | 148 |
| No legal title to land.....                        | 149 |
| If I die, who will take care of my children? ..... | 149 |
| Shunned by mothers.....                            | 149 |
| Taking my belongings.....                          | 150 |
| Poor parents too .....                             | 151 |
| Mothers' support.....                              | 151 |
| Fear of death.....                                 | 152 |
| They just come to you .....                        | 153 |
| Days not able to work: Get up anyway .....         | 154 |
| Always being the one.....                          | 154 |
| Disclosure.....                                    | 155 |
| HIV+ status already disclosed .....                | 157 |
| A mother's role .....                              | 157 |
| Relationships with children .....                  | 158 |
| If I sit there, that ten bob won't come.....       | 160 |
| <i>Jua kali</i> .....                              | 160 |
| Work change due to HIV+ status .....               | 162 |
| Networking .....                                   | 164 |
| Being up, feeling down and stress-up.....          | 165 |
| ARV prescriptions .....                            | 166 |
| Too sick to work .....                             | 167 |

|                                                              |     |
|--------------------------------------------------------------|-----|
| Not sick .....                                               | 169 |
| Being/going down.....                                        | 169 |
| Staying up.....                                              | 174 |
| I am stigma.....                                             | 177 |
| Stigmatizing words .....                                     | 178 |
| Keeping secrets.....                                         | 180 |
| What is stigma? .....                                        | 182 |
| Learning of HIV+ status.....                                 | 182 |
| Living with HIV is a challenge .....                         | 187 |
| Support groups.....                                          | 188 |
| Being community.....                                         | 194 |
| Belief in God .....                                          | 196 |
| Ending the day.....                                          | 200 |
| Cooking supper.....                                          | 201 |
| Time to sleep .....                                          | 201 |
| Chapter 6: Discussion and Conclusion .....                   | 204 |
| Poverty .....                                                | 206 |
| Women and their children.....                                | 209 |
| Stigma .....                                                 | 210 |
| Shared community .....                                       | 213 |
| Limitations of the study .....                               | 214 |
| Narrative reflections of the study .....                     | 216 |
| Where to from here.....                                      | 221 |
| Closing .....                                                | 224 |
| References.....                                              | 226 |
| Appendix A Republic of Kenya Research Clearance Permit ..... | 257 |
| Appendix B Research Authorization.....                       | 258 |
| Appendix C Community Contact Letter of Agreement.....        | 259 |
| Appendix D Intake Form .....                                 | 260 |
| Appendix E Sample Guiding Questions .....                    | 261 |
| Appendix F Participant Consent Form .....                    | 262 |
| Appendix G Exact Quotations .....                            | 263 |

## Definition of Terms

- **HIV:** Human immunodeficiency virus. This is the virus that attacks the T cells in the body and can cause AIDS.
- **HIV+:** Human immunodeficiency virus positive. This refers to the positive status of those whose blood has been medically tested for the virus.
- **AIDS:** Acquired Immune Deficiency Syndrome. It is the life threatening stage of HIV infection characterized by decreased numbers of T4 cells. Throughout this study, HIV+ is used to describe the medical condition of the participants, although reference to AIDS is contained in certain participant quotations.
- **T4 cells:** Specialized white blood cells that play an important part in the body's immune system to help the body fight infection. If the CD4 count is below 200, a person is vulnerable to opportunistic infections and is less able to fight off these infections.
- **ARVs:** Anti-retroviral treatment to combat the progression of the HI virus in the body. The term HAART, highly active antiretroviral therapy, is now the more commonly used term in the western world. It was not used by any of the participants.
- **Indigenous:** The United Nations (UN) has not adopted an official definition of "Indigenous" because of the diversity of Indigenous Peoples in the world. Instead, the UN-system body approach is to identify rather than define Indigenous Peoples. In this study the word is used as a descriptor to identify African women living in Kibera today who are generally regarded as the "original inhabitants" of a region prior to colonization.
- **Community:** In traditional western thinking "community" is a noun, something located outside of an individual. Adu-Febiri (2008) stated, "In sociological terms, a community may be formally described as a spatial or political unit

of social organization that gives people a sense of belonging “(p. 517). Examples of such communities are Chinatown and the gay community. This model of thinking emulates the ideology of human separation, scarcity of resources and “It tends to transform the pre-colonial Indigenous symbiotic relationships between persons embodied in lineages and the commons into individual and dialectical relationships. This may lead to the negation of community as Indigenous People conceptualize and live it” (Adu-Febiri, 2008, p. 15). The group of HIV+ women in this study constitute a close-knit community joined by a medical condition, gender and poverty that cuts across the traditional western idea of community because they also live community as is more in keeping with an Indigenous concept of community.

- **Tribe:** The concept of tribe was developed by the colonists during the 19th century and reflects empirical and ideological realities for self-interested purposes of domination and control. Ignoring the complexity of non-Western societies, colonizers defined the categories into which rural and urban societies were allocated. Historically determined and socially constructed, tribes are convenient community myths (Oloo, 2008; Wiley, 1981). In the post-colonial context of Kibera, individual women in this study were identified by the research community contact as being a member of a certain tribe. However, I have referred to them as belonging to certain ethnic groups of African people.

## List of Tables

|                                                      |     |
|------------------------------------------------------|-----|
| Table 1. Women in the study. ....                    | 135 |
| Table 2. Women in the study and their children. .... | 136 |

## Acknowledgments

There are many people in Canada and Kenya who have supported and guided me on this academic journey; I wish to acknowledge and thank them.

I acknowledge the debt of gratitude I owe to my doctoral committee members, Dr. Francis Adu-Febiri, Dr. Robert Dalton, Dr. Darlene Clover, and especially Dr. Laurene Shields, my primary supervisor who told me many times, “You CAN do this!” Each committee member generously provided me with maps to chart my academic way in foreign waters and strange landscapes. Many times, their kindness and honest words prevented me from crashing into rocks hidden from my gaze or from sinking into the depths of despair because I found myself lost – for that, I remain grateful.

I thank Dr. Madeline Walker who read, reread, and edited sectional draft copies so graciously. She gave her time freely, providing practical feedback when the waters were especially choppy and I lost sight of land.

I thank Dr. Lorna Williams who offered me tea and conversation when I became stuck due to foggy conditions as I navigated certain routes, uncertain how to proceed while giving due respect for the knowledge and knowing of Indigenous peoples.

I thank Heather Keenan, Clare Abuntu, and Dale Piner in the Human and Social Development office at the University of Victoria. Heather patiently answered many logistical questions; Clare Abuntu taught me the use of certain technological devices that accompanied me to Kenya; Dale was always in the office ready to answer questions when no one else was there.

I thank Mayne Ellis for transcription of my data and formatting my written words.

I thank friends and colleagues in Canada whose warmth always travels with me, who continually encouraged me to look for the horizon. My friend and neighbor, Maggie Barrett, listened to me many times when I was distraught because things were not moving as quickly as I wanted. Sheila Haegert, my dear, long-time friend and colleague kept me focused and gave me hope. Linda Crotty continues to be a friend, although so many times I declined invitations to social functions because I was busy either reading for or writing this dissertation. Peggy Waterton, whose heart is big, never failed to remind me I have *moyo* (heart) of my own. I met Heather Ferris in Canada after I had completed my data collection in Kibera. She works with care-givers of HIV+ children in South Africa and provided me with strength and inspiration to complete this written piece, I thank her. Bonnie Dale, Valerie Lewis, Julia MacDonald, Faye Thornton, Gillian Gravenor, Des and Etta Connor, Sandra McDonald, Carey Munro, Nettie Benjamin, Andrew Schildroth, Hugh O’Mahoney, and Andre Baily are others who have offered me encouragement and support at various stops along the way.

I thank Angela Mueni and Wilson Baya, Kenyans who presently live in Canada. It was Mueni who initiated my travel to Kenya and introduced me to Rose and Solomon Musimba with whom I stay when in Nairobi. Baya gave me basic Kiswahili language lessons and introduced me to his wife and son in Kaloleni. When I stayed there, I met his wife, Patricia Zawadi Nzaro, and her mother, Naomi Bahati Nzaro. I am grateful for their kindness and patience.

I thank Agnes Pareyio and the young women I met when in Nuru and visited the Tasaru Ntomonak Initiative. The girls sang for me, and Agnes's strength and passion for her work with young girls in preventing female genital mutilation provided me with determination to complete my academic work.

I thank Salome Kilenzo. She took me to Mkueni where I fell in love with the land of Kenya in which small orange trees and the mukenea plant grow.

I thank Winnie, my community contact in Kibera. She welcomed me into her life, her family; she kept me safe inside Kibera.

I thank the women of Kibera who took part in my study, Amina A., Amina B., Mama May, Loise, Lucy, Penninah, Sarah, Zakia, and Zuhura. By telling me stories, they shared parts of their lives and for that gift, I will remain forever appreciative.

I thank George Wafuko, who took me for a walk in Kibera some years ago and first introduced me to HIV+ women.

I thank Nancy Mwashimba, who was instrumental in forming the Darajani Widows Living with HIV/AIDS.

I thank past and present writers of theoretical and academic stories and those creators of art works that have moved me, resonating with an internal energy that connected me to a world so much larger than myself.

## **Dedication**

To my maternal grandmother,  
Anne Buckley Binks,  
and Rex

## **Chapter 1: Introduction**

### **Study interest to researcher**

It was another one of those stifling hot mid-afternoons in the summer of 2005, and I was walking with five women on one of the earth-trodden paths in Kibera. Having read much on the internet about this international “mega-slum,” and listened to my Kenyan friends speak angrily and sadly about the deplorable living conditions there, I wanted to see for myself.

This was my second visit to Kenya, and having made earlier electronic contact when in Canada with the executive director of a local, now defunct, non-government organization (NGO) working in Kibera, he arranged for me to meet some women and be given a “field tour”. As we walked I looked around, absorbing sights and smells that were strange and unusual for a privileged white woman. Live electrical wires hung loosely over and between the corrugated tin roofs of many of the wattle and mud buildings. Goats, dogs and the occasional pig were foraging in the mounds of garbage strewn around, while children played nearby, stopping now and again to stare at me or follow, shouting out repeatedly the friendly greeting in Kiswahili, “Habari gani? Habari gani?” which means, “How are you?” in English.

I had been warned before we started to tread carefully, to watch out for black polythene bags that lay on the ground or flew through the air now and again. Because the numbers of pit latrines are not enough to meet the needs of Kibera’s population, the menace of “flying toilets” continues. Those who have no money to pay to use a private latrine or who do not feel safe to venture out any distance at night to the latrines use a

plastic bag to relieve themselves. Then they tie and throw them through the air or merely dump them outside their homes.

We were walking to see the view from the railway line that cuts through the middle of the settlement; the railway track runs from Mombassa to Uganda. Four of the women walked ahead of me, one stayed close by my side, pointing to holes in the ground or pieces of cement, garbage, and animal and human waste that may have caused me to stumble. They watched out for me and included me at every turn as we meandered in and out of the narrow throughways in the slum settlement. I observed silently as I listened to the sounds; I heard the heaviness of our solid tread as we moved together forward, and the vibrations began to echo in my head resonating like a steady drum beat with the rhythm of my heart.

Suddenly, I was overcome with a sense of my own “smallness” and of bewildered awe as I began to think about these women who were walking, talking, laughing, and smiling with me and each other. The grinding poverty so evident in the environment, the rampant spread of disease which I knew existed belied the incredible ingenuity it must take to survive day to day in such surroundings. I admire these women.

In retrospect, I realized that I had been humbled by the generosity of spirit of these women, especially as I was informed later by the NGO director that some of the women were infected with the human immunodeficiency virus (HIV) and one was caring for children orphaned by acquired immune deficiency syndrome (AIDS). I could not distinguish which of the women were HIV+ and which women were not as all the women appeared physically healthy. Before walking with the women in Kibera, I had acknowledged that living in a slum environment would certainly present its own

challenges in the promotion of a healthy lifestyle. Still, I found myself wondering about the inner strength and power of these women and how they managed to live in such terrible conditions that would only exacerbate their daily struggle to live as HIV+ women.

Shortly after this visit to Kibera, I made the decision to return to university in Canada for the purpose of learning more about these women in Kibera and their experience of living as HIV+ women through pursuing a PhD. Although these women stare adversity in the face each day, I had sensed an enormous capacity for survival. I wanted to explore what life is like for HIV+ women who live and participate in community life in Kibera, Kenya. Although the portrait of Kibera is very real in this dissertation, there are, in fact, other similar living environments in the slum enclaves of Nairobi. However, these environments are not representative of Kenya or of Africa.

To complete my degree I worked with faculty from two disciplines, nursing and education. I have no background in nursing, I do in education, yet, because of the relevance of my research interest to nursing, at the initial stages of this academic journey, I was referred by a graduate advisor in the local university to the School of Nursing. I was accepted as an Interdisciplinary PhD student and the Nursing department became my “first home.”

Five years later, after taking those first steps in Kibera, I realized a study about HIV+ women living their daily lives and participating in community activities would be an important study. This study has the capacity to serve as a catalyst for continued action in the improvement of the quality of life for those living with HIV and is in keeping with the core agenda of the global AIDS response (UNAIDS, 2010).

UNAIDS (2011) reported that the viral epidemic was accompanied by a social phenomenon of comparable proportions and that fear, ignorance, and social disapproval of groups heavily affected by the virus has led to an epidemic of stigma and discrimination. In the preface to the current AIDS report, Ben Ki-moon, United Nations (UN) Secretary-General, referred to the continued need for governments, civil society, the UN family and other partners to work together in the spirit of shared responsibility and mutual accountability. He stated that all concerned parties in the global fight against HIV/AIDS must “forge strategic partnerships, support national ownership, engage emerging economies, facilitate South-South cooperation, link the AIDS response with broader health and development efforts and usher in a new approach to financing” (UNAIDS, 2011, p. 7). Speaking to those at the 2011 General Assembly High Level Meeting on AIDS, Ben Ki-moon acknowledged the premature deaths of individuals due to HIV and the necessity of people in positions of power to keep foremost in mind those living with HIV who will enjoy healthier, longer lives because of commitments made by agencies and organizations in attendance. My study conducted in Kibera explores the daily lives of nine HIV+ women who are receiving antiretroviral (ARV) treatment. The data in this study demonstrate how some HIV+ women live in their communities, their experiences of health, the intersections of poverty, health, care of children, and points to the needs of these women. Perhaps this study will also suggest potential strategies for governments and civil society that can better support HIV+ women with HIV/AIDS programming and health service delivery at a community based level and in a slum environment that will improve the overall quality of their lives.

### **Background for the study**

Seventeen years ago in 1995, Dervla Murphy wrote of an English doctor's outburst in Tanzania when he was addressing international attention towards the outbreak of HIV/AIDS in Africa. The focus of his comment could well have been Kenya or any other country that was experiencing visible symptoms of the global spread of HIV.

For seven years now we've been tormented by sociologists, anthropologists, psychologists and otherologists, all studying the "African Response to AIDS." Then they write papers about 'guilt patterns' and denial syndromes and what not. They never mention that many Africans can even enjoy a life they know is doomed (p. 253).

Much has changed since 1995 when the doctor voiced his observation. The medical landscape has shifted due to acquisition of new knowledge relevant to the progression of the HI virus in the body. In the Western world AIDS is viewed as a chronic, life-threatening illness with two phases, HIV infection and AIDS; no longer does it carry a death sentence as in the mid-nineties. The aging context of the disease itself has determined that HIV-infected individuals live longer too if they have access to antiretroviral drugs (ARVs). Access to ARVs increases the life span of those infected with the virus and has a significant impact on quality of life. Because of alternating periods of crisis and stability that characterize the disease, those with HIV/AIDS must continually reorganize their view of their life's expected course (Scandlyn, 2000). Chronic illness challenges a general western view that life is lived as a linear progression of events from birth to death in a predictable order. Life is no longer predictable when one has been infected with HIV (Becker, 1997). The disappointment, frustration and depression that may occur during and after a period of crisis should not be underestimated; "One consequence of chronic illness is that the responsibility for all

aspects of management – physical, mental, and social – increasingly falls on the shoulders of those who have the illness” (Scandlyn, 2000, p. 133). That said, Scandlyn reminds the reader that during the absence of crisis, HIV+ individuals must continue to care for themselves and resume what could now constitute a normal life.

Poverty compounds the complexity of all lives, but particularly of HIV+ women in this study. HIV/AIDS has become a manageable disease, although it remains difficult to overlook the continued suffering and devastation caused by the pandemic, the millions of deaths, related illnesses and the social disruption of community life. The HIV/AIDS pandemic is one of the greatest obstacles to development and health care in Africa and around the world. The ramification of this life threatening disease tears the fabric of society striking women and men in their productive years, orphaning legions of children and rendering health, education and governance systems threadbare. HIV/AIDS has become an international public and social crisis. Statistics relating to the HIV/AIDS pandemic are discussed in the literature review.

### **Significance of the study**

Biomedical and social sciences research relating to HIV/AIDS has accumulated at a dramatic rate over recent decades (Kippax, Holt, & Friedman, 2011; Mosati & Souteyrand, 2000; Parker, 2001; Storeburner & Low-Ber, 2004). However, the focus of these studies has been primarily on illness rather than health, and understanding the disease as a medical rather than a socio-economic and politico-cultural crisis. Research has leaned heavily on the side of prevention and clinical treatment without addressing the experienced realities of daily life for those living with HIV/AIDS outside of the United States of America (USA) (Doyal, 2009).

This study focuses on the experienced day-to-day reality of HIV + women who live in Kibera in Kenya. Few studies have explored how HIV+ women live and participate in community life within a sub-Saharan context. I was unable to locate any study that explored the daily lives of HIV+ women in Kibera, although much has been documented regarding the deplorable living conditions in that slum. Therefore, findings from this study provide a view into the daily lives and report on how these women's lives are contextualized by day-to-day activities in Kibera. This unique narrative inquiry is significant in developing knowledge about women living with HIV/AIDS and also provides an evidence base useful for generating hypotheses for further research (Babble, 1998; Clandinin, 2000, 2007). The study contributes a written record for learning from the storied experiences of those whose voices have been quiet, silenced in sociological margins, and recognizes that human experience is grounded in the complexity of life, in the gaps of unresolved incongruences, tensions in the human condition (Frank, 2004; Smith, 1999).

The study is based on the premise that HIV/AIDS has brought about social disruption and profound changes within the micro contexts of family life and community in Africa. The appearance of child-headed households is one phenomenon that can be linked directly to the spread of the infectious disease. Cultural norms, practices and values that historically sustained the social fabric of African communities are slowly being eroded by the pandemic. Although HIV/AIDS is now acknowledged as a manageable disease, the HI virus continues to present multiple challenges to those infected and extended family members who search for alternative ways to cope.

Undoubtedly, social structures and systems are being reshaped to meet the extraordinary needs of those who are HIV+.

When I met HIV+ women in Kibera for the first time, I became curious as to what constituted their daily lives and how they had changed as a result of critical illness. Literature concerning poverty and the role of gender in societies and the difference in effect on the lives of men and women is plentiful (Casper, McLanahan, & Garfinkel, 2008; Ehrenprels, 2008); literature that explores how HIV+ women live in poverty is scant. The women in this study live in a post-colonial mega-slum where gender and poverty have a huge impact on the quality of their lives and especially on the social determinants of their health. The relational intersectionality of poverty, gender, health and the past colonization of Kenya are underpinnings that affect the daily lives of women in their communities. These underpinnings provide the conceptual framework for my understanding of how HIV+ women experience/story their daily lives and participate in community and are developed in the literature review.

### **Purpose of the study**

The purpose of this study was to research and report on the findings of how a group of nine HIV+ women living in Kibera go about their daily lives and how they “story” their experiences. The voices of these women have rarely been heard. They may have status within their close community yet have little or no status outside of Kibera. Living in a slum, in dire poverty, they deal with multiple challenges every day; one of these challenges is living as HIV+ women.

The primary question that guides this study is: How do HIV+ women in Kibera, Kenya participate in their community and story their experiences?

Studies that address the day-to-day reality of living with HIV outside of the U.S.A. are scarce. The findings of this inquiry have the potential to benefit those who live with HIV in different global communities and close the gap in knowledge. Stories of HIV+ women that are collected, documented and interpreted through the prisms of narrative, feminist, and Indigenous methodologies, benefit society at large because experience leads to reflection and reflection has at the very least the potential to lead to agency and organization. Disparate accounts have little impact on the public consciousness, whereas a research study provides an evidenced based foundation for development at the community, national, and international levels to better meet the needs of women living with HIV/AIDS. The study also plays an advocacy role in bringing to public attention the reality of the lives of HIV+ women living in poverty in the slum of Kibera.

### **My role as researcher**

As a western and feminist researcher, I had to take a critical look at the complexity of my engagement in the research process; the women as research participants, and I as researcher, created relationships in the research context that were complex and interdependent. I concur with Besio (2003) that researchers and research participants co-position and co-construct each other in multiple and contradictory ways. For example, entering someone's home for *chai* (tea, which very often was hot chocolate) was complicated for a privileged white woman. I was invited, yet I was expected to provide the money for the milk and chocolate powder; I was a guest and hostess at one and the same time. This is in no way to suggest that I was being exploited by this participant in my study. Quite the reverse was taking place; I was being included. In the

Kenyan culture, it is the cultural norm to take with you a provision of milk, sugar, tea leaves and sometimes any form of food when you visit others. Therefore, it was not an unusual phenomenon for the host to share the gifts I bought for them. This is one of those cross-cultural experiences that require a researcher to fully understand the context and custom of the participants before entry.

As a researcher exploring the lives of HIV+ women in Kibera, I encountered the “gritty day-to-day experiencing of postcoloniality” (Pratt, 1992, p. 30). Hypothesizing that colonial relations of the past underlie social, political, and economic conditions of a post colonial present, researchers such as Battiste (1999; 2008), Besio (2003) and Smith (1999) draw attention to the asymmetries of power relations in research practice.

Kibera is a post-colonial context and I, as researcher, and the HIV+ women, as research participants, each resided somewhere along the colonizer-colonized continuum. To understand the present we must look to the past. Kenya attained its political independence more than 40 years ago, yet colonial relations are maintained and reproduced in different ways on a daily basis. Within post-colonial discourse, some scholars refer to present day neocolonialism as the last stage of British imperialism. Scholars such as Nkrumah, 1965, argue that neocolonialism is the last continued oppression of colonialism in disguised forms in former colonies whereby the colonists still maintain economic, political, ideological, cultural and social control although the colony had been granted “political independence”. Although Kibera may be discussed from the standpoint of a colonial, post-colonial or a neo-colonial context construction in relevant literature, in this dissertation Kibera will be referred to as a colonial and post-colonial setting.

Collecting data in a post-colonial setting, a cross-cultural space, prompted me to agree with Besio (2003) who wrote, “‘Being inside’ a post colonial place and doing research there is a very different intellectual location from ‘being outside’” (p. 28). As an “outsider” inside Kibera, I engaged in crossing many boundaries. Communication was the major challenge to my western training in ways of theorizing and of being in the world. I entered a research field in Africa, a long way from where I lived in Canada. I positioned myself as a reflective researcher in the “here and now,” and was acutely aware that my sense of self, both individual and social, as Andrews (2007) points out, was “built on the premise of the existence of an ‘other,’ and it is this critical construction of boundary that lies [lay] between them [us]” (p. 507).

As a western researcher, I also acknowledged my positionality within an academic post-structural paradigm; I worked hard to remain mindful of my own subjective lens when in relation with others who saw me as an “other” through their subjective lens. Differences that may have separated us, making each of us “other”, seemed to disappear and lose the sharpness of definition when we worked collaboratively and the women began to tell me stories of their lives. We connected as women sharing our time and parts of our lives (Canales, 2000).

Chilisa (2012) and Guba and Lincoln (2005) remind their reading audience that social science research historically has viewed the world in one color and has ignored the relational realities and ways of knowing that are predominant among non-Western Other/s still being colonized. My research intent was to disturb Hartsock’s (1987) observation that “the Other is always seen as NOT, as a lack, a void, as lacking in the valued qualities of the society, whatever those values may be” (p. 86). My own view is

that everyone has a story to tell, a story of equal importance. In life's mainstream, everyone has standpoints, foundations on which narratives are developed, built upon, made-up, told, scripted, shaped, moulded, listened to, heard, retold, and told again and again. The telling of stories, personal stories and stories told by others, serve to turn an academic spot-light on the focused interplay of the foundationalism of the epistemologies of individual lives, and disrupt the acting out of dominant, colonial, narrative plots. With this in mind, I utilized narrative, feminist, and Indigenous methodologies as appropriate approaches to encourage the HIV+ women to talk of their own experiences, to tell their stories using their own voices. These methodologies engendered respect for the other, creating an opening for the participants and me to develop interdependent relationships in which we constructed our own narrative identities located at the intersection of different cultures (Adams, 2007; Besio, 2003; Tan, 2005).

The participants and I used English when we met and spoke with each other although Kiswahili is the most common language spoken and understood by Kenya's majority and I became a *muzungu* in some quarters. As a *muzungu*, the Kiswahili catch-all term for anyone constructed as white, I was constantly engaged in "unpacking my white privilege" (McIntosh, 1990). I made use of my perceived position of power by some, to roam in and out of roles with careful deliberation, not without relative personal tension, to gain entry and access information necessary for my research inquiry. For example; before I began officially collecting data in Kibera, I had been directed by the Kenyan National Council for Science and Technology to report to the District Commissioner's office in Nairobi West, located in Kibera's District office compound, identify myself and present the pertinent research documentation. It was early in the

morning when I arrived and several people were already seated on the wooden bench waiting for the Commissioner who arrived almost one hour later than scheduled. After a certain amount of time and after the number of those sitting and standing had increased considerably, I left my seat to go and knock on the Commissioner's office door which was slightly ajar. As I poked my head inside the room, three people immediately stopped talking and turned to look at me. I explained myself and within a very short time my business was completed. I walked away feeling rather uncomfortable because I knew it was the color of my skin that had allowed me to "jump the queue" while others still waited as the sun grew hotter for their turn to meet with the Commissioner. This vignette is one situation in which I consciously made use of my "white privilege." To what extent the "unpacking" of my "white privilege" was successful rests in the minds of the readers. In the context of Kibera, my "white privilege" certainly did not provide me with the natural "cultural privilege" of my study subjects; I was beholden especially to my community contact for support and direction in how to conduct my research every step of the way.

### **Overview of the study**

This dissertation has six chapters. Chapter 1 provides the background for my interest in pursuing a PhD program and introduces the research topic. I review selected readings pertaining to the intersectionality of poverty and health, gender and the feminization of HIV/AIDS, and the influence of colonization in Chapter 2. In Chapter 3, I describe the relevance of narrative, feminist, and Indigenous methodologies for my inquiry; the methods I used are described in detail. A descriptive understanding of what life is like inside Kibera today precedes the introduction of each of the nine participants

and my community contact is included in Chapter 4. In Chapter 5, I offer my interpretive findings and in Chapter 6, I conclude with a discussion of the integration of findings.

In the next chapter, Chapter 2: The Literature Review, I discuss three broad conceptual frameworks that underlie the lives of the women in Kibera to-day.

## Chapter 2: Literature Review

Poverty is a stark reality in the everyday lives of women living with HIV+. As Nolan (2007) argues,

Put simply, millions of Africans are living with a virus from which they might easily have been protected if they had had access to education about it, or to the means of defending themselves. At the same time, their lack of resources led them to do things – to sell sex, to stay with a philandering husband ... that they might not otherwise have done; this too spread the disease (p. 12).

HIV+ African women face incredible barriers in efforts to maintain a standard of living that is conducive to good health and an overall well-being. Kenya is one of the hardest-hit countries for HIV infection and women “face heavy economic, legal, cultural and social disadvantages which increase their vulnerability to the epidemic’s impact” (UNAIDS, 2004, p. 43).

Twenty years ago, HIV/AIDS was more generally depicted and analyzed as an infectious disease crisis and less understood as a human rights crisis. Within the last decade more attention has been given to the link between HIV/AIDS, human rights and gender issues (Gruskin & Tarantola, 2000; Gruskin & Tarantola, 2001; Gruskin & Tarantola, 2005; Tallis, 2002; UNAIDS, 2004, 2010). The fact that HIV/AIDS affects more females than males around the world has led many researchers in the field to refer to this statistical phenomenon as the feminization of the pandemic. The vulnerability and inequality of women world-wide has placed HIV/AIDS firmly in the centre of feminist debate (Edries & Trigaardt, 2004; Lather & Smithies, 1997; Lewis, 2006; UNFPA, 2006).

To fully understand the complexity of HIV/AIDS, it is important to consider various factors which have influenced and driven this pandemic. This chapter draws on literature that examines the confluence of poverty, health, and HIV/AIDS in Africa, gender and the feminization of HIV/AIDS, and the influence of colonialism in the post-colonial research context of Kibera.

### **Poverty, health and HIV/AIDS in Kenya**

#### **Definitions of poverty**

There are many definitions of poverty. The lack of basic necessities, such as food, water, shelter, medical care, and safety is the most commonly accepted definition of poverty (Spagnoli, 2009). Spicker, Alvarez Leguizamón, and Gordon (2007) claim that poverty is defined differently by different people according to their disciplinary standpoint, position, or invested interest. While agreeing with Deleek and Van den Bosh's (1992) generalized definition of poverty as a "relative, multi-dimensional and dynamic phenomenon" (p. 2), I find Schwartz's (2005) definition more suited to the context of my research study and in keeping with the United Nations' (UN) definition of poverty that follows. Schwartz refers to an understanding of poverty as depriving individuals of goods, services and pleasures others take for granted, such as food, shelter, medical care, employment, leisure, safety, and choice. This deprivation was more explicitly articulated by the UN in 1998,

Fundamentally, poverty is a denial of choices and opportunities, a violation of human dignity. It means lack of basic capacity to participate effectively in society. It means not having enough food to feed and cloth a family, not having a school or clinic to go to, not having the land on which to grow one's food or a job to earn one's living, not having access to credit. It means insecurity, powerlessness and exclusion of individual, households and

communities. It means susceptibility to violence, and it often implies living on marginal or fragile environment, without access to clean water or sanitation (Gordon, 2005, p. 4).

The women in this study lack both choice and opportunity.

When reading the chapter on interpretative findings, the reader will do well to keep in mind that the nine women live in “absolute poverty”, a term that was isolated from the wealth of international poverty discourse by the UN in 1995, after the World Summit on Social Development in Copenhagen. Three years later, the UN’s definition of poverty was agreed upon and signed by the heads of all UN agencies. “Absolute poverty” is sometimes used as a synonym for extreme poverty and refers to a set living standard in all countries below which it is unacceptable for any individual to fall. This standard of living is characterized by severe deprivation of basic needs, including safe drinking water, food, sanitation facilities, health, shelter, education, and information (Palmer, 2007; Townsend 1979).

David Gordon (2005) developed a paper specifically for the UN which concerned the indicators of poverty and hunger. In this paper, he defined “absolute poverty” as the absence of any two of the following basic needs:

- Food: Body Mass Index must be over 16
- Safe drinking water; water must not come solely from rivers and ponds, and must be available nearby
- Sanitation facilities: toilets or latrines must be accessible in or near the home
- Health: Treatment must be received for serious illnesses and pregnancy
- Shelter: Homes must have fewer than four people living in each room; floors must not be made of dirt, mud, or clay
- Education: Everyone must attend school or otherwise learn to read
- Information: Everyone must have access to newspapers, radios, television, computers, or telephones at home

- Access to services: This item is undefined by Gordon and normally is taken to indicate the complete panoply of education, health, and legal, social and financial (credit) services (Spagnoli, 2009).

Spagnoli (2009) proposed that poverty impacts on the material, social, psychological, and political dimensions of daily life. He maintained that, while it is possible to measure, to some extent, the material, social, and political dimensions of poverty and the effectiveness of policy measures aimed to eradicate poverty, the psychological dimension is much more difficult to measure, yet of no less importance. Lacking consistent resources to provide basic necessities, some individuals may become excluded from ordinary social living patterns and become socially excluded (Townsend, 1979).

Many reference poverty purely in economic terms: how much money a person has. In a paper for the World Bank, Ravallion and Chen (2008) reviewed and revised poverty estimates. They reported that 1.4 billion people (one in four) in the developing world were living below US\$1.25 a day in 2005, down from 1.9 billion (one in two) in 1981. While overall rates of poverty have decreased, Ravallion and Chen's work revealed marked regional differences in progress against poverty still persist, and poverty is more pervasive than was thought. This is especially true in sub-Saharan Africa where the poverty rate was 50% in 2005. In Africa, the number of poor people has almost doubled from 200 million to approximately 380 million in 2005. It is predicted that, if this trend continues, a third of the world's poor will live in Africa by 2015. An even higher economic growth than for other regions is necessary to impact the depth of poverty in Africa where the average consumption among poor people was a meager 70 cents a day in 2005.

Ravillion and Chen (2008) assert the likelihood that the world will reach the first Millennium Development Goal (MDG) of halving the 1990 level of poverty by 2015, and acknowledge that poverty has fallen by about 1 percentage point a year since 1981. This worldwide progress report contrasts sharply with the realities in sub-Saharan Africa.

A recent study published at the midway point of the Millennium Development Goals (MDGs) testifies that not a single country in sub-Saharan Africa is on track to achieve the internationally agreed target of halving poverty by 2015, where the results have been dismal with relatively little progress in alleviating poverty (MalWana, 2007). During my four relatively short visits to Kenya over the last seven years, I have observed no improvement in the overall living conditions of those who live in settlements such as Kibera. Poverty and related issues were increasingly evident in the press. On my last visit to Nairobi, the local newspapers were full of articles about government corruption and the apparent lack of concern for those who were suffering. Food was more expensive due to short supplies because of drought conditions; more people were going hungry. To alleviate poverty in sub-Saharan countries more is required than good faith and rhetoric from those in high-up government positions; action is needed at the ground level.

### **Poverty in Kenya**

The HIV+ women in this study live in the sub-Saharan country of Kenya where the incidence of poverty is still extremely high despite the MDG of eradicating poverty by 2015. Every three years, in broad consultation with stakeholders and development partners, including staff from the World Bank and the International Monetary Fund, Kenya releases a Poverty Reduction Strategy Paper. The 2004/2005 Kenya: Poverty Reduction Strategy paper drew attention to the rising rates of poverty in the country and

the fact that geographical variations in the distribution of poverty are large. The macroeconomic framework that formed the core of the Economic Strategy was analyzed in gender-neutral terms which did not reflect the acute situation of many women living in “absolute poverty”. However, the working paper did acknowledge the difficulty in obtaining accurate evidence of the prevalence of “absolute poverty” and defined poverty in income and non-income terms as the relationship between economic poverty and human poverty. The poor were defined as those not only living with less income but are also disadvantaged in accessing productive resources such as land, credit, health, and education. The poor are considered as vulnerable and powerless to changes in system-wide institutions and have little capacity to influence key decisions at various levels.

In Kenya, the geographical variations in the distribution of poverty are considerable. By the use of surveys, poverty mapping, and participatory studies, researchers established that key determinants of poverty included location (urban/rural); household size; gender and level of education of the household head; access to land; ownership of livestock; unemployment; living with HIV/AIDS or a disability; being a member of a minority that is discriminated against, and living in a degrading environment. It was also determined that three quarters of Kenya’s poor live in rural areas; the majority of the urban poor live in slums and peripheral settlements (International Monetary Fund, 2004/2005). The women in this study fall within the category of the urban poor living among an estimated 1 million people on 550 acres of mostly government land in Kibera, Kenya’s oldest and largest slum in the south-western part of Nairobi’s city centre (Amnesty International, 2010).

Kenya's current Grand Coalition Government is committed to implementing the first medium term plan indicating reform measures, and projects and programmes to alleviate poverty in the country. The country's primary working document, Kenya Vision 2030: A Globally Competitive and Prosperous Kenya, acknowledged that various interventions are in process to alleviate poverty and improve equity particularly in rural areas. Poverty and inequity levels prevailing in various regions of the country are still extremely high. So, while Kenyan reports are "gender neutral", the impact of gender on poverty is still evident in some findings. There exists a wide and deepening gap between the poor and non-poor in the entitlement to political, civil and human rights (Muindi, 2010). Large disparities exist in income, access to health, education, and land and capacity to meet basic needs such as clean water, adequate housing, and sanitation. Notable disparities are reported between intra-regional, inter-regional and the impact of gender on inequities and poverty. The working document also drew attention to disparities in the HIV/AIDS prevalence across and within regions linking poverty to the disease. The report stated: "In 2004 HIV/AIDS prevalence in Kisumu and Mombassa was 18.4 and 12.3 per cent respectively, compared to 4.1 and 5.0 percent in Embu and Malindi respectively. Indeed the scourge [HIV/AIDS] affects and impacts on men and women differently within regions" (p. 4).

#### **Disparities in geographical poverty concentration**

Participants in this study are poor women who presently live in an urban slum. A slum, an overcrowded urban area is called by some a "ghetto". A "ghetto" is described in the Merriam-Webster Online Dictionary (2011) as "a section of a city occupied by a group who live there especially because of social, economic or legal pressure". Glaeser

(1997) put forth four distinct ways in which a ghetto is formed. Two of these have implications for the development of Kibera. The first deals with a majority political compulsion (usually violence, hostility, or legal barriers) to move minorities into particular areas. The British colonial government forced Nubian soldiers and African workers to live outside of Nairobi's centre. The soldiers and workers settled in an area on the outskirts of the city. Later, economic conditions encouraged further settlement by other ethnic groups who migrated from rural area and found living costs in the city too expensive. Bradshaw (2005), a western sociologist, proposed an economic agglomeration theory explaining why geographical disparities exist in the concentration of poverty occurring in the aftermath of colonization. Certain areas in many large cities generally do not attract investment development from big corporations or from the business sector. Bradshaw argued among other things that the lack of natural resources within a specified area very often translates into little return for investment. This is true of Kibera where there are minimal natural resources to attract investors and the lack of economic investment is very evident. However, what is evident are the numerous business ventures of seemingly uncaring, corrupt absentee landlords who buy or hastily construct sub-standard buildings haphazardly with no amenities and for which they collect rent (Bodewes, 2005). Living in Kibera and other slum settlements such as Matheri Valley and Kanyore is cheaper than living in other parts of Nairobi yet women who are unable to pay the rent may still face forced eviction as in any other rental situation.

Another explanation as to why geographical poverty can increase is the selective out-migration of capable individuals looking for better opportunities (Pendakur, Pendakur, & Woodcock, 2008). Many of those who migrate into urban cities from rural

communities leave behind agricultural life styles and cash crops that are no longer sustaining. They may come to escape poverty yet find once more that they have no consistent income to sustain a healthy life and be free from poverty. As a result, they may find themselves in unfamiliar places without the necessary skills to compete for employment opportunities except perhaps menial positions and often lack the financial means to pay for education upgrading or relevant training (Bodewes, 2005). This process is perhaps further complicated for women who may meet their husbands in rural villages and are brought to an urban settlement such as Kibera to live; the women may be ignorant of the living conditions in the slum before arriving at the slum for the first time.

### **Women and poverty**

Poverty affects men and women differently in different regions of Kenya. In Kibera poverty affects everyone, and those who live there suffer in relative degrees from hunger, disease, environmental degradation, and impoverishment. Often women are unable to provide for their children and have a strong sense of shame and failure. When trapped in poverty, the poor may lose hope of ever escaping from hard work for which they often have nothing to show beyond bare survival (Singer, 2009). Although in 2009 the UN reported that the number of those living in poverty worldwide had dropped from 1.8 billion in 1990 to 1.4 billion in 2005, many women continue to live in poverty.

Women, especially women in developing countries such as Kenya, bear a disproportionate burden of the world's poverty. Exact statistics on women's prevalence among the poor are difficult to gather, yet it has been estimated that 70 percent of the world's poor are women (Aveggio, 2011). That poverty discriminates and strikes women more frequently than men has been well documented; women disproportionately suffer

from hunger, disease, and environmental degradation (Chant, 2006; Chen, 2005; Day & Broadsky, 1998; Donner, 2002; McDonald & McIntyre, 2002; Thibes, Lavin, & Martin, 2007; United Nations, 1995; Wilson, 1988; World Economic Forum, 2005; WHO, 2008).

Alligood (2010) called attention to the interconnectedness of physical, mental, emotional, and spiritual aspects of every woman's being in relationship with the economic, political, and cultural influences that impact on her state of well-being. Dominant ideologies in many societies including healthcare systems are not structured in ways to support the lives of women, in particular the lives of women who live in poverty and outside the dominant group – such as the women in Kibera (MacDonald & McIntyre, 2002).

Statistics can be extremely difficult to come by or inaccurate, especially in remote rural areas or urban environments where the population is often constantly in motion; statistics can present a distorted view of situations. Marcoux (1998), a former senior officer with the Population and Development Department of the United Nations, conducted a study for the Population Council and determined that the percentages of those living in poverty were frequently asserted without evidence. His published findings challenged the 70 percent poverty rate for the world's women and his research data demonstrated that the global population of females among numbers of poor households was closer to 55 percent. However, it is most probable that the numbers of women living in poverty have increased since the 1998 findings were released. Over the last thirty years, although a steady stream of academics, health professionals, and policy makers from all parts of the globe have made rigorous efforts to raise awareness of the

subordinate economic status of women world-wide, not one country has managed yet to close the gender gap (World Economic Forum, 2005).

Multiple reasons for the global trend of women's impoverishment, including lack of income, lack of opportunities, and systemic gender biases embedded in both governments and societies are described by Chant (2006). Ensuing deprivation results in a lack of resources and opportunities to live a life with dignity, respect, and freedom (Fukuda-Parr, 1999).

### **Female-headed households (FHHs)**

The women in this study are widows, single parents and heads of their households where the impact of poverty is most profound. In the late 1980s, it was estimated that FHHs constituted 17–28 percent of the world's total households and were exposed to higher risks of poverty due to lack of income and resources (Horrell & Krishnan, 2007; Todaro, 1989). A UNESCO report indicated an increase of such households in the 1990s and the fact that FHHs in urban areas were poorer than otherwise similar households (Moghardam, 2005). The HIV/AIDS pandemic has resulted in an increase of FHHs; widows, grandmothers, and older sisters may well become the persons responsible for those whose parents have died from the disease (Bongaarts, 2001; Chant, 2003; Momsen, 2002; Schatz, Madhaven & Williams, 2011).

In Kenya the percentage of FHHs is 30 to 40 percent (Moghardam, 2005; UN, 1995b). Bodewes (2005) concluded that FHHs in Kibera were as high as 70 to 80 percent. Although it is true that members of FHHs may not, by default, live impoverished lives, the UN (1995b) report indicated the highest absolute poverty rates amongst households headed by single women are estimated at 52 percent as compared to 44.3

percent of households headed by men. The same UN report suggested that in Kenya the best predictor of whether a FHH is or is not likely to be poor is whether the female head does or does not receive support from a current partner, husband, or adult son.

FHHs existed before HIV. Undoubtedly, the HIV/AIDS crisis has witnessed an increase in FHHs, yet Clark (1984) pointed out that the role of women in FHHs are culturally defined and so, called into question are western basic assumptions about “natural” (and universal) forms for family structure and family relations. Depending on the country and region, the population of FHHs may be those primarily composed of elderly widows, divorced women, single women with children, or women whose husbands are migrants. Because of the substantial heterogeneity among FHHs, some groups are more vulnerable to falling into poverty than others (Morrison, Raju, & Sinha, 2007). However, as Amnesty International (2010) points out, the head of a FHH may be exposed to harassment, intimidation, violence, and rape because security offered by male relatives, especially at night walking to the latrines, in slum settlements such as Kibera does not exist.

### **Poverty linked to health**

Research has shown that poverty is inextricably linked to health status (Donner, 2002; Leon & Walt, 2001; Marmot & Wilkinson, 1999, 2001; WHO, 2008). How individuals live and in what social conditions they work or do not work influences and determines their health and overall well-being.

In 1948 in the Preamble to the Constitution of the World Health Organization (WHO) health was defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (p. 100). In 1978, the Alma-Ata

Declaration, heralded as a major milestone of the twentieth century in the field of public health, identified primary health care as the key to the goal of Health for All. The Alma-Ata Declaration acknowledged principles and actions that characterized Health for All at a global level which included the strengthening of equity, health gain, quality of care, gender sensitively, acceptability, participation, and cost-effectiveness. Since 1978, agencies affiliated with the World Health Organization and international health organizations have designed strategies for human development that stress equity, the well-being of populations and the alleviation of suffering and ill-health.

Building on the progress made by the Alma Ata Declaration on Primary Health Care in 1978, the Ottawa Charter for Health Promotion was released in 1986. The underlying premise of this Charter was that health was to be viewed as a resource for everyday life, not the objective of living. Identified in the Charter are basic prerequisites for improvement in health care which require a secure foundation, and which are: peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice, and equity.

Much has changed in the world since the development of the Ottawa Charter for Health Promotion. The Bangkok Charter for Health Promotion in a Globalized World (2005) complements and builds upon the values, principles, and action strategies for health care promotion, reflecting these changes. Critical factors that now influence health or health care include:

- Increasing inequities within and between countries
- New patterns of consumption and communication
- Commercialization
- Global environment change
- Urbanization

Motivated by social justice and equity issues, public health care professionals and concerned politicians have proceeded with urgency to move away from an individually focused lifestyle approach to a more collaborative approach for health promotion that requires partnering with other sectors to combat the challenges associated with the social determinants of health (Bruner, 1997; Sutcliffe, Sarsfield & Gardner, 2007). The Bangkok Charter for Health Promotion in a Globalized World (2005) called upon governments and politicians at all levels, civil society, the private sector, international organizations, and public health communities to work together to provide the achievement of health for all. This Charter importantly acknowledged that women and men are affected differently by determinants of health and that the vulnerability of children and the exclusion of marginalized, disabled, and Indigenous Peoples has increased.

Additional factors that influence health now include rapid and often adverse social, economic and demographic changes that affect working conditions, learning environments, family patterns, and the culture and social fabric of communities. The combination of enhanced information and communications technology and improved mechanisms for global governance, plus the sharing of experiences, presents new opportunities for global cooperation to improve health and reduce transnational health risks. To achieve the common good of humanity, it is imperative that levels of government, United Nations bodies and other organizations, inclusive of the private sector, work together ethically and are coherent in matters of compliance, transparency and accountability with international agreements and treaties that affect health. This has

not yet become a reality as is evidenced by the social environment and health care of those whose home is in a slum settlement such as the women in this study.

The global disparity of health damaging-experiences is directly related to issues of the unequal distribution of power. WHO (2008) reported that the unequal distribution of health-damaging experiences is not a “natural” phenomenon:

[It] is the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics. Together, the structural determinants and conditions of daily life constitute the social determinants of health and are responsible for a major part of health inequities between and within countries (p. 1).

Where people are born and live influences their overall health for the duration of their lives, and are important factors when considering social determinants that affect the health status of individuals.

Health researchers and professionals in the field of community health stress the importance of the impact of the social gradient of poverty as it affects the overall health of individuals in different contexts. Health, most definitely, is related to issues of inequality and has an interdependent relationship with other areas in the field of social development (Brunner, 1997; Marmot & Wilkinson, 1999). By examining international data from World Health Reports, and their own collaborative research studies with British civil servants, Marmot and Wilkinson (1999) suggested that sufficient evidence was available to argue the following:

- Differences in health between population groups are due to characteristics of society.
- When people change social and cultural environments, their disease risks change: people’s disease rates are responsive to the environment in which they reside.
- The health gradient is not a function of poverty alone. Health inequality is not a question of poor health for the poor and good health for the rest. It is a problem

across the socio-economic spectrum – as an individual moves down the social hierarchy, life expectancy gets shorter and mortality rates are higher.

- The health gradient can change quickly.
- The health gradient is not a matter of selection. Ill health can be a barrier to success in life, but the effect is relatively small. By and large, health does not determine social position, social position determines health.

Although Marmot's research data was collected from non-Indigenous Peoples and Marmot was himself a westerner, his findings do have relevance for the Kenyan women in this study. According to Marmot, the social determinants of health are not restricted to and may include income and social status, gender, employment and working conditions, biology, education, healthy child development, health services, culture and ethnicity, personal health practices, social support, physical environments, and social environment (Marmot & Wilkinson, 1999; WHO, 2007). Biology is a huge term referring to genetic susceptibility to illness and to external influences such as pollution. As has already been referred to earlier, WHO (2008) reported that the toxic mix of bad policies, economics and politics is in large measure responsible for the fact that a majority of people globally do not enjoy the good health that is biologically possible.

When considering the impact of poverty on health, although it is important to think of income as a social determinant of health, it is more important to give attention to the relationship between income and health. It is the unequal global distribution of income and wealth that contributes to social inequalities and affects adversely the health of individuals and whole populations (Donner, 2002; Kawachi & Kennedy, 1997; Kawachi, Levine, Miller, Lasch, & Amick, 1994; WHO, 2008). Smith (2009) deliberated on the social cohesion research by Kawachi et al. (1994) and wrote, "a large gap between the rich and poor in a society inhibits social integration that limits public policy

development and investment in social programs. These limitations yield an inadequate support system for all members of society” (p. 23).

Poor health is not merely confined to the poorest of the poor. Poor health exists in most countries and follows a social gradient: the lower the socioeconomic position, the worse the health (WHO, 2005) The 2001 World Health Report, an annual publication of WHO, maintains that good health is essential to human welfare and to sustained economic and social development. The 2011 Health Report is significant because it provides an action agenda for countries at all stages of development and proposes ways that the international community can better support efforts in low income countries to improve the health of its poorest citizens. Member States affiliated with WHO are working towards the target of developing their health financing systems to ensure that all people can use health services while being protected against financial hardship associated with cost. These are noble goals, yet the stark reality remains that the lives of those who are infected with HIV, particularly in non-western countries as this study demonstrates, indicate that the global community has a long way to go in alleviating poverty and suffering. This study examines the lives of HIV+ African women who live in poverty and struggle every day to generate money to provide even the most basic of necessities for the health and care of their children and themselves.

#### **HIV/AIDS within a global context**

The HIV/AIDS phenomenon is now in its fourth decade and has reached historic proportions. The rampant spread of the illness has robbed countries of resources and capacity on which both community security and development depend. Although the virus has been under the microscope, scrutinized by health professionals and subjected to

intensive scientific study for more than thirty years, it continues to thrive (UNAIDS, 2010). The magnitude of this pandemic is unprecedented. It is the first and only worldwide disease that has generated a common consciousness and brought about a dedicated United Nations (UN) organization, UNAIDS. The enormous scale of the global HIV/AIDS pandemic required a coordinated effort at all levels to encompass different approaches such as service delivery, capacity building, research, and advocacy and was incorporated into all sectors of society (UNAIDS et al., 2004). The HIV/AIDS crisis heralded a universal awakening for global cooperation and collaboration to deal with a chronic disease caused by a virus that crossed international borders without a passport.

### **Linking poverty, health and HIV/AIDS**

Linking poverty and health within the HIV/AIDS context, UNAIDS reported:

Since 1999, the year in which it is thought that the epidemic peaked, globally, the number of new infections had fallen by 19%. Of the estimated 15 million people living with HIV in low- and middle- income countries who need treatment to-day, 5.2 million have access – translating into fewer AIDS-related deaths. For the estimated 33.3 million people living with HIV after nearly 30 years into a very complex epidemic, the gains are real but still fragile. Further progress will depend heavily on the joint efforts of everyone involved in the HIV response (UNAIDS, 2010, p. 7).

The numbers of new HIV infections have been falling since the late 1990s and the overall growth of the global HIV/AIDS epidemic appears to have stabilized yet the levels of new infections are still considered high (UNAIDS, 2010). Two thirds of all people living with the AIDS virus live in sub-Saharan Africa although this region contains little more than 10% of the world's population (UNAIDS, 2008). Large variations exist between the patterns of the spread of HIV in different African countries and within

different regions within those countries. In some countries, HIV prevalence is still growing as in South Africa while in countries such as Zimbabwe the HIV prevalence trend appears to have stabilized. UNAIDS (2010) reported that, between 2001 and 2009, the incidence of HIV in thirty-three countries had decreased by 25 percent. Twenty-two of these countries are in sub-Saharan Africa. However, there are regions in Eastern Europe and central Asia where the HIV incidence has increased by more than 25 percent in the same time interval. The significant reductions in mortality rates equates to an increase in the number of people living with HIV worldwide. The combined effects of stigma and discrimination, lack of access to services plus punitive laws may have a profound influence, making the pandemic worse (UNAIDS, 2010). Those who live with the chronic disease are far more susceptible than others to secondary diseases, opportunistic infections such as tuberculosis, and require careful attention from health care providers. It is no surprise that the HIV/AIDS pandemic continues to be the most serious of infectious disease challenges to public health (UNAIDS, 2010; UNAIDS/WHO, 2007).

More than 5 million people are now receiving HIV treatment. In 2009, 1.2 million people received HIV antiretroviral therapy for the first time – an increase of 30% in the number of people receiving treatment in a single year. However, 10 million people who are living with HIV who are eligible for treatment are still in need (UNAIDS, 2010).

### **HIV/AIDS in Kenya**

Kenya is home to one of the world's harshest HIV/AIDS epidemics in sub-Saharan Africa although the HIV incidence has fallen by more than 25 percent, while the HIV incidence has stabilized or shown signs of decline (UNAIDS, 2010). In Kenya, the

HIV/AIDS epidemic was not declared a national emergency until 2001, by which time 140,000 people had died from complications caused by HIV (UNAIDS, 2004). However, UNAIDS (2010) reported that AIDS-related deaths in Kenya decreased by 29 percent between 2002 and 2007 and within the African context, Kenya was recognized as showing success in the fight against the disease. In 2006, Kenya was hailed for reducing the prevalence of the spread of HIV due to government prevention efforts (UNAIDS/WHO, 2007). Yet, in 2008, an estimated 250,000 HIV-infected people across the country in need of antiretroviral drugs had not received treatment (Human Rights Watch, 2009).

In 2010, Kenya's population was estimated to be 39 million with a life expectancy of 58 years (UNGASS, 2010). Two years earlier, Kenya AIDS Watch Institute (KAWI) (2008) released a report that announced that approximately 2.5 million people, 15 percent of Kenya's adult population, were living with HIV, and reported that 700 Kenyans died of HIV/AIDS related diseases every day. This reflects statistics released at the height of the pandemic in Kenya. In 2009, according to the Central Intelligence Agency, 80,000 Kenyan adults and children died of AIDS. Approximately 75 percent of the country's population live in rural areas where the absolute number of people living with HIV is higher (one million adults) than in urban settings (0.4 million adults). However, HIV prevalence is higher in urban areas, 8.4 percent, than in rural areas, 6.7 percent (UNGASS, 2010). It was estimated that the HIV/AIDS prevalence rate in Kibera was 14 percent, which is almost double the national prevalence rate. The high risk environment for HIV/AIDS in Kibera is attributed to factors which include poverty, unemployment, substance abuse, a high frequency of women being involved in the commercial sex trade,

lack of access to essential services such as health services, and the result of gender-based violence (Amnesty International, 2010; Gullis, 2004).

Studies have determined that HIV prevalence is higher among certain groups and differs according to location, gender, and age. “Most at risk” groups include sex workers, injecting drug users, men who have sex with men, truck drivers, and cross-border mobile populations (UNGASS, 2008). As some of these groups are marginalized within Kenyan society, they are difficult to reach and so the extent to which the virus is affecting them has not been fully researched and is unknown. For example, homosexuality is illegal in Kenya and is punishable by up to fourteen years in prison, so few homosexuals are willing to stand up for the count as it is too dangerous. In 2008, there was an estimated 33 percent increase of new HIV infections within the five key affected groups (UNGASS, 2010).

It was most likely pressure from the WHO community that convinced Kenya’s President Kibaki in June, 2006 to announce the availability of free ARVs to HIV+ adults; a step in the right direction, but much more was needed. BBC correspondents noted that fees were only one reason why only 60,000 of 200,000 eligible Kenyans were taking ARVs (BBC, 2006). The high levels of poverty in Kenya and frequent food shortages mean that many living as HIV+ individuals are unable to eat a healthy, balanced diet (IRIN, 2009). UNGASS (2010) reported, “Evidence shows that malnourished people are less likely to benefit from antiretroviral treatment and are at a higher risk of quicker progression to AIDS. In addition, taking treatment without food can be very painful” (p. 6). Many of those infected with HIV receiving antiretroviral therapy start treatment late which limits the overall impact of HIV treatment programs (UNAIDS, 2010). Marston &

De Cook (2004) pointed out the irony in providing antiretroviral drugs to populations that lack access to safe water or food that is not captured in the language of treatment advocacy. Global warming exacerbates a food crisis particularly in northern Kenya and this becomes a hunger crisis that may hamper the effectiveness of ARV programmes (UN, 2010). Obtaining a regular supply of nutritious and healthy food for poor HIV+ people is often difficult and, as Kako (2008) in a study exploring health needs of HIV-infected women in Kenya pointed out, “The question of inadequate food among HIV-infected persons has been consistently identified as a major problem among HIV-infected persons in sub-Saharan Africa” (p. 192).

Poverty presents an enormous challenge to HIV+ individuals who require continual, regulated medication and a healthy, balanced diet to prevent them from dying. In 2008, Unge, Johansson, Zachariah, Some, Van Engelgem, & Ekstrom conducted research in Kibera examining issues related to non-compliance and unsatisfactory antiretroviral treatment. The findings revealed that many diagnosed HIV+ people lacked necessary health literacy skills, and the power to overcome the existing barrier of poverty, and were too poor to buy the necessary food for a balanced diet. Reporting that their findings were instrumental in guiding a number of urgent policy related changes within the Kibera ART (Anti-retroviral Treatment) programmes, they stated that all ART eligible individuals are now offered nutritional supplementation providing a ready-to-use food.

### **Pre-requisites of health**

The HIV+ women in this study live in a slum environment that is not conducive to a state of good health. Unge et al. (2008) wrote that “Poverty dominates people’s lives

in urban slums regardless of HIV status” (p. 147). For those who live with HIV, poverty presents an even greater challenge in keeping themselves and their children alive and well. Participants in this study live in a congested urban area and Davis (2006) wrote that they live “in supercrowded Kibera in Nairobi, where more than 800,000 people struggle for dignity amidst mud and sewage” (p. 94). Bodewes (2005) noted that “the normal measure for adequate space in refugee camps is about two or three times greater than the current density in most of Kibera” (p. 57). There is no accurate census data available as the estimation of the population living in Kibera varies according to different sources and there are no known statistics that break down gender differences. Nevertheless, according to Nguu (1995), the majority of research findings estimated that between 600,000 and 700,000 people lived in Kibera. This number has increased to approximately one million (Amnesty International, 2010). Bodewes (2005) draws attention to the difficulty of accurate statistical data collection as Kibera’s night population or the number of people sleeping there at night is significantly higher than the daytime population. The numbers who sleep there may also vary considerably from night to night as friends, relatives who have no permanent home in the slum, may spend the night and add to the variables when thinking in terms of a reliable count.

Living in a slum exposes women and their children to many diseases because of a lack of infrastructure and basic amenities. The more densely settled an area, the more acute challenges of waste disposal and sanitation become. Women are exposed daily to squalid conditions that infringe on health and hygiene standards because of the lack of clean drinking water, poor sanitation, drainage, and rubbish collection (Bodewes, 2005; Davis, 2006; Cairncross, Hardoy, & Satterthwaite, 1990; Black, 1994, 1996). These

challenges are compounded in narrow alleys, bustling backstreets where congestion and the lack of facilities is not only a serious public nuisance but is also a health hazard (Smith, 1996). Linking clean water and proper sanitation to health, Davis (2006) noted the lack of both in Kibera and the difficulty this presents for women especially who struggle to provide for their families. He wrote, “Although clean water is the cheapest and single most important medicine in the world, public provision of water, like free toilets, often competes with powerful private interests” (p. 144). Slum residents unable or unwilling to pay high prices for water which costs more whenever there is a drought that results in a national shortage sometimes resort to “the use of sewerage water, skipping bathing and washing, using borehole water and rainwater, and drawing water from broken pipes and risk sickness from water-born diseases” (Amuyunzu-Nyamongo & Taffa, 2004, p. 7). The high price of water drains family resources, and in Kibera malnutrition is often a compounding factor which increases physical vulnerability to infections, diseases, and general poor states of health (Black, 1996, 1990). The efforts of slum residents to practice protective hygiene are thwarted at every turn by the ubiquitous contamination of drinking water and food by sewage and waste defeats. In recent years, Kibera has been ravaged by cholera and other excrement-associated diseases, and diarrhea associated with HIV/AIDS is a grim addition to the problem (Davis, 2006).

It is graphically evident that social determinants for good health are sadly lacking in Kibera. Every day, mothers such as the women in this study strive to maintain a standard of living that supports their health and keeps them and their children safe, alive, and free from sickness and disease which requires an incredible amount of ingenuity,

resilience, and resourcefulness. The determinants of health are further confounded by a basic lack of access to and knowledge of health.

### **Health literacy**

The term “health literacy” is a relatively new concept referring to the ability of individuals to obtain, understand, and, more importantly, to use health information in positive ways (Rootman et al., 2007). If the HIV+ women in this study are unable to understand their physicians’ directions regarding their antiretroviral treatment, they may face an early death because of the progression of the HIV infection. Literacy and health literacy are closely connected, related directly and indirectly to health outcomes (De Walt, Berkman, Sheridan, Lohr, & Pigrone, 2004). The findings of health literacy studies conducted with female immigrant populations in Canada suggest that women have lower health literacy because of their lower reading and comprehension scores (Simich, 2009). Health literacy is important because women play a central role in caring for their families and other social networks. It is essential that mothers read and comprehend instructions for administration of medicines for their children (Rootman & Gordon, 2008). The medical condition of the HIV+ women in this study requires numerous visits to medical practitioners and it is vital that the correct procedure for the intake of prescribed medications is correctly understood.

Health literacy is a multidisciplinary field in which relatively little research has been done, especially on diverse groups such as HIV+ Kenyan women who live in Kibera (Simich, 2009). Dunn and Dyck (2000) have determined that health literacy is a vital social determinant of individual and population health as it interacts with other factors such as poverty, education, and social networks and thereby contributes to differential

social outcomes and health disparities. For optimum results of health care, it is crucial that those who require medication or medical services receive treatment in a language they can read and comprehend completely the full scope of the prescriptive medicine or directions. If HIV+ individuals do not fully understand the importance of taking their ARV drugs every day, they will die.

### **Gender and the feminization of HIV/AIDS**

As this study explores the lives of women who are infected with HIV, I will present a brief overview of HIV/AIDS.

#### **Brief overview of HIV/AIDS**

The first wave of the HIV/AIDS pandemic focused on identification of the virus which causes AIDS, modes of transmission and defined those “at risk” as men who have sex with men, sex workers and drug users. During the second wave, HIV was recognized as a serious threat to most sexually active women, including those who were monogamous (UNAIDS et al., 2004). Gender became a central issue in the third and fourth waves in which the significance of gendered systemic social structures were recognized, and acknowledged publicly by health professionals (Bova, 2000; Klot & Nguyen, 2009). At the same time, the spread of HIV/AIDS and the effect of HIV on children became of universal concern. The numbers of reported cases of mother to child transmissions increased and the number of children who became orphans or were known as vulnerable children due to the sickness or death of one or both parents increased at an alarming rate. Social determinants to health, women’s rights, and human rights became identified as crucial to understanding the spread of the disease and broadened the scope of professionals in the fight against the spread of the virus (Gruskin & Tarantola, 2000,

2001, 2002, 2005; Mann & Tarantola, 1996; Tallis, 2002; Tarantola, 2006; UNAIDS, 2004).

Societal traditions that favor male dominance have resulted in the low status of women; male-centered assumptions about women, long standing patterns of sexism, racism, and other symptoms of oppression affect the health of women and their health care in different ways from their effects on men's health and health care (Sen, Ostlin, & Asha 2007; Torpy, 2003). Women's vulnerability to HIV infection in sub-Saharan Africa stems not only from their greater psychological susceptibility to heterosexual transmission, but also from the severe social, legal, and economic disadvantages they often confront (UNAIDS 2009).

Women and girls are particularly vulnerable to HIV and are disproportionately affected by the virus. According to UNGASS (2010), in 2008/9 women had an HIV prevalence rate of 8%, while for men it was 4.3%. This disparity is even greater for young women between the ages of 15 and 24 years who are four times more likely to become infected with HIV than men of the same age. In Kenya, a possible contributing factor to the higher incidence of HIV infection among women is the high rate of violent sexual contact reported by women. In 2003, a nationwide survey showed that almost half of the women who participated had experienced violence, and one in four women between the ages of 12 and 24 had been raped, and lost their virginity by force (UNGASS, 2008). In 2008, UNAIDS/WHO documented the high estimate of Kenyan women living with the virus to be 1.1 million.

To better understand the feminization of HIV/AIDS, it is beneficial to provide an historical examination of gender on the African continent.

## Gender

Much has been written about the androcentricity of gender stratification, male dominance and female subordination, yet it must be remembered that “Gender is a social, not a biological, construction: that is, it is the result of social definition rather than the fact that females have two X chromosomes while males have an X and Y chromosome” (O’Kelly & Carney, 1986, p. 3). Socially constructed roles, relationships, behaviors, characteristics and relative power between the sexes are considered in gender discourse (Donner, 2003). In this study, the use of the term *gender* refers specifically to the social order rather than the biological component of what it means to be a male and a female. The patriarchal nature of gender relations in many global societies including Kenyan has systematically produced the subordination and inequality of women (Ertürk, 2004).

Colonization in Africa imposed foreign social structures and disrupted well established gender relations that caused cultural and social fragmentation within Indigenous contexts (Kovach, 2009). Prior to colonization, African societies were intent on production and reproduction and had, according to Kako (2008), “generally developed self-reliant social systems ensuring the physical, emotional, and spiritual well-being of the population” (p. 39). Patriarchal systems of governance initiated in the colonial era separated both women and men from traditional social structures that defined roles and responsibilities. Both men and women became disconnected from traditional ways of being that respected the contribution of both genders and women particularly struggled, and still do, to maintain a position that is equal to that of men in social, economic and private spheres (Valaskakis, Stout, & Guimond, 2009).

During colonization, British colonists purposefully singled out wealthy men from their tribal communities and set them up and apart as leaders although village elders

already existed. Men were preferred over women by the colonizers (Elkins, 2005; Shaw, 1995). Kako (2008) wrote that, prior to European and Islamic impositions, “traditional African cultural principles and social status allowed women to participate publicly in society” (p. 40). Historically, in certain African societies, women once held positions of importance in their villages and had a public voice, yet the colonization process silenced them and took away their power. Kako draws attention to Obbo’s (1995) hypothesis that colonization is to blame for reducing women’s solidarity and networking, and making married women more dependent on their husbands. Gender hierarchy and subordination of women that was already evident in some African cultures became more so during the sixty-year colonial rule before Independence and continued afterwards (Mikell, 1997).

Mikell (1997) identified four main categories to explain why African women were demoted in social position as a consequence of colonial and Islamic influences.

They are,

- Christian religion, which valued monogamy for women, and female domesticity and subordination.
- Westernized education, which gave men advantages over women.
- Differential marriage systems, which prioritized western versus traditional marriage.
- Alternative legal systems with colonial magistrates occasionally treating woman as minors needing male guardians (Mikell, 1997, p. 17).

Individualism followed in the wake of colonial patriarchy and challenged the communalism deep within African traditions (Mikell, 1997). The socially constructed hierarchy in gender roles is still very much in evidence today in relationships of politics, economics and culture (Kako, 2008).

It is within these contexts of individualism and gendered hierarchy that the social status of many women became lowered and they became vulnerable to the affects and

effects of patriarchal systems of governance. A toxic mix of culture, religion, and economics often leaves women unable to do anything about the risk of becoming infected with HIV. Women's economic dependence on men and society's acceptance of different standards of sexual behavior for men and women make it difficult for many women to negotiate safer sex with male partners (Tallis, 2002).

It is the custom in Kenya for "women to display sexual passivity, and to defer to the sexual pleasure of men. Women lack control of their sexuality" (Kako, 2008, p. 24). Married Kenyan women are not taught to negotiate or abstain from sex, and to do so demands not only a behavioral change. A cultural change in perspective is also required (Kako, 2008; Tallis, 2002). Women who refuse sex to their husbands may put themselves in danger and risk being physically abused. Kako contends that factors which will influence this behavior change as well as change in the cultural perspective are still elusive in sub-Saharan Africa.

Three major factors that contribute to the vulnerability of women and girls were identified in 2004 by a joint report of UNAIDS, UNFPA and UNIFEM when addressing the spread of HIV infection. They are,

- The culture of silence; many women are not encouraged to speak up and have no voice in the decision-making procedures that affect societies and the communities in which they live.
- Exploitive transactional and intergenerational sex; women and girls are expected to comply with the wishes of men in sexual matters. It has been a traditional practice in some African communities that, when a husband dies, the wife is "passed on" to one of her husband's brothers.
- Violence against women within relationships – many women and girls experience violence at the hands of men within and outside of marriage.

Kako (2008) concurs with Akinsola & Popovich (2002), and UNAIDS, UNFPA, and UNIFEM (2004) that "Understanding these factors in the context of poverty and

inequality is crucial to accurately discerning issues surrounding women and HIV/AIDS in Kenya” (p. 28).

Biologically women are more vulnerable and more at risk than men when it comes to the transmission of HIV infection during each act of heterosexual intercourse because their bodies are different. Women have greater areas of mucosal cells to which the virus attaches itself and their genital tissue is more likely to tear during sex making them far more susceptible to virus transmission (Tallis, 2002). However, Tallis cautions against thinking only in terms of the vulnerability of women as it may serve to further entrench a misguided notion that women are not capable of agency in any aspect of their lives. Vulnerable and vulnerability are terms that have been contested by some as they promote an image of powerlessness and a victim mentality. Mann and Tarantola (1996) define vulnerability as the opposite of empowerment and Tallis (2002) does concur that it is possible for women to be vulnerable in certain aspects of their lives and not others.

### **Stigma**

HIV/AIDS stigma is a global phenomenon; “most chronic illnesses carry a stigma” (Scandlyn, 2000, p. 132). Stigma is an attribute that causes a person to deviate from the expectations of normal behavior or appearance determined by a particular society and deviant people are viewed as somehow being responsible for their abnormality (Goffman, 1986; Sontag, 1989). It has been suggested that discriminatory acts generated by stigma have ancient roots buried deeply in the cornucopia of cultures and that discriminatory actions against HIV+ women are generated by power inequities and gender differentials (Tarantola, 2006; WHO, 2008). Unge et al. (2008) reported that HIV+ related stigma against women is high in Kibera and “Despite occasional awareness

campaigns, knowledge about HIV is still rudimentary” (p. 148). Those infected with HIV may not seek medical support until the need for antiretroviral treatment is urgent. Many are then referred by doctors and social workers to support groups where they benefit from education about the AIDS virus and learn skills to cope with stigma. Stigma is integrally related to knowledge (Forsyth, Vandormael, Kenshaw, & Grobbelaar, 2008; Odimegwu, 2002/2003; van Brakel, 2005), and understanding why many poor women are not exposed to HIV/AIDS information or act on the relevant knowledge is complex with more research required in this area.

HIV/AIDS is a disease that was not heard of in Africa before colonization and the impact of urbanization that introduced Western ways of thinking and a mix of missionary religious fervor to the continent (Powers, 2002). This is not to imply that HIV/AIDS was brought to Africa by colonization; it was not heard of anywhere in the world before the 1970s. In Kenya, HIV infection is most commonly transferred through sexual contact, and those who admit to being HIV+ (even though they contracted it from their husbands) are very often seen by others and maybe themselves to be admitting to sin or violation of community mores (Nolan, 2008; UNAIDS, 2004).

Link and Phelan (2001) isolated four components of stigma which are shaped by invisible forces of economic and political power. These four components are,

- Distinguishing and labeling difference
- Association of human difference with negative attitudes
- The separation of “us” and “them”
- The loss of status and discrimination.

Accordingly, stigma becomes a process and impacts in overt and inverted ways on the lives of HIV+ women (Holzemer et al., 2007). The stigmatization of individuals among collective groups allows people to delude themselves into thinking that it happens

to “them”, not me (Holzemer et al., 2007; Mill, Edwards, Jackson, Maclean & Chaw-Kant, 2010; Nolan, 2008).

Women experience stigma far more than men and there has been a general male denial of responsibility in the spread of HIV (Amnesty International, 2010). Therefore, it is generally women who become the targets for blame and shame within the context in which they live. Stigma is associated with shame. Nolan (2008) wrote, “Stigma is one of the most used words in the AIDS pandemic, a two-syllable shorthand for the shame and fear that cling to this disease” (p. 132). Historically, there has been remarkable abhorrence of diseases such as leprosy and the plague where the sick are seen to be responsible for their own misfortune. A particular shame is invoked when a disease is thought to be transmitted by sex, such as HIV/AIDS (Nolan, 2008; Sontag, 1989). And, for those not well-informed, HIV/AIDS is one such disease whereby the infected person is often held responsible for their own demise.

Within some African societies is the belief that a certain act on the part of one individual or individuals can cause others to experience shame on various levels. Traditionally, most ethnic Africans have lived in various sized groupings located in the diversity of rural environments. Simply put, individual behaviors were shaped by the collective need for the survival of a group. If any behavior on the part of an individual was deemed to threaten group cohesion, that individual was dealt with in accordance with local tribal customs and practices. Only rarely, as in the case of murder, would an individual be ostracized or banished from the community (personal communication: Francis Adu-Febiri, October 25, 2010).

The stigma of living with HIV/AIDS may become internalized. Those who engage in “self-stigmatization” are generally more connected to their traditional roots and removed from western influence (Alavi, 2010; Holzemer et al., 2007; Mill et al., 2010; Unge et al., 2008). More in-depth research is required in this area. Women may fear community ostracization or overt shows of discrimination once their HIV+ status becomes public knowledge, so open discussion is often silenced. This may result in possible delays of effective medical responses for those who fear disclosure of their HIV+ status. The burden of living with the disease becomes heavier for infected individuals who keep their secret and who become sicker and sicker until it is often too late to begin ARV treatment to prevent death (WHO, 2008).

The impact of stigma and discrimination on marginalized and Indigenous populations further contributes to the lack of access to services particularly for women. This is especially true for women in African countries where medical services are not as proliferate as in western countries (WHO, 2008). Discrimination and stigma, a powerful combination, continue to influence the degrees to which women will keep secret or speak openly about their HIV+ status. The factors that affect women speaking out openly about their HIV+ status are complex, and include:

- The living environment context.
- Gender relations.
- Personal knowledge regarding HIV.
- Fear of reprisals because of discrimination caused by stigma (WHO, 2008).

I have surveyed the field of stigma; what is not acknowledged is a possible connection between stigma and the embodiment of intergenerational traumas that are invisible, yet exist (Duran, 2006). Much has been written in the last decade about post

traumatic stress syndrome (PSTS) and in the last ten years there has been a notable increase in scholarly Indigenous writing about embodied intergenerational trauma linked to shock wave residue caused by colonization. Intergenerational trauma is understood as unresolved trauma that is transmitted across generations (Cane, 2005; Caruth, 1995; Duran, 2006, Duran & Duran, 1995; Levine & Frederick, 1999; Staub & Pearlman, cited in Brahm, 2004). Holocaust literature bears out this notion: second-generation survivors have been raised by traumatized parents. In Canada, Indigenous residential school survivors provide another example of individuals who cope with intergenerational traumas.

While individual trauma is thought of in terms of a blow to the psych that breaks through one's defenses, intergenerational or "collective trauma is a blow to the basic tissues of social life that damages the bonds attaching people together and impairs the prevailing sense of communality" (Eyaa-keen, 2005). Rupert Sheldrake (1988) hypothesized the presence of the past in the DNA makeup of the human body. Underlying this hypothesis of past actions stored in a human body, particularly in memory is the notion that intergenerational trauma crosses collective boundaries as each new generation moves forward in time. This may particularly impact Indigenous Peoples who live with a stronger sense of communality than westerners, thus the link between intergenerational trauma and stigma may be more pronounced for Indigenous peoples than for westerners. Cane (2005) argues that stigma like trauma "is never [only] an abstraction, but shows itself in human faces and individual histories" (p. 3).

### **Colonization and its influence**

The women in this study live in the post-colonial context of Kibera that has shaped and continues to shape their identity. A colonial overview of Africa serves to provide the reader with an understanding of the country in which the women live while providing glimpses into the historical background that affects their present lives. The women live in Kenya, an African country which became a British protectorate in 1895 and a colony in 1920. On December 12, 1963, the country became Jamhuri ya Kenya [the Republic of Kenya], independent from British rule. Kenya is now recognized internationally as a developing country where mercy, “affirmative action”, and pity reign, not equality (Aukot, 2008).

Prior to the nineteenth century the rest of the world knew little about the African continent. In 1884–1885 European effort to colonize Africa reached its zenith; to avoid a war over conflicting claims, the British, French, Dutch, German and Portuguese attended the Berlin Conference which became known as “The Scramble”. During the course of the Conference these foreign government representatives debated and formulated the ground rules for colonizing the whole of Africa. By 1915, with the exception of Ethiopia, all of Africa was divided into countries which became European colonies (Nosotro, 2004).

Colonization on the African continent may be viewed as a tsunami yet there have always been waves and rogue waves of cultural importance that have changed the course of history. However, a binary notion that colonization was entirely bad or entirely good oversimplifies the situation. If colonization is looked at as a European “invasion” it gives a distorted view of Africa’s history. All cultures have positive and negative practices, histories and attitudes. Africa has its own history of violence, slavery, misogyny,

patriarchy, and internal racial/tribal conflicts that pre-date European conflict and has been plundered in the past by other cultures (Fanon, 1965; Gandhi, 1998).

Colonization did little to develop countries in Africa and exploited natural mineral resources to support industries on fronts without reciprocating in the area of development (Nosotro, 2004). During the last seven centuries the influence of European, Arab, and, to a lesser extent, Asian origins, has consciously or unconsciously been absorbed by the greater part of Africa (Konadu, 2007). There is a repeat performance of colonization taking place presently in the twenty-first century. The new scramble is not for the redefining of borders but for the continent's medicinal plants, oil, diamonds, timber, gold, ivory, natural gas, and other natural resources (Kaure, 2008). In the past, there have been commercial invasions from India and now the United States and China are expressing interest in Indigenous knowledge related to the healing properties and cultivation of medicinal plants. China is especially interested in the mineral resources buried deep in African soil (Behar, 2008; Fanon, 1965; Gandhi, 1998; Karombo, 2011; Konadu, 2007).

In international circles, a host of multi- and transnational corporations, easterners, westerners, and elite African politicians often swayed by western values of self-interest, sit in boardrooms and make decisions that ultimately affect every person in the society, whether it is in a macro context or a micro context such as Kibera (Kaure, 2008). Decisions made at the top levels of government trickle down to the community and determine to a large extent the quality of ordinary lives for such individuals as the women in this study. Money allocated for the distribution of free antiretroviral drugs and programs to support those infected and living with the chronic disease of HIV/AIDS invariably drain resources essential to the country's broader health and other systems of

governance. This is to suggest that, in wake of HIV/AIDS pandemics, governments may be required to “re-organize” the allotment of expenditures while acknowledging that monies spent on ARVs and HIV/AIDS programs is money well spent.

The influence of colonization is often reflected in a state’s economic, socio-political, ideological, and religious systems that are in place in countries which traditionally had alternative ways of organizing and socializing diverse Indigenous peoples. Since Independence, the present education and government system in Kenya emulate the British system. Many who now hold political positions of power in African countries have internalized colonial ways of thinking and have developed a colonial mentality in the governance of a country and its people (Fanon, 1967). Much has been written and continues to be written to re-right (pun intended) the affects and effects of particularly the Eurocentric attempts to dominate and oppress Indigenous peoples (Battiste, 2000; Battiste & Henderson, 2000; Fanon, 1965; Gandhi, 1998; Said, 1991, 1993).

### **Past meta-narratives of the colonizers**

It is important to keep in mind the values and belief systems that colonizers brought with them to the countries on which they landed. The worldviews of the colonizers differed greatly from the worldviews of African peoples. Past meta-narratives of colonization were predominantly based in an ethnocentric belief that the morals and values of the colonizer were superior to those of the colonized. This blindness in perspective is linked to racism and pseudo scientific theories dating back to the eighteenth and nineteenth centuries (Fanon, 1965, 1967). In a consciousness that was decidedly western, this line of thinking led to a proto-social Darwinism that placed white

people at the top of the animal kingdom; Fanon is one who argued against the premise that white races came by their “positional superiority” naturally. The early white colonizers arrived on foreign lands with a sense of their own self importance and used this western cultural misnomer in much the same way as raw materials and military might to strengthen and legitimate imperialism (Smith, 1999).

During colonization, Indigenous knowledge and many Indigenous ways of knowing were disrespected, prohibited, silenced, and replaced by ways foreign to people who connected strongly with the land, cosmology, and ancestors who had gone before.

Religion was often used to further dominance of colonial views; religious dogma slowly, yet determinedly, dismantled and pushed underground traditional beliefs and values embedded in the diversity of African cultures (Achebe, 1958; Amadiume, 1997; Antsen, 1997; Bourdillion, 1990; Gellar, 2006). Culture is only one dimension of people’s experiences (Anderson & Reimer-Kirkham, 1998), and according to Johnson, Bottoff, Brown, Grewel, Hilton, and Clark (2004) represents more than the beliefs, practices and values of particular groups. Cultures are inextricably tied to power differentials and social inequalities located within the constantly shifting “network of meanings enmeshed within historical, social, economic and political processes” (Anderson & Reimer-Kirkham, 1998, p. 63).

Many sub-plots exist within a colonial grand narrative. Fanon (1967) argued against an oversimplification of colonialism by the use of binaries – the colonizer versus the colonizer. He maintained that colonization is best understood as a network of complexities and internal power imbalances nested within the broader categories of colonizer and colonized. He suggested that any expectation of genuine separation on a

collective level from colonial subjugation via a national consciousness would always be thwarted by Nationalist leaders who often mimicked and replicated the systems of coercion and domination that shaped colonial rule.

### **Separating land and people**

Before European strangers came to their land and the process of colonization began, African peoples had lived freely on the land. The colonizers claimed the land as their own. Colonial rule imposed unfamiliar divisions among ethnic groupings and initiated identification of these groups as ethnic, paving the way for national mistrust (Elkins, 2005). Relationships with Kenyan ethnic groups created in the process of past colonization continue to shape post-colonial relationships in the present. The post-election violence in Kenya towards the end of 2007 and the beginning of 2008 demonstrated deep tribal divisions that stem for the most part from past colonial practices such as claiming land for the British Empire. The 2007–2008 post-election riots in Kenya received much media attention and many argued that the violence was driven by tribal separations and affiliations. Oloo (2008) argued that, contrary to mainstream clichés, Kenyan politics has not always been dominated by the driving force of ethnicity. He claims that, because national patriotic formations were considered a grave threat to the colonial status quo, former British colonial governments were intent on strengthening tribal identities as a way to thwart the growth of a collective national consciousness. The 2007–2008 post-election violence was extreme in Kibera. Inter-tribal clashes resulted in terrible human atrocities, destruction of property and massive internal displacement of people. Chikwanha (2008), a senior research fellow in Nairobi with the African Human Security initiative of the Institute for Security Studies, argues that Kenyan political

parties have often used violence as a means to leverage their interests and push forward their agenda and this has occurred in every election since 1992. She is of the opinion that the violence observed during and after the election was forced violent behavior and not necessarily behavior that was chosen; those who commit acts of violence may be paid or rewarded for their actions by those in political positions of power.

### **A genealogy of Kibera**

The women in this study have their homes in Kibera, the largest of Nairobi's slums. Understanding the political backdrop of Kibera is essential to understanding how the physical environment has been determined by outside government forces and those in positions of power. Kibera is an unauthorized settlement that first emerged due to the displacement of Africans by the arrival of British settlers and remains as a colonial legacy (Bodewes, 2005; Ferraro, 1978/9). In the late 1880s, British colonists settled in an area once frequented by the pastoral Maasai people of Kenya. This region became known as Nairobi, and was initially a colonial railroad camp on the Mombassa-to-Uganda railroad. The British government controlled who came to live in Nairobi and the growing metropolis was reserved for the white settler colonial population; Africans were not permitted to enter the city without a permit. The Africans, mostly men who were formally employed as menial workers, were issued semi-permanent housing that met only the most basic of living requirement. Living in a separate enclave, these African natives were viewed as temporary residents in the urban areas (Achola, 2002; Macharia, 1992).

In 1897, Nubians, Sudanese soldiers from central Sudan, were enlisted by the British government to suppress rebellious uprisings against British rule in Somalia and became known as the King's African Rifles (KAR). In World War 1, the KAR fought

alongside the British against the Germans in Tanzania and as a reward were encouraged to settle with their families in a forested area close to Nairobi. Six years later, the British officially surveyed the area and publicly designated it as a military reserve. The area became known as Kibera which comes from the Nubi language word *kibra* meaning green forest. Nubian families were allowed to settle there, rent free, in recognition of services rendered to the British colonial cause, as a form of an unofficial pension. However, the residential permits were considered temporary and given only to soldiers who had served for at least twelve years (de Smedt, 2009a; Parsons, 1997; Wangui & Darkoh, 1992).

#### **Administrative change and land disputes**

In 1929 the British army handed over administration of Kibera to the Nairobi Municipal Council at which time all existing permits were cancelled; those living in Kibera at the time had to prove their Nubian connection. If successful, they became Tenants of the Crown and remained in Kibera on the understanding that tenancy could be terminated any time by the Commissioner of Lands. The knowledge that the government retained the right to demolish any structure at any time and use the land for their own purposes influenced the type of housing and other constructions that the Nubians built. Temporary buildings were constructed of mud and wattle which were relatively cheap, easy and quick to erect and, therefore, quick to pull down (de Smedt, 2009a; Parsons, 1997; Schwarts-Barcotte, 2001).

Since colonization those who have established themselves and made their homes in Kibera have always been concerned with issues of land ownership and since 1992 there has been continuous effort on their part to secure legal title of the land. The Carter

Commission of 1932, a Kenyan Land Commission, was initiated to manage the numerous land disputes during the colonial period and included the dispute concerning Nubian land entitlement in Kibera. The hidden agenda of the Kenyan government to evict all Nubians was prohibited by the Commission, yet the Nubians who had settled in Kibera were denied legal entitlement. No immediate public or political action was generated by the Commission's decision due to the premise that the Nubians would all eventually die and leave Kibera vacant once more. This premise was unfounded and perhaps somewhat naïve as the Carter Land Commission survey found that half of Kibera's residents at the time were women and two-thirds were Kenyan-born Africans (Parson, 1997).

There was a migratory flow into Kibera during the 1930s and 1940s although the colonial government continued to recognize Kibera only as a temporary settlement. Consequently, there was no effort on their part to develop or provide basic infrastructures of any kind to the area and, in fact, quite the opposite occurred. The administration, Parsons (1997) noted, "began a policy that can only be considered malicious neglect in an attempt to force the Sudanese out by rendering Kibera unlivable" (p. 103). Government orders were issued to prevent the setting up of permanent services that affected public health and hygiene such as clean water, electricity, a regular garbage collection, schools, and health facilities. However, this did not deter the influx of tribal peoples from further relocation into the slum which was fast gaining the reputation of being the cheapest Nairobi settlement in which to live (Bodewes, 2005). The Mau Mau rebellion of 1952–1958, Kenya's State of Emergency, witnessed large numbers of Kikuyus leaving Nairobi by force or by choice to be replaced by new migrants, including many from western Kenya who settled in Kibera while the government did virtually nothing to impede the

expansion of the area (Clark, 1979; Ekdale, 2011; Etherton, 1971; Wangui & Darkoh, 1992).

### **Thwarted attempts to develop Kibera**

In the mid-1950s the government came up with a new plan for development in Kibera. According to Schwartz-Barcotte (2001), the plan was to “transform Kibera from a ‘Sudanese Ghetto’ into a planned settlement open to all” (p. 49). The boundaries of Nairobi were expanded to include Kibera and procedures were put into place to demolish and replace semi-permanent structures that met City Council standards. In 1969 Kibera was acknowledged as government owned land which meant that no one person or ethnic group had any legal claim on or to the land. During the 1960s and 1970s, the Kenyan government began a concerted effort to “take back” and reclaim land in the settlement. They began a process to replace certain housing structures in the small ethnic villages that had sprung up in different sections of Kibera with government-owned, middle-class housing estates. However, the overall development plan was never realized because of corruption (Amis, 1984; Bodewes, 2005; de Smedt, 2009a; Hardoy & Satterthwaite, 1989).

Kinia Kamau was appointed Chief of Kibera by Nairobi City Council in 1974. According to Schwartz-Barcotte (2001), he “single handedly ruined the National Housing Corporation policy of resettlement by allowing immigrants to settle and build temporary housing in Kibera” (p. 531). By many accounts, bribes and kickbacks were taken from those who wanted to build structures, whether for their own interest or to rent out for personal gain, and little was provided in the way of resistance by Nairobi City Council. The numbers living in Kibera continued to rise dramatically and the 110 hectares that had

been under-populated became completely filled with semi-permanent structures (Bodewes, 2005; de Kruijff & Chana, 1980; Muwonge, 1980; Obudho & Aduwo, 1989).

In 1969, the Kenyan Parliament agreed unanimously that the Nubians in Kibera were to have legal title to the land on which they lived, yet this agreement was never ratified. Parliament has not endorsed legal ownership of land on the part of Nubians or any other ethnic group and to this day Nubians continue to lobby for land titles that are legal. The belief that the land rightfully belongs to them because their ancestors earned it by fighting for the British is still cause for tribal disputes which erupt when different ethnic groups compete for a place to live or to set up a place of business.

Many different groups of African peoples make their home today in Kibera. Although the slum is referred to most often in general terms there are at least 13 villages inside the settlement. Each village has its own unique ambiance and it is the majority ethnic group living there that is the key factor in characterizing village life (Lugano & Ngubdo, 2001).

To understand the present, we need to look to the past. The enormous impact of colonization on the lives of African Peoples and their land in times gone by is still reflected in their lives today. Africans, more so than westerners, are connected symbiotically to the relationship of people with their surrounding social and natural environment. When environments change, individuals and whole communities must adapt or become extinct (Bourdillion, 1993). Many Africans are struggling desperately in the aftermath of colonization and face everyday coping with living a life in poverty.

The global HIV/AIDS crisis too has had a devastating effect on the lives of those who become infected with HIV, especially women in the sub-Saharan countries of

Africa; Kenya is one such country. Their struggle to stay alive and cope, caring for themselves and their children, is compounded by patriarchal systems that initiated and continues to foster inequalities between men and women while doing relatively little in the way of providing practical support. Supplying HIV+ poor women with free ARVs is not enough if the women are unable to meet basic needs such as safe drinking water and a balanced diet to remain healthy.

In the next chapter, Chapter 3: Methodologies and Research Methods, I discuss the methodologies and methods I used to collect, interpret and analyze data for my research study.

### **Chapter 3: Methodologies and Research Methods**

To understand the lives of HIV+ Kenyan women living in Kibera, and how they participate in community, and story their lives, I listened to them tell their own stories about their own experiences. It was important that I chose methodologies that would allow me to work collaboratively with the women while respectfully listening, in confidence record, and later report, my findings for a public audience. Acknowledging that stories relating to everyday life merge many aspects of living and cross many boundaries that separate human beings, I wanted to use a convergence of approaches within a post-colonial paradigm to inform my research. My study is fundamentally a narrative inquiry informed by feminist, Indigenous, and post-colonial perspectives. This methodology complements my de-colonizing purpose in a research approach by providing inclusive spaces for diverse perspectives when viewing and understanding the world. Riessman (2008) wrote that narrative “is cross-disciplinary, a many layered expression of human thought and imagination” (p. 13). The intersectionality of three methodologies enabled me to craft a methodological synthesis for the blending of the multiple perspectives of nine financially poor women with HIV living in Kibera (Kincheloe, 2001).

My inquiry is a naturalistic study. The goal of a naturalistic study is to understand behavior from the perspective of the participants in a natural setting and to understand the meanings people give to their experiences. Lincoln and Guba (1985) remind the reading audience that “the design of a naturalistic study ... cannot be given in advance; it must emerge, develop, unfold” (p. 225). Therefore, specific details about what I did and why it

was done are included in the latter part of this chapter (Kovach, 2009; Patton, 1991). Before I begin my unpacking of narrative, feminist, and Indigenous approaches and, given that story is the foundation of my research exploration, I offer some definitions of story for clarification purposes.

In this chapter, I first discuss the concepts of story and narrative as they relate to my study. Then examinations of narrative, feminist, and Indigenous methodologies provide the rationale and philosophical assumptions that underlie my research approach. This is followed by an overview of the methodological convergence. The chapter concludes with the methods I used to conduct my research; the methodologies I chose determined these procedures.

### **Story**

Stories are a fundamental way in which people communicate with each other and make sense of the world around them. Whenever there is a study of human experience stories are told, listened to, recorded, stored, and “restoried” for future use in the construction of meaning in and for particular social contexts. Every story has multiple meanings and includes accounts of historical diversities, world-view differences, social norms of the times and context which become apparent upon deconstruction (Coombe, 1993; Kovach, 2009; Mitchell & Egudo, 2003; Reissman, 2008).

Kovach, an Indigenous scholar, claims that Indigenous stories are rooted in the past and remind the teller and listener alike of who they are. She writes, “Stories hold within them knowledges while simultaneously signifying relationships” (p. 95). The HIV+ African women purposefully composed stories for me. These stories spoke of many relationships: relationships with their children, other family members, friends, and

their church as well as relationships with their HIV+ illness. As I listened to each woman tell me personal stories of day-to-day realities in their lives, I moved away from abstractions of what life was like for women living with HIV/AIDS in a slum environment and was able to see their life experiences far more realistically (Ellington, 2006; Wilson, 2008). Yet I remain mindful that, although I heard similarities in stories, each story was unique and contained its own truth (Kavoch, 2009).

The stories I listened to serve as conduits to give these women voice, bring them out of isolation, and connect them with others who live with HIV as well as those who do not (Frank, 2004c).

### **Narrative**

Story becomes “narrative” and I become a narrative researcher within a western research paradigm. Riessman (2008) draws the reader/practitioner’s attention to the fact that narrative in western research is a term often used synonymously with story, as I have done throughout this chapter, and is used in a variety of ways by different disciplines. Narrative can be used to refer to the sequence of events described in a narrative, and a narrative can be told by a character within a larger meta narrative. Barthes (1996) addressed the universality of story and listed the many sites of narrative expression, including myth, legend, fable, novella, epic, history, tragedy, drama, comedy, mime, painting, stained glass windows, cinema, comics, news item, and conversation. Narratives are present in every age, place, and society and began with the very history of humankind, and, like life itself, stories are simply there (Riessman, 2008).

The content of the story becomes the subjective focus for the researcher; it is the object of study and requires close examination for interpretation and analytical purposes in narrative methodology (Riessman, 1993; 2008).

### **Narrative methodology**

Narrative methodology was most suited to my study of HIV+ African women who live in the slum of Kibera and whose lives are still unfolding as is the global impact of the HIV/AIDS pandemic. The women and I worked collaboratively; they told me stories about living with HIV and I crafted new narratives about women living with HIV. My finished text demonstrates that “the researcher does not find narratives but instead participates in their creation” (Neader & Skott, 2006, p. 297).

How people make sense of events and experiences in their lives by examining the stories they tell is the focus of narrative methodology. As do feminist and Indigenous methodologies, this approach to research comes under the umbrella of qualitative research of which the central principles “are taken from a relativist orientation, a constructivist ontology and an interpretivist epistemology” (Sarantakos, 2005, p. 37). Qualitative research emerged as a recognized and valued approach during the late 20th century and is located within the postmodern paradigm that challenged modernist philosophical assumptions of rationality, universal truth, and the application of scientific empirical methods of knowledge production. The social nature of knowledge creation and the premise that knowledge is value-laden is emphasized in postmodernism and reflects multiple realities and multiple truths capturing the diversity of social representation (Coombe, 1993; Mitchell & Egudo, 2003; Wells, 2010). The social construction of new knowledge is ongoing as is the field of narrative study (Chase, 2005).

Yet narrative research is far more than the collection, processing, and recording of analysis and interpretation of data in the process of creating knowledge (Kovach, 2009; Wolcott, 1994). Focusing on the organization of human knowledge and the acknowledgement that each person has a different story to tell of equal importance, narrative research is an effective and powerful tool for knowledge transference and thereby contributes to understanding the rich diversity of human kind.

### **A narrative researcher**

As a researcher, I play a part in the survival of peoples, cultures, and languages. However, recognizing that narrative does hold a contradictory potential for strife and division, my intent was to use personal stories of HIV+ women to foster individual and group solidarity in agency for the pursuit of social justice issues. The multiplicity in stories told and those who tell them hold possibilities of speaking to a shared human respect for life (Reissman, 2008; Smith, 1999; Somerville, 2006). Narrative research advocates for an understanding of an interdependence of the human species. Narrative research links the human spirit in efforts toward “finding a shared ethics, and generating the hope – the oxygen of the human spirit – that is essential for our humanity” (Somerville, 2006, p. 2.). Scholars and researchers from the humanities, social sciences, and education have turned to narrative as “the organizing principle for human action” (Clandinin, 2007; Reissman, 1993).

### **Narrative use and narrative research**

Narratives do not exist in a vacuum; not only are they influenced by the historical moment, those who tell stories have multi-agendas which may concern personal subject matter inclusive of power differentials operating in their lives. Stories are always told for

a purpose and with an audience in mind. Bamberg and McCabe (1998) list six classifications of narrative use that are, to remember, to argue, to justify, to persuade, to engage, and even to mislead an audience. Reissman (2008) asserts that narratives are always strategic, functional, and purposeful, while Freeman (2002) claims that stories as sense-making tools inevitably do things – for people, for social institutions, for culture, and more, although those who tell stories may not always be conscious of how others will interpret and use the story content (Dentith, 1995).

Narrative methodology has been historically used to understand first-person accounts obtained in interviews. Unlike other forms of analysis, the storied nature of data is retained to make possible qualitative analysis of life experiences that have traditionally been untold or unrecorded in academic circles. This methodology invites opportunity for alternative, imaginative ways to approach research that does not privilege the denotative, scientific way of knowing (Arslanian-Engoren, 2001; Estrella & Forinash, 2007, Reid & Tom, 2006; Wells, 2010). Active listening is an important skill to perfect when engaging with this methodology because a narrative premise highlights the singularity or chorus of voices in relationships when exploring social phenomena in cultural, social, and political contexts (Chase, 2005).

### **Feminist methodology**

The use of a feminist research methodology was suitable for my study of Kenyan HIV+ women living in poverty in which I took a personal, political, and engaging stance with the world (Sarantakos, 2005). Walker (2005) wrote that “Crucially, feminist research aspires to be for women as much as it is about women” (p. 66). A feminist methodological exploration of the experiences of HIV+ women reflects the reality in their

daily lives and advances the goal of equitable social and economic development (Beetham & Demetriades, 2007).

During the 1960's and 1970's traditional ways of conducting research from masculine starting points were challenged by feminists such as Harding (1987) and Spender (1982) who drew attention to a male sexist bias embedded in the production of knowledge and the construction of social reality. In attempts to shape a less distorted view of reality women appeared in and on the research field. Harding emphasized the importance of the researcher's positionality, Lennon and Whitford (1994) noted "Knowledge bears the mark of its producer" (p. 2) and so the notion of voice becomes central to feminist research methodologies (Walker, 2005). My starting point as a feminist researcher was my interest in how African HIV+ women living in Kibera experience their daily lives and one of my overall goals was to as accurately as possible reveal the "reality" of the lives of these women. I did this by listening to their voices; it is these voices that are at the heart of this research study (Brayton, 1997).

Feminist epistemology that underlies feminist research remains a complex issue and invokes strong arguments for and against from those who stand on either side of the "we/them" divide and has resulted in many break-off branches of feminist discourse. However, fifteen years ago DeVault (1996) identified three shared commitments still relevant today in feminist research. Feminist research shifts the focus of practice from men's concern to reveal the locations and perspectives of women; feminist research minimizes harm and control in the research process, and the methodology supports research of value to women and leads to social change or action that is beneficial to women.

**Difference**

It is well to remember that all women do not share the same worldviews and black feminists particularly have questioned whose experience informs the creation of knowledge from a perspective of differences among women themselves (Collins, 1990; Harding, 1987; hooks, 1984). Feminist praxis takes up an emancipatory stance based on the assumption that the world is socially constructed and organized by gender and moves away from empirical positivistic methodologies while rejecting the idea of the value-free nature of research (Haig, 1997; Punch, 2000). A feminist approach to research works individually and collectively in diverse social contexts to end all forms of oppression (Benini, 2000; Cott, 1987; Ellington, 2006; Maquire, 1987; Sarantsakos, 2005; Vinyard, 1998). Although universal oppression of women has been acknowledged, “ethnic and race differences mean that this oppression is differently inflected for different women, and in some circumstances women themselves might be positioned in an oppressive relationship to other women and even to some men” (Walker, 2005, p. 68).

Western models of feminist thought are challenged in post-colonial literature and by new scholarship that addresses the diversity as well as the commonality of women’s lives; the experiences of lesbian women and disabled women add to the mix of feminist perspectives (Olsen, 2000; Walker, 2005). It is more common for today’s feminist research to convey the complexity of the interplay between gender and other points of difference (Walker, 2005).

**Multi-methods**

Feminist research incorporates multi-method approaches; there is “no single set of agreed upon research guidelines or methods” (Maguire, 1987, p. 74). The emancipatory,

feminist spirit of breaking free from methodological traditions provides emergent opportunities for creative methods of “doing” research, borrowing methods and designs from other methodologies and focusing on social change. There is presently in use a wide range of feminist methods which have moved from the modification of conventional, andocentric biases towards approaches that are more inclusive of the nature of women’s ways, to women’s intuitive rationality, and to feminist political commitments (Stanley & Wise, 1993). Collaborative and non-exploitative relationships between researcher and researched make feminist research more effective in a world comprised of women and men (Farber, 2001; Pfeifer, 2000; Sarantakos, 2005).

True to feminist principles, my research goals included giving voice to those women who are seldom asked to speak in public forums (Reinharz, 1992). By giving women voice to speak about social life from their perspectives, feminist research seeks to expose the invisibility of patriarchal systemic infrastructures that contribute to global inequalities (Harvey, 1990; Sarantakos, 2005).

### **Indigenous methodology**

Literature concerning research in African contexts is scarce. Given that I was able to locate little information regarding research specific to the diversity of Indigenous communities in Africa, I referred to the Canadian Institutes of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People (2007) while preparing for my research. My intent was to conduct research with Kenyan HIV+ women in an Indigenous context in culturally competent ways that were ethical and in “keeping with Aboriginal [Indigenous] values and traditions” (CIHR, 2007, p. 2). Relationship-building that valued honest communication and genuine collaboration was paramount to this

approach and enabled the research to “proceed in a manner that [was] culturally sensitive, relevant, respectful, responsive, equitable and reciprocal” (CIHR, 2007, p. 19).

There may be similarities between the Indigenous peoples of Canada and those in Africa, yet there are many differences. A marked difference is that the Indigenous peoples of Canada are in the minority while people Indigenous to Africa are in the majority. The Indigenous methods I used for conducting research are discussed later in this chapter.

### **A decolonizing agenda**

Smith (1999) wrote, “Historically, Indigenous peoples have been marginalized by western traditional research methodologies which are inextricably linked to European imperialism and colonialism” (p. 1). The lives of Indigenous African women are the central focus of this study. Therefore it was critical to use a research methodology that was anti-oppressive, resistant to dominant western ways and consistent with Indigenous knowing and ways of being in the world. By using an Indigenous methodology I promote the distinctive experience of an Indigenous collective with the use of a decolonizing agenda (Anderson, 2008; Battiste, 2008; Brown & Strega, 2005; Kovach, 2009; Smith, 1999; Wilson, 2008).

I am mindful that “Indigenous methodologies are often a mix of methodological approaches and indigenous practices” (Smith, 1999, p. 143) and reflect the academic training of researchers and the common-sense parameters of research practice which determine how Indigenous communities and researchers define their movements. Although I have no formal training in conducting research in an Indigenous context, I realized via talking with a Canadian Indigenous colleague and reading relevant literature

that I was drawn to the idea of a methodology that emphasizes the value of interdependent relationships and showing respect for individual difference.

### **Authenticity**

It is important to pay attention to matters of authenticity when engaged in research with Indigenous women. Authenticity is a technical term used in psychology and concerns itself with staying true to one's own personality, spirit or character despite outside influences of the material world (Wikipedia, 2011). Like Thomas (2005), "I wanted to authentically tell another's story. That is, I was concerned about how I could tell someone else's story when I was the researcher (both the listener and the writer)" (p. 246). I can only re-tell another's story which I have respectfully done in the next two chapters.

I am quite comfortable in different social contexts; presenting myself as an authentic person comes naturally and stood me in good stead for working with women whose life experiences have taught them to be wary of those who talk from "both sides of their mouth," are dishonest, and motivated only by self-interest. Those who live in Kibera are often exploited by foreign strangers who come to talk, take photographs, and then leave to publish papers and books and make money.

### **Networking**

Within an Indigenous paradigm "networking" is considered an important research skill. Smith (1999) emphasized the importance of "networking" whereby Indigenous peoples check out credentials, not just political credentials but personalities and spirit, within the field of research. She wrote, "Networking is a process which Indigenous Peoples have used effectively to build relationships and disseminate knowledge and

information “(p. 157). Meeting the HIV+ women in Kibera’s communities, not only at the time of the “official interviews,” served as a networking process where each woman checked me out personally for authenticity and integrity purposes. Networking face-to-face also enabled ongoing negotiation in ethical decision-making that affected the direction of my emergent inquiry.

### **Difference**

When conducting my research I did not want to dwell on the differences of human beings which I believe grounds a Euro-Western view in a separated, disconnected transcendent epistemology while doing little to resolve national and international conflict in which alternative worldviews are at play (Ellsworth, 1989; Thayer-Bacon, 2003). Researching in the midst of multiple cultures called for a “relational epistemology,” grounded in a notion of people as “social beings-in-relation-with others” (Thayer-Bacon, 2003, p. 246).

Conducting research in a non-western community with non-western women required close attention to the appropriateness of skills I had acquired in a western-oriented university. For example, “collaborative research” is a term very much used within western qualitative research, yet it is a term to be wary of when used as a veneer to justify intrusive demeaning and arrogant entries into the lives of Indigenous peoples (Smith, 1999). The idea of a homogeneity of Indigenous peoples is a false idea, as is the idea of a monolithic western culture. Therefore it was important that I entered the research field in a way that was culturally aware, appropriate, and respectful. I discuss how I did this later in the methods section.

### **Relational interdependence**

Indigenous peoples experience the world as a large web of relational networks because many Indigenous groups identify with a belief in the interdependence of life and yet there is no one homogenous culture, only a plurality of cultures and cultural norms (Smith, 1999). Western and Indigenous cultures are philosophically diverse. Indigenous peoples perceive the relationships in the world differently than those with western worldviews; “Indigenous knowledge (and epistemology) embodies the cosmologies, values, cultural beliefs, and webs of relations that exist within specific indigenous communities” (Denzin & Lincoln, 2008, p. xiv). Cajete (2004), affirming a relational perspective of Indigenous knowledges and ways of knowing, wrote about the importance of honoring the primacy of direct experience, the interconnectedness of interdependent relationship, holism, quality, and value of life. Many Indigenous worldviews are based upon an animistic philosophy which attests to the human entity as but one clan group within its relational family. My inquiry does not explore any aspect of Indigenous knowledge per se, yet understanding the importance of an interdependent connectedness in the worldviews of the women in this study makes, for example, the effect of their HIV infection more disturbing when I think in terms of the breakdown of family networks caused by the HIV/AIDS pandemic.

The use of an Indigenous methodology permitted me multiple expressions because it honors multiple truths, the beauty of which lies in the freedom to move and centre epistemic roots without a dogmatic interpretation. It also acknowledged that “all we can know for sure is our own experience” (Kovach, 2009, p. 49).

### **A methodological convergence**

I braided narrative, feminist and Indigenous methodologies to create a research paradigm to tell personal stories of HIV+ women's experiences in Kibera. My intention was to challenge the idea of universal truths by using their own words in narratives to serve as a public call for action and advocate on behalf of those whose stories spoke of what it means to be human, how we relate to each other and our world, and how we make and find meaning in life (Frank, 2003; Somerville, 2006). Although the "once upon a time" stories produce value-laden knowledge, the feelings and consequences of human suffering are clearly exposed by the women as they reflect on their lives living with a chronic illness in a slum environment (Frank, 2003; Kovach, 2009; Mehl-Madrona, 2007; Mitchell & Egudo, 2003). Yet the stories are neither finished nor complete; they continue on in the interdependent relationships that follow in daily life (Mehl-Madrona, 2007; Wilson, 2008).

Relationship is central to and overlaps in each methodology, and addresses issues of culture, language, and the invisibility of systemic political contexts which serve to advance an understanding of the interdependence of humanity. In narrative methodology individuals become the embodiment of lived stories and participate in creating new stories; first person accounts and choruses of voices promote agency and may initiate action for social justice. A feminist approach explores the multiple subject positions of women's ways of knowing and their personal and political relationships in a world that is for the most part governed by men while calling forth critical analysis of gender inequalities. Indigenous methodology intent on an agenda of decolonizing western methodologies (Smith, 1999) focuses on social beings in relationship with others, the

primacy of direct experience, and the interconnectedness of interdependent relationships. Indigenous ways of coming to know acknowledge multiple truths in the diversity of human experience, and respect the holistic quality and value of life.

Each methodology values relationships in the research process, particularly between me as researcher and the research participants. Developing rapport and a relationship with my Kibera community contact person was essential in preparing me for my role as a researcher conducting research with Kenyan HIV+ women in an Indigenous context. Her continued input was vital and indispensable for the integrity of my research; she was both a knowledgeable and revered source for ongoing positive culture-specific relational interactions. The pivotal role played by my community contact is discussed in detail later in this chapter.

With the use of a methodological convergence, I was given inclusive space to listen to stories that addressed the complexity of the human condition, the dynamism of individuals within communities in Kibera, and drew attention to the lives of women who have often been constructed as marginalized. I examined issues such as gender and colonization in relation to the experiences of HIV+ women in a world where, although change is escalating and dramatic, poverty remains a constant in their lives.

When I collected my research data, I remained quiet for the most part as stories unfolded. As a westerner not trained in the art of silently listening and as a woman who continues to work hard to have her voice heard, at times, I found it difficult to keep quiet and concentrate on the task of collecting data specific to answering my research question. Stories are “Products of the brain to make sense of the world for a variety of purposes, these stories are often about larger systems in which we find ourselves or with which we

are interacting” (Mehl-Madrona, 2007, p. 121). Each woman became her own authority in protagonist roles in made-up tales of experience. Actively listening, I heard several stories providing me with different perspectives, different frames of reference (Harding, 1987; Mahl-Madrona, 2007). As I read and reread the recorded stories of the HIV+ women, I came to know it is the rigor of reflection that fuels the capacity for individual meanderings in and out of storied conversations for interpretation and analysis purposes.

Analysis according to traditional western academic standards presented particular challenges within this research convergence because it was not possible to neatly deconstruct all the data, although this was never my goal (Kovach, 2009; Wilson, 2008; Mehl-Madrona, 2007). The women told me stories of their lives, and life does not necessarily proceed in a linear fashion; events and stories do not always have a beginning, middle or end – they simply are (Kovach, 2009). Therefore, I chose to interpret my findings along story lines (Riessman, 2008) while remembering that “All stories are didactic to varying degrees, but... rarely have built-in analysis – analysis is the job of the listener” (Kovach, 2009, p. 101).

Narrative, feminist and Indigenous methodological tools supported my research praxis and completion of my dissertation. I was granted license to travel back and forth across borders, internal and external, with ease and a relative freedom. As a western stranger, I was able to walk and talk with a group of women in an African country, each telling new stories about living with HIV. We spent time together; they shared parts of their lives and I shared parts of mine, albeit not nearly so much, and we looked to the future. Wilson (2008), an Indigenous scholar described research as ceremony and wrote, “Through going forward together with open minds and good hearts we uncovered the

nature of this [research] ceremony” (p. 132). I resonate strongly with this research metaphor.

### **Research methods**

Included in this next section is a detailed discussion of the methods I used to conduct and complete my research study.

#### **An international site for research**

This study was conducted in Kibera, Kenya, an international site for research. Kenya became independent of British colonial rule on December 12, 1963. In 1964, under the official title of the Republic of Kenya, the country joined the Commonwealth and is now recognized as a democratic country. British traditions are woven into the Constitution of Kenya (last revised in 2001) which is the supreme law of Kenya.

Enshrined in this Constitution of Kenya are pertinent articles that legally sanctioned this research. These articles included in Chapter V of the Kenyan Constitution are: Article 70, Fundamental Rights and Freedom of the Individual; Article 71, Protection of Right to Personal Liberty; Article 78, Protection of Freedom of Conscience and, in Article 79, Protection of Freedom of Movement.

Research permits are a requirement for all research projects, not only for non-Kenyans, and so before I began my research in Kenya, it was necessary to apply for such a permit from the Kenyan National Council for Science and Technology. Once I had provided the necessary documentation and paid four hundred American dollars, I was issued the research permit (Appendix A). At the same time, I was also issued an official letter for “Research Authorization” advising me to report to the District Commissioner and to the District Education Officer, Nairobi West District, before I embarked on my

research. This letter informed me too that upon completion of my dissertation I am expected to submit two copies of the written text to the office of the National Council for Science and Technology (Appendix B).

### **Ethical considerations**

Research requires strict attention to ethical conduct. Perhaps this is of more concern in an Indigenous context where colonization has reigned and historically ethical transgressions have ensued. “‘Doing ethics’ is an exercise of power because people act or refrain from acting on the basis of the arguments and reasoning ethicists put forward” (Somerville, 2006, p. 4). Marlene Brandt-Castellano (2004), an Indigenous scholar, suggested that “Indigenous ethics can never be limited to a defined set of rules: they are about knowing who you are, the values you hold, and your understanding of how you fit within a spiritual world” (p, 146). Ethical issues emerge from multiple points of view and deal with breaking down dichotomies of power (Battiste, 1999; Smith, 1997; Somerville, 2006; Wilson, 2008).

Ethical considerations in an Indigenous context are particularly problematic because ideals underlying western research ethics are not necessarily congruent with power relations in non-western contexts where power is not always from the top down (Smith, 1999). Ethics concerns itself with the distribution and exercise of power within different contexts, so the principles of “situated and shared ethics,” whereby ongoing collaborative negotiations take place between all parties in the research process is better suited to an Indigenous research context (Somekh & Lewin, 2005; Smith, 1999; Somerville, 2006). Change and action are an inherent part of the research process, not just called for as a result of the findings. There is no single reality and the western idea of

dualism does not capture the diversity in life. The relational nature of circumstance in life and emergent behaviours coupled with the researcher's gaze determines power differentials in context and requires on-going negotiation.

The need for constant negotiations regarding methodological activities as new findings emerge is necessary because all decisions impact on individual lives. Stages of research are interactively sequenced in unpredictable ways; one interpretive role of a researcher is to pay attention to the meaning-making in stories told as well as in what stories do not tell. Congruent ethical care as demonstrated in decision-making reflects the narrative, feminist, and Indigenous research aspiration to "do good" (Frank, 1995; Gilligan, 1982; Noddings 1984; Somerville, 2006).

Gvekve (1996) called for a closer look at ethics as carried out in African contexts with peoples whose moral values are founded essentially on the experiences of living together harmoniously. This calls for an ethic of social responsibility, whereby each member of an ethnic group shows by her/his actions concern for the needs and interests of others. Gvekve wrote, "Responsibility to others is thus considered the supreme moral principle – the highest good. The ethic of altruistic responsibility does not ignore individual rights or does it insist on their priority" (p. 71).

An ethical stance when engaged in research with Indigenous peoples is to rigorously seek agency that is grounded in Indigenous ways of researching, gaining knowledge and respecting the diversity of the human condition (Anderson, 2008; Battiste, 1999, 2008; Gvekve, 1996; Kovach, 2009; Smith, 1999; Somerville, 2006; Wilson, 2008). Recognizing the multiple and diverse ways of knowing is to acknowledge

an ethical universal responsibility that shapes humanity – a shared ethics (Somerville, 2006).

### **Entry into the research field: Community contact in Kibera**

Having located no guidelines for conducting research with Indigenous women in Kenya, Africa, I adhered to the 2007 document, Canadian Institute Health Research Guidelines Involving Aboriginal People. Acknowledging Indigenous African women to be Aboriginal, it was crucial that all stages of my research process proceeded in a manner that was culturally sensitive, relevant, respectful, responsive, equitable, and reciprocal. Honest collaboration with a respected local community leader was important for the recruitment of study participants. Indeed, ongoing open and honest dialogue with my community contact was vital for ongoing positive working and ethical relationships at all levels in my research process. Through previous visits to Kenya in 2005 and 2006, I had begun to develop a relationship with a woman called Winnie in Kibera; we had established a connection supported by e-mails and, on my part, the occasional telephone call.

This woman fulfills the role of an Elder as in a Canadian Aboriginal community. Winnie was always accessible, always willing to meet with me to talk, and always interested to hear how my “research was going”. After we talked about ethical issues and the University of Victoria requirements, she signed a Confidentiality Agreement (Appendix C). Winnie guided me in appropriate and culturally sensitive ways and did her best to protect me in an environment that can, at times, be dangerous for a single white female. There are individuals in Kibera who may think me an easy target to rob. In

Chapter 4 I have provided more information about Winnie and the development of our relationship.

### **Participant selection**

The population of interest for this study is HIV+ African adult women living in Kibera, Kenya; Chapter 586 of the Laws of Kenya, 2001 defines an adult as any human being over the age of eighteen (18) years. Seven to ten adult women were to be invited to take part in this study. These were to be consenting, competent adults, fully informed as to participation requirements. An initial process of snowball sampling, word of mouth, on the part of Winnie, located women who spoke and understood English, had known of their HIV+ status for at least one year, and had expressed a willingness to become part of this study.

Living for one year as an HIV+ woman was considered a time interval that provided the space for personal reflection of this new reality. The women had to be willing to talk about and reflect upon their experiences and speak about how their lives have been affected. The women had to have access to a cell phone to contact me or Winnie should it be necessary. This was not such an unusual request as most people in Kibera have the use of a cell phone which is used more often to text messages because the service is free.

### **Participant recruitment**

Communication with my community contact was critical in the recruitment process to guide me in ways that were culturally sensitive, relevant, respectful, responsive, equitable, and reciprocal (CIHR, 2007; Smith, 1999).

Before I came home to Canada with my Kenyan research permit, Winnie and I agreed that, when I returned to Nairobi in January 2010, she would connect me with members of the Darajani Widows Living with HIV/AIDS group whom she thought suitable for the study. This group first came together in April of 2008 after the post election violence in Kenya between the end of 2007 and the beginning of 2008. These HIV+ widow women were then temporarily internally-displaced people. They had been displaced from their homes in Kibera by acts of violence and were living in makeshift constructions that served as living quarters in the Jamhuri Show Ground, an open area at the far end of the slum. In the aftermath of the violence many of the women were desperate; they had no access to their regular ARVs, some were suffering from tuberculosis, and others were extremely sick with various other diseases. With aid and support from the local Red Cross most of the immediate issues were resolved. However, the women remained greatly traumatized and experienced continuing anguish and stress when the violence subsided and it was considered “safe” to return to their various homes. Not knowing what to expect when they returned, they faced the dismal prospect of “starting over.” Having been unable to work, they had little or no money.

It was at this time that the community based organization (CBO) the Darajani Widows Living with HIV/AIDS was initiated, and was officially registered by the Ministry of Gender and Social Services in Kibera, West Nairobi District. “Darajani” is a Kiswahili word that means “bridge.” The use of the word is in reference to the women crossing over from trauma and ruined businesses to a hopeful future. Nancy Mwashimba was instrumental in forming this organization. However, because Winnie lives in Kibera,

whereas Nancy does not, and we already had a relationship, it was Winnie who became my community contact.

Before I returned to Africa, I e-mailed Winnie regularly to keep her informed of my expected arrival date back in Kenya, and more specifically when next I would be in Kibera. Several weeks before I stepped on a plane leaving Canada to return to Kenya, Winnie e-mailed, “The women are waiting for you. They are ready to work with you.” I was excited and somewhat apprehensive when I thought of the daunting task I had ahead of me.

#### **Meeting up with my community contact**

The plane flew into Jomo Kenyatta International Airport, Nairobi, early one day at the end of January 2010. I called Winnie the same afternoon who told me she had the names of nine women suitable for my study. Winnie had written down their names in a book with details of ages, number of children, which ethnic group they belonged to, and a contact phone number. We agreed to meet in downtown Nairobi at nine o’clock the following morning outside the Ambassador Hotel, a noted landmark in Nairobi, and together we crossed the busy Moi Avenue, a main artery in the road system of Kenya’s capital city. There we stood and waited for a number 32 bus bound for Kibera’s insides. Travel time was generally twenty-five minutes from downtown Nairobi to Kibera yet, given traffic jams, the ride could be expected to take up to an hour and possibly longer if the “jam” was bad which it inevitably was.

Once inside Kibera, Winnie drew my attention to the Holy Trinity Anglican church. This building was visible from the bus window and for future visits became my “cue” for rising from my seat and indicating by some Kiswahili phrases that I wanted to

get off. I alighted from the vehicle as quickly as I could without stumbling when the bus jerked to a stop; the drivers always seemed to be in such a rush. We walked a very short distance, stepped through a wrought iron gate barely attached to the hinges of a very rickety wooden frame-way, and were inside the Holy Trinity Anglican Church compound where Winnie has her small office and working space in the building she shares with a woman who cooks rice and *sumawiki* (green, leafy vegetables high in iron) in large pots to feed some of the school children.

The compound is home to the Church, a primary school, and a dentist's office; at one time there used to be a dispensary there, too. Two security staff, one for overnight and one for the day-time, live on the premises and each have families who live elsewhere in rural parts of Kenya. There is constant noise inside the compound which I found at first distracting when in conversation but after a time I became accustomed to it. The noise permeates, to differing degrees, whatever building you enter, and may originate from the steady stream of vehicle traffic in and out of Kibera, the sounds of people talking as they walk past in either direction, the voices of those who live in close proximity, the voices of children playing in the grounds or reciting in unison lessons learnt by rote in the classrooms, or the loud screeching of the ibis birds as they fly low overhead.

### **To tell their stories**

Each of the nine women was called and a time arranged to meet in Winnie's office that day or the next. It took two days to meet the women for the first time and complete an "Intake Form" (Appendix D). Winnie was present when I met each woman for the first time; she was not in attendance on the two occasions when I listened to the

women's stories specifically for purposes of my research data collecting. Because Winnie and Nancy had previously discussed my research intent and the criteria for participation the women I met for the first time, all members of the Darajani Widows Living with HIV/AIDS proved suitable for the study and were recruited.

Out of a total of eighteen, I met fifteen times with study participants to listen officially to their stories. We met in a room in one of the compound buildings close to where Winnie worked. Once our conversations were completed, we invariably walked over to her office and came together. After a short conversation in Kiswahili with each woman (my understanding of Kiswahili is limited), the conversation switched to English. I really do not know what was discussed, yet I suspect Winnie was checking to make sure the woman was feeling comfortable and had been treated with respect. We then drank hot chocolate prepared by Winnie, provisions provided by me, and on occasions ate fresh *mandazi* (fried, triangular shaped sweet bread considered a breakfast delicacy); this became a welcomed ritual. I had intended that after each meeting, when I was in the process of collecting data, I would immediately find a private place in the compound to write up field notes; this never happened as I thought it more important to share that time with the women. My field notes were completed later when I returned to the Flora Hostel. My decision to move into the Flora Hostel for the duration of the data collecting in Kibera was supported by Winnie and Nancy. The Flora Hostel, run by the Consalata Sisters, is a secure, gated, Catholic mission compound within walking distance of the slum, and provided safety and privacy.

In-depth, semi structured storied conversations rather than formal interviews were the primary mode of collecting data and took place at a time and location that were

mutually convenient. My purpose was to understand the world from the participants' point of view, to explore their perceptions of experiences prior to scientific/academic explanations (Kvale, 1996). Open-ended exploratory questions and active listening skills were conducive to the unfolding of emergent stories, and guided the participants in the re-storying of their daily experiences. Examples of open-ended exploratory questions are: Tell me your story of living with HIV. How do you talk about living with HIV? How are you treated by your family, friends, and others in the community? What else would you like me to know about living your life as an HIV+ woman? A list of open-ended questions I prepared beforehand can be found in Appendix E. I found these open-ended questions useful too to keep me on track in remembering the focus of my research intent. Two semi-structured, storied conversations, each about one hour in length, were conducted. I had thought they would take two hours approximately, yet they were much shorter.

Prior to the beginning of the first storied conversation, each woman was given a printed copy of the "Participant Consent Form" (Appendix F). I read each section carefully and reviewed it with them, answering any questions that arose. Once I received verbal consent that they agreed to be part of the study, they signed the form. Before the actual conversation began, I attached a small microphone to a piece of clothing closest to each woman's mouth. I thought the use of a small digital microphone would not be too intrusive, and would allow me to be more attentive to the emergent stories rather than the positioning of the digital device. In actuality, there were moments when the clothing slipped causing the microphone to move around, especially when attached to a Muslim hijab (headdress), as certain participants became quite animated in telling their stories.

This resulted in static in some of the recording which made transcription a little more difficult.

Rapport was developed during the first official storied conversation and a 10–14 day interval between the two research conversations allowed participants to reflect on the experience and me to review the data and make notes for further exploration in the second storied conversation.

Prior to the start of the second storied conversation, each participant was given a copy of her signed “Participant Consent Form”, asked if there were any questions or concerns, and whether she wanted to proceed. One woman wanted me to explain again how this research was to benefit her and other HIV+ women; all women chose to proceed.

At the end of each storied conversation, participants were asked for permission to be contacted for clarification purposes if necessary and reminded that they could contact me too, if need be.

### **Participant observation**

Participant observation within the community was a secondary mode of collecting data. I was invited to attend the celebrations for International Women’s Day that took place in the District Officer’s compound of Kibera. As I began to feel more comfortable in the community, I walked around alone and quite often would see one or more participants going about their daily business. Whenever I was noticed, I was always acknowledged with a wave of the hand, nod of the head, or by an approach and conversation at the participant’s initiative; I was never ignored.

**Other meetings**

I regularly met with Winnie before a storied conversation; these times alone with her became important. In a separate book I recorded words and expressions I did not understand from earlier recorded interviews after completing an initial, long-hand transcription the night before. Alone with Winnie, I asked for clarification of the use of an English word in a certain context or for a translation of an African word that may have been used and I “checked-in” with Winnie regarding data collection decision-making. For example, one of the women called me the night before we were scheduled to meet the next morning at seven o’clock. She wanted to meet half an hour earlier, and I agreed. However, because it was still dark as I left the Flora Hostel, crossed the Ngong road to wait for transportation, and arrived in Kibera before the sun was fully up, I had difficulty seeing. I was unable to see anyone who may have been standing behind a bush or building and I did not feel safe. Winnie and I agreed that, for future interviews, I would meet with no one until the sun was up.

**Storied conversations in homes**

When filling out the “Intake Form”, there were some women who expressed a wish to meet and talk with me in their homes. Winnie was supportive of this initially. Yet after conversations in three homes, she changed her mind and wanted all future conversations to take place within the compound. I asked for an explanation and was told that I had now seen homes inside Kibera so there was no need to see any more. When pressed further, Winnie alluded to the fact that she was concerned for my safety as it was becoming common knowledge in the local community that I might be “carrying”. In

other words, some people might think I had on my person amounts of money or goods that would make it worth their while to accost, mug, or attack me.

### **Storied conversations in the compound**

Storied conversations conducted on a Sunday took place in Winnie's office; other interviews took place in a room that was once part of the dispensary and now serves as a meeting place for a variety of activities. This room had to be unlocked and locked again each time by one of the security men who had the key. On one occasion, an interview was unexpectedly interrupted by the night security man who came barging into the room unannounced. Without saying a word he changed his shirt and left as abruptly as he had arrived. After discussing this incident with Winnie, she decided the security men were to be offered some of whatever we were eating or drinking and they would be informed that the women and I were conducting private interviews. By including the security men, there was less chance of them interrupting future research conversations or other relevant activities.

### **Reporting of findings**

Before I left Kenya and three Saturdays after my last "official" conversation as agreed to with the women, I presented my findings, verbally, at a regular weekly meeting of the Darajani Widows Living with HIV/AIDS. This meeting took place in one of the old dispensary rooms in the Church compound, the same room where I had conducted some of the data collection conversations. Meetings of all sorts usually took place in the early morning so the women are able to go about their business the rest of the day. I had wanted to provide each woman with a soda to drink during this meeting. However, they received milk which was distributed at the end of the meeting; all the women took it

home. Giving out milk instead of soda was Winnie's suggestion. She informed me that most of the women could rarely afford milk and it would be a healthy treat.

To prepare for presentation of findings to the women, I listened to the recorded stories. After each recording, I reflected while I silently wrote out, by hand, a transcription of each conversation. By reading several times these hand-written transcriptions, I was able to draft a brief overview of my findings which I presented, as previously arranged, to the women before I left Kenya.

I hope to return to Kibera early in 2012, taking two copies of my finished text to the Kenyan National Council of Science and Technology to fulfill my legal and moral obligations for receipt of a Kenyan research permit. An extra copy will be left with Winnie; if interested in reading the written piece, the women can borrow it from her. When I checked with Winnie regarding the appropriateness of an English version, she told me that the women preferred reading written English rather than reading reports written in other ethnic languages. Why this was would be interesting to explore; I did not engage in this exploration at this time.

### **Data analysis**

I am acutely aware of the chasm between Western and Indigenous ways of analyzing data; the western convention to "pull apart" bits and pieces from the whole conflicts with meaning-making holistically, as is the Indigenous way (Kovach, 2009; Wilson, 2008). Analyzing is detective work and there is no one right way of presenting an analysis of data; it has been pointed out that in "narrative analysis there is no one method ... [It] has to do with how protagonists interpret things, and how we [researchers] can go about interpreting their interpretations" (Bruner, 1990, p. 51).

My narrative analysis is informed by Riessman's (2008) idea of dialogical/ performance analysis in which I, as investigator, become an active presence in the text, and acknowledge that story and story-telling, like performances, are expressive, shaped by the contextual, reciprocal interaction of teller and listener. Dialogical/ performance analysis draws on components of thematic and structural analysis although I know that within an Indigenous paradigm "thematic groupings conflict with making meaning holistically" (Kovach, 2009, p. 129). By using narrative analysis, I found the voices of the women in a particular time, place, and setting (Connelly & Clandinin, 1990), and appreciate that "Narrative analysis (one component of the broader field of narrative inquiry) refers to a diverse set of methods, a 'family' of interpretive approaches to spoken, written and visual texts" (Riessman, 2008, p. 183).

The recognition of alternative analysis approaches reflects the expansive nature of narrative research, and the diversity of narrative data sources. Riessman (2008) contended that polyphonic multi-voices in narratives provided an open stage for new, non-dominant voices for interpretation, implying that "the author (speaker) does not have the only word, that is, the authority over meaning is dispersed and embedded" (p. 107). Concurring with Bakhtin (1975), Riessman acknowledged the power of language to bring the past to the present, and words that "carry history on their backs" (p. 107).

Back in Canada each of the recorded interviews was transcribed verbatim by a professional transcriber. Microsoft Word was used to create relevant documents; copies of "works in progress" were saved on a back-up disc and a USB for future use and security reasons. There has been ongoing e-communication with Winnie regarding data

details that required clarification. For example, I wanted confirmation regarding the names of hospitals in Nairobi and the correct spelling of certain Kiswahili words.

Upon receiving the transcriptions, I double-checked them for accuracy. Several times I listened “generously” (Remen, 2011) as I had done when engaged in the process of interviewing with an open heart and mind to the voices of the women in the recordings. I reread the transcriptions many times and, when I worked from my computer, strategically positioned photographs of each woman kept me company as I composed new stories about each one of them. Writing about each woman separately and living conditions in Kibera, I was able to reflect once more on the daily lives of these women and then thought myself ready to draw out storylines which transcend their individual lives. I developed a color coding system to identify similarities and differences while addressing patterns of common themes and used no software tools to assist in categorization. The storylines are discussed at length in Chapter 5.

Limitations to this form of research analysis were determined by the “window glimpses” provided by the women into their daily lives. The HIV+ women chose what to share and what not to share with me about living in the Kibera slum.

Feminist and Indigenous perspectives are folded within the broader narrative methodological cloth and provided interdisciplinary stitches to interpret and analyze the empirical data collected for my study. The result is an innovative, integrated analysis that actively sought multiple routes to enhanced understanding. Describing, interpreting, and analyzing moved me towards the larger process of meaning-making, of generating new knowledge (Somekh, Stronach, Lewin, Nolan, & Stake, 2005).

**Anonymity and confidentiality**

Prior to my data collection in Kibera, the issues of confidentiality and anonymity appeared quite straightforward. Each participant was to be recruited individually and each participant was to be interviewed individually. Issues of confidentiality and anonymity were to be explained during the initial meeting and were included in the content of the “Participant Consent Form” (Appendix C). Only two women chose the use of a pseudonym. Other women wanted me to use their given African names.

When preparing my research proposal in Canada for approval by the University’s Ethics Board, I had been very concerned that participation in the study might have had some negative affects within the local community. I had presumed that those who took part would prefer anonymity, would not want to be seen openly with me in Kibera, and might not want to acknowledge me should they see me walking around the community. I had assumed that publicly acknowledging me would expose them to the risks of identification as an HIV+ woman. I was wrong. I was always acknowledged by participants whenever and wherever we met in Kibera; I was invited to meet individual women at certain places in the community and then walk with them to their respective homes. I was invited to attend community functions and, at times, women accompanied me to places in Nairobi where I had business. There appeared absolutely no reticence on the part of any of the women to be seen in my company, quite the reverse. And I was unsure of why this was. When I talked with Winnie and Nancy about this, I was informed that the women were “empowered.” and had been trained how to protect themselves from situations in which they may be exposed to danger because of HIV/AIDS-related stigma or discrimination.

**Reciprocity**

Participants were acknowledged by way of an honorarium, *chai*, a small monetary gift which did not exceed what could conceivably be earned in a day by other means. An approximate day's earnings are 85c – \$1Cad. They received the equivalent in Kenya shillings of \$1 Cad. at the end of each interview.

Participants were informed that they could withdraw from the research at any time and still receive the appropriate amount of honorarium. The Consent Form stated: “If you decide to participate, you may withdraw at any time without any consequences and or explanation. If you choose to withdraw, you may choose whether the data collected can be used in the study or if you would like all data deleted from all data bases and all print copies destroyed.”

Reciprocity is a valued quality within Indigenous and feminist contexts. “Giving back does not only mean dissemination of findings, it means creating a relationship throughout the entirety of the research” (Kovach, 2009, p. 149). Ongoing collaboration with both Winnie and the study participants, authenticity in all personal interactions, and ongoing vigilance regarding ethical issues nurtured an atmosphere of reciprocity while conducting my research.

**Trustworthiness and validity**

Riessman (2008) wrote, “when a group of scholars eventually comes to accept a particular way of working with narrative data as a basis for empirical investigation and theorizing, the approach can be considered trustworthy” (p. 195). Narrative, feminist, and Indigenous research approaches are accepted within research communities, yet it remained important for me to pay heed to issues of congruency and transparency

especially in the reporting of the research process. According to Riessman, providing details about how methodological decisions are made; describing how interpretations are produced, including alternative interpretations; and making primary data available to other investigators when appropriate provide a functional measure of validity.

My reason for choosing narrative, feminist, and Indigenous methodologies was to approach my research in ways that were anti-oppressive. I wanted to adhere to research principles that included honest collaboration with the participants, relationship building, and multiple perspectives. I exposed my own vulnerability in situations within the research context and often looked to my community contact for reassurance, clarification and/or confirmation (Brown & Strega, 2005). Attention to thoughtful, purposeful, and congruent procedures in research contributes to the validity of an inquiry piece and determines to a large extent if it will be considered trustworthy by other investigators (Riessman, 2008). I believe my study to be trustworthy and valid.

### **Reflexivity**

Reflexivity is an essential component of qualitative inquiry; it is referred to by Clandinin and Connelly (2002) as wakefulness. Throughout the data collection process, I kept a daily journal, reflecting on days' events and my personal experience of what took place. This journal was part of, yet kept separate from, the field notes and my book of "words to check out with Winnie." A qualitative methodology is a vital and emergent process and I was unsure before I began my dissertation write-up whether the journal entries would be included, they are not. However, it is my voice that has determined the shape and form of the final integrated written product that answers my research question,

“How do HIV+ women in Kibera, Kenya experience and participate in their community and story their lives?”

To maintain a committed and wakeful purpose in unearthing new knowledge in research fields that is valid and trustworthy remains an ongoing challenge for the researcher and impacts on the choice and progression of a research methodology. In keeping with a narrative, feminist, and Indigenous perspective, personal reflection on the part of the researcher must keep in sight a focus on the significance of the effect of the methods on the overall well-being of individuals, community, and humanity.

When back in Canada, I found it difficult to sit in front of a computer to write up my findings because the hardships in the lives of the women in my study became so viscerally clear. To integrate my strong emotions, I found myself, at times, recollecting “bits and pieces” of my data collecting process while in Kibera. Using a different font and italics, I have included my narrative reflections in Chapter 6. The reader will note too that, rather than include some personal reflective observations in footnotes in Chapters 4 and 5, I have included them in the main text; these are identified by a different font and italics.

### **Liberties taken**

Language, like culture, is not stagnant. In the interviews, the women sometimes used a hybrid form of language. The women in the study all speak and understand at least three languages, their Mother tongue, Kiswahili and English. In all probability, they are able to converse in other ethnic languages. Interviews were conducted in English and the narrative genre of the women may not always be clear to outsiders who are not familiar with listening to certain non-western voices tell stories. Therefore, after deliberation, I

have edited some quotations. I have replaced verb tenses and pronouns, I have included missing words necessary for meaning; I have deleted repetitious words and provided English translations of Kiswahili words. For readers who may be interested in the exact quotations, I have taken one quotation from each participant's narrative and included them in Appendix G. To do so for all the quotations would serve no particular purpose for the intent of this study.

In the next chapter, Chapter 4, Understanding the Research Context and Meeting the Women, I present an overview of daily life in Kibera so the reader has an understanding of the research setting. Then I introduce Winnie and the nine women in this study.

## **Chapter 4: Understanding the Research Context and Meeting the Women**

In this research project, understanding the context is integral to understanding the lives of the nine women. To better understand the lives of the nine HIV+ African women in this study and how they experience and tell their lives today, it is helpful to have some appreciation of the living conditions in Kibera, the slum in which these women live.

Therefore I have provided some background information regarding life in Kibera.

In 2005, Christine Bodewes, an American lawyer interested in human rights issues, particularly human rights regarding land and housing, conducted a research study in Kibera that explored the living conditions and infrastructure of the settlement. I have located no other document that provides the significant details that affect and influence the quality of life of those who live in such an environment.

Today Kibera is a sprawling shanty town seven kilometers southeast of Nairobi City, capital of Kenya. It is internationally recognized as the largest and most densely populated slum in all of sub-Saharan Africa (Matrox, 2002) and spreads over 110 hectares of land. It has been observed that “The normal measure for adequate space in refugee camps is about two or three times greater than the current density in most of Kibera” (Bodewes, 2005, p. 57). No accurate census data exists, as the estimation of the population living in Kibera varies according to different sources and there are no known statistics regarding a breakdown of gender differences. Nevertheless, the majority of research findings estimate that between 600,000 and 700,000 people live in Kibera

(Nguu, 1995). This approximation of those who live in Kibera is 16 years old and is now likely closer to one million people.

Many groups of African peoples migrate to Kibera, not only those from rural parts of Kenya. Those who come from countries such as Ethiopia, Somalia, Tanzania, Uganda, and Sudan bring with them their own different languages, cultures, customs, and traditions which add to the rich mix of ethnic diversity in the slum population.

Kibera has gained a national reputation as being the cheapest place to live within Nairobi's enclave of informal settlements. Creative life skills and personal ingenuity on the part of those who live and work there provides a standard of living that is far below the poverty standard. One female participant in a research study that focused on life inside Kibera commented, "I like Kibera because *sukuma wiki* [sic] is very cheap and I can live on less than 1US\$ a day" (Bodewes, 2005, p. 51). The building quality of many homes and work places are not conducive to personal safety or health, yet still people appreciate having somewhere to live and appreciate being able to stand up straight inside buildings. For example, a Tukana woman from northern Kenya remarked, "I am here because the houses are nice, you don't have to stoop to enter the room and you can stand up inside" (p. 53).

The lack of infrastructure inside Kibera is dangerous to the overall health of all individuals who live there and presents many challenges. I turn now to the "basics" of life in Kibera.

## **The basics of life in Kibera**

### **Water**

A supply of clean, safe drinking water is a major and constant source of worry as Nairobi City Council (NCC) provides no official water meters in the slum because of its illegal settlement status. This has advanced the sale of water on the black market by those who purchase licenses from the Water and Sewage Department and exploit the residents.

My community contact, Winnie, reported in a personal communication to me that,

In the case of water, most of the major towns have access to clean and healthy water as per my local judgment. Most of us slum dwellers buy water from various points since some guys have invested in it. Financially stable individuals or groups apply for water, buy tanks, buy pipes or hire labor to enable water [to] reach where they want. There are many points of tap water and we usually fill quantities of 20 liters, 10 liters or 5 liters depending on the weight one can carry. Water is sold at a price of Ksh 3 for every 20 liters of water. Then you fill and carry to whatever destination your house is at. However, sometimes there is [a]shortage and at this point we buy the same measures at between Ksh 30 – Ksh 50 for every 20 liters. And if you live far, you may need to pay an extra 10 shilling for transportation of every gallon (November 14, 2008).

Residents of Kibera pay about Ksh 140 (\$1.60) per cubic meter of water while the people who live in Nairobi's middle class estates pay NCC an average of Ksh 50 for the same quantity of water. Difficulty is sometimes also experienced in accessing clean water from the pre-filled tanks often controlled by landlords. Burst water pipes and the rationing of water access by NCC add to the anguish of Kibera's residents. Many of the pipes used to haul water are unhygienic because they are made of plastic and often crack, allowing dirt and sewage to enter the water supply. When water is rationed and in short supply, rather than walk a long distance to the estates to buy water, women and children are known to stand in long lines for up to three hours at the water kiosks. Those who

cannot afford to buy water use dirty water from the Nairobi Dam which is now a repository for much of the slum's sewage, or they carry water from rivers and water collected from roof tops. Therefore, most of the water in Kibera is contaminated and it has to be boiled or otherwise treated before it is safe to drink (Bodewes, 2005).

### **Electricity**

NCC provides very few electrical hook-ups in Kibera. Live electrical wires can be seen hanging loosely over many roof tops. At times birds the size of a crow land on an exposed wire and cause a fire. Bare wires on the ground can be seen in some areas and children while playing may accidentally contact a wire and be electrocuted. During the rainy seasons, the risk is much higher. The wires on the ground may come into contact with water, become exposed and electrocute an unsuspecting person walking by. Dogs and cats quite often fall victim to the live wires, barking nosily as they feel the current. Winnie wrote in a personal communication to me,

About electricity in Kibera, not many houses have legal electricity supply. Just like my case, I have mine from a local neighbor who I just bought a wire and my son since he is an electrician just did the wiring Then I pay Ksh 300 per month. But the costs could be higher if you are in a place when you pay a local electrician without any qualifications to do the wiring (November 14, 2008).

While people are creative in finding sources of electrical power, at the same time, they put themselves and others at risk because they have little or no knowledge regarding safety precautions that need to be in place to prevent death from electrocution.

### **Garbage and drainage**

Disposal of household and human waste presents an enormous ongoing challenge and is a major health hazard to everyone in Kibera. At present, there is an average of one

toilet for more than 2,000 people (BBC, 2008). Non-Governmental Agencies have been successful in constructing a small number of pit latrines, yet there are not enough to meet the needs of Kibera's population and so the menace, as noted in the introduction, of "flying toilets" continues. These polythene bags add to the mounting piles of garbage; some make their way to the drainage system that is made up of open canals and ruts dug in the earth. It is into this make-shift system that people dispose of wastewater, refuse, and human waste. Drains are shallow and, when they become blocked, overflows pour onto footpaths and into individual homes. During the rainy season, the stagnant, smelly water and sludge that surround most houses becomes run-off water which flows openly throughout Kibera (Bodewes, 2005).

Disposing of garbage in ways that do not contribute to personal health hazards presents its own problems. It is reported that "On average, Kibera residents produce 140 tons of garbage per day. Yet, the NCC has not provided services to pick up refuse in Kibera for over ten years" (Bodewes, 2005, p. 63). Garbage is strewn everywhere, footpaths are littered with rotting waste, plastic bags which are not biodegradable choke the rivers and there is a lot of dumping along the Mombassa-Uganda railway line which runs through the middle of Kibera. Goats and dogs forage in the dumps. Children and adults can be seen constantly rummaging in the dumps for things to use or sell and children play near dumping and drainage areas.

### **Health facilities**

When adults or children become sick, they must travel to one of the hospitals outside of Kibera as inside Kibera there are no government or NCC health facilities. Although there are an increasing number of private clinics and dispensaries operating in

the slum, there is cause for varying degrees of alarm concerning the quality of care. Many clinics are not staffed by trained nurses, doctors or pharmacists; medications sold may be overpriced and the date may be long expired (Bodewes, 2005).

To take care of health concerns and a variety of personal ailments, individuals frequently consult with traditional doctors, *waganga*, for a price. They may seek a love potion, a spell to find work, or something to treat a physical illness such as mental anguish, headaches, wounds, or infertility.

### **Housing**

The homes in which family groupings live are small. Buildings have been put up randomly, crammed together without prior thought given to an overall land use plan. The few available open spaces are small and used as playing areas attached to schools. New buildings are erected only when old ones burn down. Those living in Kibera have no physical address and few can afford a post office box in Nairobi. Communication inside and outside of Kibera is done mostly via the use of cell phones, especially among young people.

A typical home consists of one room that is 3–6 square meters in size. There is no plumbing or electricity and many have no window. If there is a window, it is small and provides poor ventilation and little natural lighting. The walls are usually made from mud and wattle and the floor is earth; second-hand corrugated iron is often used for the roof. Wood, plastic, cardboard, and polythene are some other materials that people use to build a home. Stones, bricks or cement are prohibited as building supplies and, if used, the chief or another local officer will remove them. When it rains, the water may come through the roof or into the room from other holes in the walls making the floor muddy.

Some walls and ceilings are lined with newspapers, poster materials, and strips of polythene or plastic bags in efforts to keep out the rains and the cold night air.

The rooms most often contain a single bed which is used at times for sitting on, and furnished with a number of stools and a small table. There may be a simple, home-made sofa and a small table in the home. A piece of cloth or sheet hung across the middle of the room sometimes separates the sitting area from the sleeping/cooking section. When it is time to sleep the furniture is rearranged to make more room for sleeping bodies on the floor. The cramped sleeping quarters provide little in the way of privacy and protection of women and children from sexual abuse by family, extended family members or casual acquaintances who spend the night. “Traditionally, sleeping quarters for young people are to be separate to avoid incest” (Bodewes, 2005, p. 117), so the practice of children sharing a room with parents is a break with traditional custom (Mbiti, 1969).

Many families in Kibera cannot afford a second room and it is uncommon for grandparents or extended family members to live close by.

### **Fear of eviction**

Those who rent their homes in Kibera live in constant fear of eviction. The land belongs to the government and the Government Lands Act gives the Kenyan President the power to give and allocate pieces and parcels of land to whomever he chooses. The Commissioner of Lands assists the President in this task and, although procedures were established to ensure transparency of land allocation, they have never been followed (Bodewes, 2005). Much of the land is presently owned by the Kenya Railways, a public corporation (Kibera Urban Environmental Sanitation Project, 2005).

There have been several initiatives for slum upgrading in Kibera which have only resulted in gentrification and made life even harder for many people whose homes are taken away. At such times the ranks of internally displaced persons swell as the upgrading often benefits those who come in from the outside. For example, in the 1980's, the National Housing Corporation demolished temporary structures in one of Kibera's villages, Soweto, and put up permanent buildings that became known as "Highrise", an estate for the middle-class, not the poor (Centre on Housing Rights and Evictions, 2004).

Kibera has a history of development projects that have never reached completion. Disputes among international donors in 2001 halted a World Bank water and sanitation project leaving the majority of residents without toilets, clean water or proper drainage (Bodewes, 2005). Other development initiatives by international agencies such as Oxfam are constantly thwarted by bureaucratic delays and politics.

Corruption and illegal allocation of land has resulted in a complex pattern of land ownership in Kibera from which three different classes of people have emerged. There are non-resident structure owners, resident structure owners, and then there are tenants who pay rent and who make up between 80- 90% of the population. Although structure owners own the construction material, they do not have legal entitlement to the land (Gitau & Washington, 2002). Abuses at the executive levels are compounded by politicians, chiefs, elders, and the police at the local levels who in exchange for bribes add to the complicity by granting permission for land development of new buildings or renovations of old ones.

**Mobility**

Traffic and activity in the settlement present another set of challenges to Kibera residents and is routinely cause for caution as people go about their daily business. In the early morning, the human foot traffic is very heavy as people rush to work or to Makina Market, the main wholesale market owned by NCC, to buy fruits and vegetables to hawk or sell on the streets during the day. In the late afternoon, and evening, the foot traffic is again heavy as people return from work. Approximately 75% of residents in Kibera work in the industrial area of Nairobi and to save money they walk to work which takes between 30 and 90 minutes each way (Bodewes, 2005).

Overflowing wheelbarrows with heavy loads jostle with pedestrians, and privately-owned mini-buses used for transportation purposes compete with cars and buses for room on the main arteries of path and roadways. Paths are dry and dusty except during the rainy season when they become muddy, slippery, and especially difficult for passing. Garbage, goat and other animal droppings, along with human sewage litter the roads and throughways. In the hot sun, the stench is almost unbearable. Pedestrian bridges for walking in and out of the different sections of Kibera frequently lack maintenance and Bodewese (2005) reports that dishonest individuals remove temporary bridges at times so they can charge those who need assistance in passing through.

The congestion of businesses close to the roadways adds to the difficulty of a consistent flow of traffic. The roads and paths are often too narrow for cars to pass each other, in some areas so narrow that no vehicle can get in or out. In January, 2002, it was reported that over 100 homes burnt down while fire fighters could only stand by and watch because the fire truck could not reach the flames. It is also very difficult to transport a sick person from the inside of any building structure. Therefore, slum

residents do their best to prevent such catastrophes when cooking with charcoal or using candles for night light which may result in the loss of their meager possessions, homes, and even life. Ambulances or other vehicles are invariably unable to navigate the narrow roads and “so a sick person is normally carried out on a sack or in a wheelbarrow” (Bodewese, 2005, p. 58).

### **Political and community life**

There are many self-interest groups and individuals in Kibera who compete for power positions and this can be dangerous for community members; corruption at the collective and individual level is common. Interpersonal or community outbursts occur quite often and may result in injury or death. Kibera has been described “as a political hot spot largely because of the potentially huge voting bloc that the population represents” (Republic of Kenya, 2001, p. 47). Much of what happens in the slum communities is the result of political will influenced to a large extent by the governing party that plays one tribal interest against another.

In addition to the national parliamentary structures that operate within Kibera, there is also a complex and overlapping system of urban governance which includes elected councilors and the Provisional Administration (PA). According to Bodewes (2005), councilors and the PA do little to actually help those who live in the slum because much of their time is spent vying for power and control over the other (Bodewes, 2005).

Relatively recently, a new control group has emerged in Kibera, the youth wingers. This group competes for power with the *wazee wa vijiji* (Council of Elders), the chiefs, assistant chiefs and the PA. This group, “[t]he youth wingers (who are not necessarily young given their ages range between 20–45 years) are groups of idle men

who are hired to do the bidding of political parties and local politicians” (Bodewes, 2005, p. 80). Youth wingers intimidate people through various forms of violence. During the post-election violence early in 2008, groups of youth wingers roamed around Kibera, looting, raping, and killing. Winnie wrote this to me about that time,

[S]omehow the world went upside down for us. Our houses were robbed {of} all the useful things that we had, especially food, money, sewing machines that were my bread winning [sic] tool. And so much that is endless to talk about...others had their houses burnt to ashes and we just don't know (January 05, 2008).

Despite the many forms of corruption that take place in Kibera and the daily challenges of providing for families, people for the most part are hospitable and community-minded. Women swap stories from neighbors and friends when they meet in the dukas (markets) and many stay informed primarily by battery-operated radios that connect them with the news at the local, national, and international level. Television sets are owned by a few and provide the latest news from around the globe. When friends and family visit from up-country with the latest news of relatives and friends, it is usually a time to rejoice and share what little food and shelter there is.

Sundays are set aside by many for church activities and for visiting neighbours. Participation in religious ceremonies appears important for most living in Kibera. “On Sunday mornings, a cacophony of songs, prayers, and preaching rises to deafening levels throughout Kibera” (Bodewes, 2005, p. 83). Bodewes reports that there are more than 300 Christian churches which include small traditional African churches. Some sects hold services in the structures in which they live or on the roadside, and Kibera is home to Catholic parishes as well as three mosques.

### **Changing traditions**

The process of urbanization is reflected in the decreasing number of African traditional practices. However, four African traditions are still practiced openly today in Kibera; these traditions are death and burial rights, naming of children, polygamy, and witchcraft. There is agreement among many in Kibera that the loss of some traditional practices has had “both beneficial and negative effects” (Bodewes, 2006, p. 118). No longer are there forced marriages between young girls and old men because girls generally are better educated and will run away to escape marriages they do not want. Ironically, some women migrate from rural area to Kibera to escape just such a marriage.

Wife-inheritance, if practiced in Kibera, is done so secretly because NGOs and church groups have made residents aware that the practice is responsible for an increase in HIV/AIDS infection. Traditionally, in some groups such as Luos and Luhyas, the wife of a deceased man was inherited by one of the deceased’s brothers (Mbiti, 1969). One young woman commented, “If my husband dies, I do not have to be inherited by his relatives because of AIDS. But I will suffer because I will inherit nothing to help me raise up my children. Women can still be inherited if they agree but they can also refuse these days” (Bodewes, 2005, p. 119).

Many family structures too have broken down in Kibera. Traditionally, the roles of family, extended family, and community members were clearly defined within African contexts. The husband was the head of the family and, if he died, one of his brothers might take over. However, the HIV/AIDS pandemic has impacted greatly on families, and the disease has left many homes without mothers or fathers.

Some youth who live in Kibera are losing touch with connections to their past, systems of traditional practices, and their ancestors. Grandparents, the link for youth with

the old ways and with the ancestors, may die leaving no oral legacy; parents may be from different ethnic groups and the children may never return to visit the rural home of either their mother or father, and may be uninterested in learning traditional ways of bygone times. Yet, not all youth in Kibera abandon responsibility. As a result of the loss of parents due to the HIV/AIDS pandemic, the numbers of child-headed households has increased as have the numbers of grandparents who raise their grandchildren (Ayisi, 1972; Bodewes, 2005; Kirwen, 2005, 2008; UNAIDS, 2004).

Elders in villages were traditionally the community leaders in many African societies and it was usually the men who took charge of village affairs. A participant in Bodewes's (2005) study commented,

They were men who had to have good qualities like wisdom and calmness. Drunkards and rumormongers could not be leaders. In the village, the leaders were men who had many cows and usually many wives because it was assumed that if a man took care of a big family he could take care of the larger community too" (p. 120).

In Kibera, leaders have been those who are wealthy and "connected"; positions of power are often determined by tribal affiliation to political leaders. Most leaders do not live in Kibera. Bribes are paid to those who hold important positions such as Chiefs, the council of Elders, commonly known as *wazee wa vijiji*, and the youth wingers; the bigger the bribe, the greater the favor. For example, people can be forced to vacate a structure that they have occupied for years if someone else decides they want it for personal use and pays the landlord a bribe. Women are the most vulnerable to such dealings because of their lower status within the patriarchal system that operates not only in Kibera but also in most of Kenya.

Community conflicts with neighbors or friends in rural areas were traditionally resolved by village Elders. In the settlement sprawl, much has changed in the way that individuals relate to their neighbors. Chiefs, youth wingers and the *wazee wa vijiji* have taken the place of Elders in present day Kibera. As one male resident observed, “The courts of today are the youth wingers who lack wisdom and respect. They don’t know how to make decisions. And they must be paid in advance before they will make a decision. The amount of money paid determines the outcome, not the merits of the case” (Bodewes, 2005, p. 122). Consequently, there is much criminal activity in Kibera, bribery is common and there is a lot of distrust among those who live there. It is the norm rather than the exception for people to tell lies. Stealing is considered a serious crime. Today, rather than returning the stolen article, paying a fine, and asking for forgiveness, a thief may be swarmed, beaten, burned, killed, or taken to the police. The closeness of the living quarters affords little privacy and often results in tension amongst neighbours.

### **Language**

The main language spoken in Kibera is Kiswahili although many people communicate in English and much of the time a variety of ethnic languages can be heard. It is the older generation, especially the women, who still converse in their tribal language and many children are taught their Mother tongue by adults. Knowing and speaking their tribal language enables youth to communicate with their grandparents and other relatives when they visit in rural areas and keeps them connected to their ancestral roots.

There is another language gaining momentum; many youth use Sleng to talk with each other. Sleng, a combination of Kiswahili, English, and several other local languages

such as Kikuyo, Luo, Kamba, and Nubian was initially developed by urban youth as a way to talk amongst themselves without adults knowing what was being said. “It is an organic language and changes as new words are continually being added” (Bodewes, 2005, p. 119). This secret language contributes to community fractioning inside Kibera and adds to a growing sense of separation and exclusion between generations.

### **Education**

Knowledge gained through formal education is power in the minds of many who live in Kibera and mothers often work several jobs to send their children to formal school. Although primary education in Kibera is now free, there is only one formal government school in the settlement, while there are approximately 65 informal schools operated by private individuals, community and or religious groups (Bodewes, 2005). Many primary aged school children do not attend school because care-givers cannot afford the uniform or school supplies.

### **Employment**

Many of Kibera’s residents are employed in the informal sector, doing menial jobs such as office cleaning; many are subjected to long hours, unsafe and unclean working conditions. Many human rights are violated on the work site, yet “[b]ecause employers know that most workers cannot afford a lawyer, they exploit and harass their employers with impunity” (Bodewes 2005, p. 66). Women seek positions as house girls or office cleaners on a casual basis when full-time employment is not available. Over the years, formal work opportunities have declined while the available working population has increased. *Kibaru*, casual workers, work for daily or weekly wages and much of their work week is spent waiting in line-ups to be hired.

In 1996 King identified the *jua kali* sector (people working in the hot sun) as a sub-set working within the informal sector. These *jua kali* businesses are informal retail or hawking of goods, especially perishable goods such as vegetables, fruits, cooked food, fish, meats, and sweets. Non-perishables include products like cigarettes, charcoal, water, second-hand clothes, and soft drinks. The group makes up 65% of the total informal sector in Kibera and averages between 50 (0.58c)–150 (1.70c) Ksh per day.

UN-Habitat (2004) reported over 73,000 business enterprises in the slum community and 30% of all families operate between one and three such enterprises out of their homes, on the verandas, in roadside kiosks, or nearby structures. Carpentry, tailoring, shoe-making, furniture-making, and welding are among the working activities in the informal employment sector. To supplement incomes, some illegally grow crops on vacant land close to Kibera's boundaries. Crops such as maize, beans, tomatoes, and onions are farmed on the open spaces across from rivers and around the Nairobi Dam. Goats, ducks, chickens, and pigs are reared and fattened to sell for meat. "In the absence of viable income, people resort to theft, prostitution, smuggling, and illegal brewing of alcohol to survive" (Bodewes, 2005, p. 68).

There are a number of individuals – the exact numbers are not available – who start up their own micro-economic business with a small loan from a local NGO. Winnie, my community contact, is one such person. She told me in a personal communication that, "I started hawking bags, sandals, jewelry from money I borrowed" (March 20th, 2006). With a start-up amount of 5,000 Ksh. which is equivalent to approximately \$58 in Canadian money, Winnie was able to start up her own informal business and in a

relatively short time was able to make enough money to purchase three sewing machines to make clothes and to give tailoring lessons to young girls.

### **Donor support**

There are many donor-finance groups that work in Kibera with the main objectives of poverty alleviation, medical assistance, HIV/AIDS awareness, and primary education. However there is a general distrust and resentment towards many NGOs and other groups by those who live in the slum because they see little evidence of money spent to improve the quality of their living standards. NGO staff and researchers alike have earned a reputation for self-interest. Those who go to take pictures to raise money for community improvements are perceived generally to not “follow-through”. One resident commented, “We are not animals to be looked at like on safari, this is our home” (Bodewes, 2005, p. 40).

Kibera, one of Kenya’s colonial legacies, is a prime example of “over-urbanization” driven by poverty; it lacks the most basic of public amenities (Gugler, 1988). An appalling lack of political will in the past has resulted in a lack of infrastructure today which directly impacts on the lives of all who live there. Yet, despite such enormous disadvantages, the people display determination, ingenuity, and resilience in an environment that presents so many challenges. It is within this environment that my community contact and the nine HIV+ women in this study live.

### **My community contact: Winnie Manga Mwarcharo**

Winnie was one of the five women who in 2005 led me on my first walk inside the Kibera slums in Nairobi. I was introduced to her by the male Executive Director of a now defunct local NGO. At the time, she belonged to a “merry-go-round,” a micro-

economic project, one of the activities supported by the NGO and she is the leader of the Ujuzi Youth Organization. As the walk came to an end, I was informed that four of the women were HIV+, although she was not one of them. She and I talked while exchanging e-mail addresses, she makes use of a cyber-station close to where she works.

A 49-year-old grandmother, Winnie self-identified with the Taita people of Kenya and lives in one room with her two sons, Dickson and Jackson, a daughter, Beatrice, and one granddaughter, Patience. She is a tailor, has lived in Kibera for 25 years and works in a small room next to her office space in the compound of the Holy Trinity Anglican Church. For a minimal fee Winnie trains girls from the slums in cutting and tailoring clothes. This Anglican Church compound is close to the Ngong Road entrance to Kibera, yet quite a distance from her home in the heart of the settlement. She is usually in her office six days a week, arriving there with the early morning sun, between 6:30 and 7:00 am and stays until around 4:00 or 5:00 pm depending on what is happening. Every day Winnie juggles multiple tasks: she accompanies women to the hospital, she participates in local community meetings on various subjects such as T.B. education, and she is a member of several “merry-go-round” projects. Her cell phone is constantly ringing and women drop by all the time en route to somewhere else just to say “Jambo” (hello) or talk.

In 2006 when I made the decision to return to university to complete a PhD program with the intent of conducting research with HIV+ women in Kibera, my e-communication with Winnie became more frequent. I forwarded her my research question and details of the necessary criteria for recruitment and selection of participants, requesting her support. She agreed and indicated her willingness to make informal

contact with women who met study requirements. I began the course work for my PhD program in January, 2007.

In September, 2009, all my course work and candidacy examinations were successfully completed and my airplane ticket to Nairobi was booked. One week before I was scheduled to leave Canada, I received e-information that the University of Victoria Human Research Ethics Board would not sanction my research proposal without proof of a Kenyan research permit. Learning that it could take up to six weeks to be issued such a permit from the Kenyan High Commission in Ottawa, Canada, I made the decision to use the ticket and traveled to Nairobi to apply for a research permit in person. The Kenyan National Council for Science and Technology issued me a permit within ten days, yet I stayed in Kenya for three weeks spending time with Winnie in and out of the slum. It was during this time that she first introduced me to Nancy Mwashimba, program coordinator for the group, Darajani Widows Living with HIV/AIDS.

During this stay in September, 2009, Winnie invited me to her rural *boma* (place of birth, homestead) in Voi. She, her daughter, and I traveled on a public, long-distance transportation bus for about six hours in the middle of the night. Winnie's two sons came to see us off, waited for the bus to leave, making sure all their mother's packages and boxes of various shapes, sizes, and weights were secure on top of the bus before they waved us off.

Perhaps there may be readers who are now wondering why this long narrative. I have included it to demonstrate the importance of relationship within an Indigenous community and the necessity of establishing trust by "networking" with those who are included in the circles of my research community contact contacts. I established this

mutual trust with Winnie over a period of time; this aspect of developing relationship in a wider community picture is pivotal to an ethical process in Indigenous communities and was integral for my Indigenous methodological approach.

We arrived in Voi, at the marketplace bus terminal, early the next morning when it was still dark and sat on boxes, ignoring rude remarks from circling strangers, while we waited for the sun to rise. Then we took a taxi to Winnie's brother's home to "drop off" sugar and other supplies, her sister-in-law made us *chai* (tea) and *mandazi*. We traveled in the same taxi to the marketplace which was now swarming with people and caught a *matatu* (privately owned mini-van) to her family compound. This journey took approximately three quarters of an hour.

As the vehicle sped along it took us into terrain with less signs of human habitation yet many signs that elephants were nearby; tree trunks were stripped bare, branches broken, and elephant dung littered the landscape. When we arrived at our destination, a thatched lean-to in the middle of no-where or so it looked to me, Winnie nudged me into wakefulness. I stumbled down the vehicle steps and watched as everything belonging to Winnie was quickly untied and thrown higgledy-piggledy to the ground. The *matatu* left in a cloud of dust and I received the first layering of red topsoil as I gasped for air and rooted in my bag for something to cover my nose and wipe my face.

Several cellular phone calls later and a moderate wait, a group of three women appeared in the distance, walking directly towards us; one of them was Winnie's sister. Packages were silently and quickly lifted onto heads, others were left to be collected later, and we began walking toward the *boma's* compound. We entered the compound by

moving aside and passing through a sturdy wooden gate in the middle of a man-made fence of thorny bushes; one woman made sure the gate was replaced securely.

Winnie introduced me to her family and friends who undoubtedly “checked me out” and reported back to her. I am sure they wanted to see if I was an honest and authentic person with *moyo* (heart) whose motives for being in Kenya were not purely self-centered or for self-interest.

We stayed overnight. I shared a bed with four other women in a *rotunda* (round house made of wattle and thatch) and met her father, mother, and sister, others in her family, neighbors, and *rafikis* (friends) who came from every direction to see and talk with Winnie. Knowing I had an interest in elephants, Winnie’s father took me on an elephant “trek.” Together with Winnie’s daughter, we set out in single file quite early the next morning to look for a small herd of elephants that had been sighted passing by shamba (farm) fences on their way to water the day before.

The reader is now familiar with the environment in which Winnie and the women in my study, with the exception of one, presently live. Winnie introduced me to the nine women; now I introduce them to the reader. Each woman is introduced by way of a short haiku-like poem that speaks to the essence of my relational experiences with each one.

### **Meeting the women**

#### **Amina Abdul**

Pragmatic woman.

Relaxed.

Comfortable in chair,

in her skin.

Amina Abdul tested positive for HIV infection in 2001, one month after the death of her husband from complications caused by the chronic illness. At that time results were not known immediately so she waited two weeks to learn of her positive status. ARVs were very expensive at that time. A friend referred Amina to a United Nations Children's Fund [UNICEF] clinic where her blood was tested again and ARV medication was given free of charge. Because of an allergic reaction and the development of a "hollow look" to her face, her initial ARV drug treatment was changed and having no adverse reaction to these drugs she continues to receive a three month supply of the second ARVs from this clinic. She comments, "I do not consider myself sick because I am O.K. ... I am taking drugs, I'm O.K. I'm doing my job. I'm happy to live, I'm living. It's almost ten years, I'm still alive."

A member of the Nubian ethnic group, Amina is 33 years old, was born in Kibera and presently lives with her three HIV negative children and one sister. Because she is receiving free antiretroviral treatment, her medical condition is no longer her main worry; she is now more concerned about finding money to pay school fees and providing food and shelter for her family. Although UNICEF provides money for one meal every school day, she has to pay extra for the cost of cooking fuel and for the services of a cook.

Amina works three days a week outside of Kibera for a woman who works at Kenyatta Hospital. She walks one hour each way to the woman's home where she cleans, washes, and irons clothes and prepares meals for the woman and her children. She finds it difficult to request time off work from her employer for regular medical check-ups and to receive the next supply of ARVs saying, "It's very hard to ask for them – they let me go

to the clinic, they ask me, ‘What doing for?’ You know, some people, they don’t want people who have HIV to work for them.”

Her mother and sister were very supportive of Amina when she first learnt of her HIV+ status and encouraged her to attend post-test support groups. She finds these groups helpful, has made many friends and when attending, “feels happy ... from making our stories.” Although she keeps her positive status a secret from those she suspects may discriminate against her, she is not afraid to talk openly about her own experience to use as an example to newcomers in groups. Amina feels “... like a born again” since learning to live as an HIV+ woman and has come to understand that “the thing that killing people is stigma.” Stressing the importance of HIV/AIDS testing she acknowledges that adults must choose to take the test and believes, “they [adults] are not kids, they are not small; you cannot catch them and check [take them] the hospital, no – you have to talk to them, just try.”

One day when her children have completed school and she is still alive, Amina intends to tell them her story. Her children are a great source of strength and she prays for them to grow up, get jobs and get wives so she can become a grandmother. She also finds comfort in attending a mosque some distance away from the community in which she lives because she wants to protect herself from stigma and discrimination.

Amina lives positively knowing that death is always there and comments: “Because death is there if you don’t have – if you don’t have HIV, if you don’t have HIV, death is there, yeah. You will die, one day, one time, yeah.”

**Amina Bashir**

Beautiful peaceful woman.  
Composed in quiet strength  
of purpose.

Amina's husband, a policeman, traveled to her village, Baringa, to marry her and bring her back to live in Kibera. She is 32 years old and belongs to the Nubian ethnic group.

In 2004 when she was pregnant with her third child, she tested positively for HIV and tried unsuccessfully to persuade her husband to accompany her for couples' testing and he refused. After he "started to be a bit violent," she considered leaving him and commented, "I had to get courage, I had to compose myself very quickly because [of] the other kids. I, I had already two boys ... Because my husband was not ... somebody what I could trust so much to take care of the kids. So I composed myself and pick up."

Returning home from the hospital after the birth of a healthy baby girl, Amina found her husband gone to marry another woman and she had little money. Within a week she was working by taking care of another family outside of Kibera. Still bleeding and weak from giving birth, she wrapped a *lesso* (piece of material used for clothing) tightly around her middle and kept her eldest son from school to care for the baby and feed it watered down milk. Her employer was a kind man who gave her extra money and food to take home after he learnt of her circumstances, yet Amina became very sick. She had a breakdown and commented, "It [the sickness] had already become so worse. I could not wake up from the bed, I was sick ... my baby was now crying, just cry. I could

not even lift her because of the stress.” So she called her sister in Baringo who came immediately and helped her emotionally and financially.

When school was closed for holidays and her husband had given his permission, Amina and her children traveled home to her rural village where they were taken care of by her mother and sister. One month later she returned to Kibera, “I was changed completely ... I was just like normal.”

Amina’s husband became sick and his mother consulted with witch doctors in Kenya and Uganda who accused her of being a witch and putting a curse on him because he had married another woman. However, when he was able to walk, her husband came to see her, apologized for infecting her with the virus, and together they threw witchcraft articles in the local river. Later when he again became sick, she nursed him during the day when his second wife was at work and her children were at school. When he became extremely weak, unable to walk by himself, she carried him on her back to Kenyatta hospital where two weeks later she remembered, “He just died. And I lost him like that.”

To generate money Amina makes and sells “ice” (a sweetened crushed-ice drink) and *mabuyu* (a sweet prepared by heating, coloring, and sweetening bits of seed from the Baobab tree). She said, “If you have no income, it becomes difficult, difficult, very difficult to run your family because everything is money.” And so she also washes clothes for other people and braids hair too. Amina is a community activist volunteering her time as a paralegal to deal with the many issues in Kibera regarding issues of family and child abuse.

Her Muslim faith keeps Amina strong and because “the rate of people dying here [Kibera] is very high,” she continues to speak openly about the need for HIV testing. Her

children provide her with hope, courage, and strength “to live more than the other person [who is not infected] .... I really want to see my children learned so that they cannot – they – they cannot live the life I am living now. They can be employed. I believe they will help me on the future because I still have life ahead.”

**Loise Anyango Mango**

Smiling face woman.

Walking, talking, selling

Tomatoes, green and red.

Loise cancelled her first appointment for an HIV/AIDS test as she “really felt bad” when she realized her life had been at risk because of secrecy surrounding her husband’s health diagnosis; he, his family, and doctor kept the information a secret until his death as a result of HIV/AIDS. When she was hospitalized for the first time, she remembered his relatives “knew I’m HIV. And actually, they thought I was going to die the very week, Even that had decided, taking my properties. Even the blankets, they [relatives] were carrying – they saw me as I was just useless.”

She is the mother of three children, belongs to the Bahuya group of Africans, and is 34 years old. Diagnosed in 2005 as an HIV+ woman, she has been hospitalized twice since with respiratory complications and is very wary of catching cold so no longer washes clothes for other people as a way to make money. Instead she makes hard soap from “leftovers” she collects from Nairobi’s industrial area and sells it. She also sells tomatoes, onions, and groundnuts, which are peanuts she roasts to make tasty. Not having a permanent place to sell her wares, she walks around Kibera villages selling directly to customers who contact her by phone or text messages.

When Loise was hospitalized it was the church that paid her rent and provided support for her and her children. She is a member of the Mothers' Union and helping others "with what I have" gives her a sense of accomplishment. She thinks most days she is a "happy woman because, nowadays, waking up, if even the next day is not very easy, so thank God and when you're – when you wake up normal, you must be happy."

Loise believes it is her faith in God that has allowed her to carry on with her life, "to go in the market again and to live to this day."

### **Lucy Njeri**

Capable woman.

Looking for new home,

Making *bajia* to pay the rent.

Lucy, a 33-year-old Kikuyu woman, and her five children had nowhere to live when I first met her. The landlord had locked all her belongings inside her home because of unpaid back rent and her family had been unwilling to support her financially or otherwise.

When she was in hospital being treated for tuberculosis in 2004 Lucy tested HIV+. Upon learning of her positive status her husband immediately left her and moved in with another woman; he died of HIV complications in 2006. She had been hospitalized several times and the last time her mother expected her to die, telling Lucy's oldest child, "If your mother die, I take these boys to the children's home and you go and find the work for bar."

Lucy believes she has changed since learning of her HIV+ status, "I see different, I learn my body." She no longer drinks and no longer has sex with men, saying, "Escaped

that because you drink you die: You sleep with another man you will die. So I stay me and my children, I try to work hard because of my children.” Making *bajia* (round, spiced pieces of potatoes that look yellow when fried) which she sells from the roadside is how Lucy generates an income.

Attending support groups and performing in local drama skits are activities that Lucy enjoys. She is often asked to play the patient in scenarios that promote community awareness of health issues such as tuberculosis and the need for personal hygiene and cleanliness in homes. Lucy takes pride in being a “good” parent and says, “I’m a good mother! I want my children, ‘you know this, you come and sit...’ If your children, they don’t know how to work in the house you get trouble.” She attends church regularly and, when having a particular challenge, will stand up at the appropriate time and ask the congregation to pray for her. She believes strongly in the power of prayer and because she now feels well she proudly announces, “I’m O.K. I see the miracle in God.”

### **Mama May**

Visiting woman.

Caring for grandson

While searching for a daughter.

Mama May has been caring for her grandson for eighteen months. She lives in rural Machakos, an approximate two-hour drive from Nairobi and has lived in Kibera “on and off” since 1987. She is a 43-year-old Kamba woman who returned to Kibera this time to look for her oldest of three daughters to return her young son.

Mama May became a widow in 1982 when her husband was killed in a work-related accident in the Congo. Shortly after her husband was killed, she was chased away

from her husband's home and land by his relatives who shouted after her, "What are you doing here in this home? I don't want to see you. You don't have a baby boy; you only have ladies who can't care for the family." It was not until 14 years later that she tested HIV+.

Learning of her positive status, Mama May became so distraught that she climbed the hospital stairs to the ninth floor with the intention of killing herself by jumping from one of the open spaces that serve as windows, "I wanted to throw myself, to die. Me, I was thinking that time of just going in the coffin." She was prevented from jumping by another HIV+ woman who had followed her and talked with her about free antiretroviral treatment and of living positively as an HIV+ woman. Mama May continues to receive only one month's supply of the necessary drugs at a time and has been warned by doctors, "Listen, we are going to change this medication because this one is not working. But if you don't use ... new medication properly, Mama May, I'm telling you, there is no third life if we put you on second, second life." She continues to look very thin and is often told that she is not eating a balanced diet to which she responded, "Now to eat properly, is when you have money. I don't have money." She remembers a time when she had no money and so chewed her ARV drugs thinking that would replace solid food in her stomach.

Mama May worked as a bar maid in the same bar for seven years and presently has no regular work for which she gets paid and said, "No, I'm not working, I have my children to rely – rely upon. I rely on my children and I'm not working; I'm a single parent... and the young men, they don't like me." However, she recently learnt in a

community workshop how to make cooking fuel from paper and hopes to make some money from this activity when back in Machakos.

She finds attending support groups helpful, “the pains in my head disappear” when she speaks out about her life as an HIV+ woman. She values the emotional support she receives by sharing, talking, and being with other HIV+ women and appreciates people who are “socializing with me, keeping me time to talk with me, to stay with me.” Living as an HIV+ woman for Mama May “is still hard ... You know, you cannot build a house without a foundation. It isn’t enough to put stones down the foundation. But now, I’m zero negative because I don’t know where to start and where to head.”

**Penninah Ngina**

A softly spoken woman.

Preparing mouth

To open, shout loudly, smile.

It was in 2008 after “always being sick” that Penninah, a 38-year-old Kamba mother of five, tested HIV+. Then she knew little about the illness and thought it was a death sentence.

Penninah did not know what her husband died of in 2005 and, when she learnt of her positive status, she was living with another man. When she disclosed to him her HIV infection, he left her and returned to his wife; “He ran away, he went to a – the wife, has a wife at home.” She became very sick and called her youngest sister who came to support Penninah until she became strong enough to start work again selling sweets and clothes. Before becoming sick, she used to make chips (potato fries) and buy *sumawiki*

from the retail market in Nairobi to sell in Kibera. She no longer has the strength to carry the vegetable bundles on her shoulders or walk the distance both ways.

On the days Penninah does not feel well enough to sell at the side of the road, she stays home sleeping because her “head is achy.” Support groups exclusively for women offer her comfort and she said, “When we are into this support group ... we are like twins, we are like friends, we are like the childrens of one parents ... because we share stories for helping.” Penninah loves her children and worries about what will happen to them if she dies soon and “goes away.” She has not told her children why she takes “dawa” [drugs] regularly as she does not want “to make them to be always thinking about their mother.”

Going to church is an important part of Penninah’s life. She attends a church service every Sunday and prays at home each day. She believes that “God is the One who will make me to be – now. I am going to pray Him ... always caring for me.”

### **Sarah Chelangt**

Big-hearted woman.

Buying, selling chickens

To care for ten children.

Sarah, a 41 year old Kalenjin woman, shares a two-roomed home with ten children and another HIV+ woman and her two children. She has five children of her own, cares for her sister’s four children orphaned by HIV/AIDS, and one grandson.

Her husband died in 2003 from tuberculosis. Two years later she began to feel sick. It took much encouragement from her eldest children to persuade Sarah to have an AIDS test in 2005. When the result was positive, she became extremely distressed. Again

with a lot of encouragement from her children and counselors, she began to attend relevant support groups and to learn about living positively with the disease. She said, “I see so many persons I know in that room.” She came to realize that to “stay alone” is not good for her and when with other HIV+ women sharing stories, she feels free and is given *moyo*.

Sarah makes use of several “merry-go-round” micro-credit systems to buy and sell chickens by the side of the road. When she is unable to sell the chickens herself because her grandson, who is HIV+, is sick or she needs to attend a clinic, a neighbor will help out, yet she always wants to lock up the chickens safely for the night. Her oldest children contribute to household expenses whenever they can by washing and cleaning shoes and cars.

She keeps her HIV+ status a secret from those she suspects may discriminate against her and is concerned that, if her status becomes known, she may be asked to leave the compound in which she lives. Sarah is most concerned about what will happen to all the children in her care if she were to die. Even in the rural area of Kiecoh where she was born, she does not have legal title to land. She knows her mother will not be around much longer and thinking of a future for her children causes her a great deal of stress. Sarah does not want her children to gravitate to the streets of Nairobi and become *chokora* (street youth) if she were to die and make them orphans.

A deep faith in God provides Sarah with an inner strength and helps her to live day-to-day. “When I talk to God, I feeling well ... my body is – is – feeling well,” she says, and prays to live another twenty years to be there for her children, yet worries that this may not be. Going to church regularly and talking with her Pastor gives her hope and

encourages her to live each day. She asks God for “another years or more years. Even now, I feel well. I say, God help me and keep me another time too, yes.”

**Zakia Yusufu**

Tall, wise woman.

Walking like a lion.

Proud, determined to succeed.

Zakia is a 43-year-old Muslim woman who belongs to the Nubian ethnic group. She lives with her 13-year-old son. In 2004, her husband was killed by robbers on the road and she began to notice marked changes in her health. A niece encouraged her to go for an AIDS test and, after requesting a second test to confirm the diagnosis, she reluctantly accepted the fact that she was HIV+. When she became so weak she was unable to care for herself or her son, she went to stay with her mother who was unsupportive and isolated her and her son to one part of the home. However, her grandmother did support her, did not stigmatize her, and gave her confidence to regain her health. Zakia found ways to generate an income again and move into a home of her own once more.

Before she tested positively, Zakia knew little about HIV/AIDS but then made a concerted effort to educate herself about all aspects of the disease. She now lives by the creed, “Forward ever, backward never”. She sees herself as an HIV/AIDS ambassador and says, “Yeah, I’m empowered. I’m walking like a lion because I’m proud. I know what I’m going through; I know how to live ... I, I’m ready to counsel even someone who is tested.”

Before she knew of her HIV+ status, Zakia was a hairdresser working in a high-end salon in Nairobi. She no longer works in a salon although she continues to braid hair for people in the community. She supports herself and her son financially in other ways, too.

She makes liquid soap, washes clothes, crochets tablecloths, runners, and antimacassars; she also cooks and does catering when called upon. She makes a point of networking with men and women outside of Kibera because there is always the possibility of a call for work of some sort.

A devout Muslim, Zakia attends a mosque regularly; it is her deep faith in God that gives her the strength of will to get up each day and continue with her social justice activism, the volunteer community development work she engages in. She acknowledges that some Muslims remain in denial concerning the presence of HIV/AIDS, and that contributes to the spread of the disease. According to Zakia, “a lot of Muslims doesn’t ... want people to know that are living with HIV because ... it will mean that these people ... are ... going out of ... their faith.” She contends that, by not accepting people living with HIV/AIDS as being in need of various levels of support, those Muslims are also “going out of their faith” because the Koran teaches that “man must care for his neighbor.”

**Zuhura Odhiambo**

Gentle, hard, shrewd woman.

Looking to future

For heath, good fortune.

Zuhura, a Nubian Muslim woman, was born in Kibera, is 36 years old, and lives with her four children. She became a widow in 2001 when her husband died from HIV/AIDS complications, yet it was not until five years later when she was pregnant that she became aware of her own HIV+ status.

Before she became sick, Zuhura was a professional cleaner for several years until her employer requested that all employees be tested for HIV. Although it is illegal to fire someone just because they are HIV+, she was afraid her secret would mean her dismissal. She commented, “And now you are afraid to continue to work; you did the work ... You come back and stay in the house.” Zuhura talks of a future when she will feel stronger and once more find a professional cleaning job that pays her well. When she is not “feeling down” she makes samosas for people to buy from the roadside and washes clothes for other people saying, “But people who know me. They just call me. I go one day. I wash, I put on the lines, they pay me, I come home.”

Zuhura’s mother, also a widow, cooks *ugali* (maize) and *sumawiki* each evening for her and her grandchildren; after eating they return to sleep in their own home. Two of her sisters know of her HIV+ status, yet Zuhura does not think her mother or children know. Unsure of the local community’s reception should they learn about her health condition, she remains protective of her children and does not want them to experience any discrimination as a result of HIV/AIDS-related stigma.

Having lived in the slum all her life, Zuhura has come to accept that “[y]our problem is your problem here in Kibera. Now you fight for yourself to get what you want.” She is wary of many support groups where nepotism reigns and “those at the top” are only interested in statistics and the use of names for funding purposes. Being a

founding member of Darajani Widows Living with HIV/AIDS, she feels included in group decisions and comments, “When we are together, we are free, very free. We talk very nice.”

It is her children who give Zuhura both hope and strength. When she senses the respect they have for her, it makes her “feel strong and want for my children a good life.” Being solely responsible for her children is a constant challenge and causes her a great deal of stress in dealing with their “problems” because, she says, “Their problems, sometimes, I don’t know what is right... they need this and this, you start to stress, you become sick again ... Stress, I think stress is the biggest thing that – that make people go down.”

A practicing Muslim, she follows the principles of the Muslim faith, prays five times a day, and attends a local mosque. One of her future goals is to educate Muslim women about HIV because, “You know, Muslims, they don’t accept HIV/AIDS.” She knows that anyone can become infected, and is aware that, even though ARVs may prolong her life, she may not live as long as she would like. “You don’t know what God is planning for you. But I’m willing to stay long.”

### **Summary of the research participants**

The nine women in the study are all active members of the Darajani Widows Living with HIV and live within a walking distance of fifteen minutes from each other in the villages in Kibera.

They range in age from 32 years to 43 years, a span of 11 years. One woman is 43 years old; two women are 41; one woman is 38; one woman is 36; and one woman is 34.

Two women are 33 years old and the youngest is 32. The average age is 37 and among them, they have 331 years of wisdom (Table 1).

The women belong to five different African ethnic groups. Amina Abdul, Amina Bashir, Zakia, and Zuhura are members of the Nubian group; Mama May and Penninah are Kamba. Lucy is a Kikuyu, Sarah is a Kalenji woman, and Loise belongs to the Baluhya ethnic group. Four of the women have lived all their lives in Kibera. Five women were not born in Kibera; they were born in rural areas outside of Nairobi and still have relatives or other contacts living in villages there.

One woman's husband died twenty-eight years ago in a work-related accident in the Congo where he was drilling a borehole. The other eight women became widows during a five-year interval, from 2001–2006. Five women reported that HIV/AIDS was the cause of their husband's death. One woman was informed by medical personnel that her husband died of tuberculosis, most probably complicated by the HIV infection, and one woman's husband was killed by robbers. One woman reported that she did not know the cause of her husband's death.

It was in 2001 that the first woman in this study group was diagnosed as HIV+. In 2004, four women learnt of their HIV+ status, and the next year, 2005, another woman tested positive for HIV. In 2006, two more women tested positive and, in 2008, the ninth woman found out she was infected with the disease. The average time length of knowing their HIV+ status is five years.

Three women learnt of their HIV/AIDS status before the death of their husbands. Four women became aware that they were HIV+ after the death of their husbands, and two women tested positively in the year that their husbands died.

**Table 1. Women in the study.**

| NAME     | AGE AT TIME OF INTERVIEW | ETHNIC GROUP | BORN IN KIBERA | YEAR WIDOWED | YEAR OF HIV DIAGNOSIS |
|----------|--------------------------|--------------|----------------|--------------|-----------------------|
| Amina A  | 33                       | Nubian       | Yes            | 2001         | 2001                  |
| Amina B  | 32                       | Nubian       | No             | 2006         | 2004                  |
| Loise    | 34                       | Baluhya      | No             | 2005         | 2004                  |
| Lucy     | 33                       | Kikuyu       | Yes            | 2006         | 2004                  |
| Mama May | 41                       | Kamba        | No             | 1982         | 2006                  |
| Penninah | 38                       | Kamba        | No             | 2005         | 2008                  |
| Sarah    | 41                       | Kalenjin     | No             | 2003         | 2005                  |
| Zakia    | 43                       | Nubian       | Yes            | 2004         | 2004                  |
| Zuhura   | 36                       | Nubian       | Yes            | 2001         | 2006                  |

Four women each have three children and one of these women presently takes care of her grandson. Two women have four children each, one woman has five children, and one widow has one child. One woman has five children of her own and cares for her grandson and her dead sister's four children. Presently, the nine women in this study are responsible for the care of, in total, 36 children.

These widow women gave birth to 30 children in all; all these children have, to date, tested negative for HIV/AIDS. Two women had a child after the deaths of their husbands and after they had tested positive for HIV. One woman's three daughters were born after she was widowed. Twenty-five children were born before their mothers tested positively and before the deaths of their fathers. One of the women has the care of her

grandson as well as caring for her sister's four children. Her grandson was being treated for tuberculosis and was receiving antiretroviral drugs for HIV/AIDS at the time of my data collection.

**Table 2. Women in the study and their children.**

| NAME     | NUMBER OF CHILDREN | AGES OF CHILDREN             |
|----------|--------------------|------------------------------|
| Amina A  | 3                  | 17 / 15 / 13                 |
| Amina B  | 3                  | 13 / 18 / 4½                 |
| Loise    | 3                  | 17 / 15 / 10                 |
| Lucy     | 5                  | 19 / 16 / 14 / 12 / 1½       |
| Mama May | 3                  | 23 / 15 / 12                 |
| Penninah | 4                  | 18 16 / 14 / 12              |
| Sarah    | 5                  | 24 / 23 / 20 / 18 / 16       |
|          | 1 grandson         | 6                            |
|          | 4 of sister's      | 15 / 14 / 13 / 5             |
| Zakia    | 1                  | 13                           |
| Zuhura   | 4                  | 17 / 13 / 12 / 2 + 10 months |

In the next chapter, Chapter 5, Interpretative Findings, I provide the interpretative findings of my research data collecting in Kibera.

## Chapter 5: Interpretative Findings

The main purpose of this chapter is to interpret the answers to my research question, how do HIV+ women in Kibera, Kenya experience and participate in their community and story their lives? Through narrative analysis, I have identified nine storylines which serve as sub-plots in the overall *story-ing* of the nine HIV+ women's daily experiences in the face of poverty. The storylines are:

Beginning the day

An African woman

If I die, who will look after my children?

They just come to you

If I sit there, that ten bob won't come

Being up, feeling down, and stress-up

I am stigma

Living with HIV is a challenge

Ending the day

As the narratives emerged, I could see that the stories were embedded in the invisible social and political systems in which these women lived. Bringing them to the surface they become visible and I hold them in the light for examination purposes. Nevertheless, no matter how mindfully I engaged in this process, it was impossible to segregate one linear storyline from the matrix of interconnectedness that is the descriptive analysis. Each storyline is supported by quotations taken from the recorded transcripts of conversations.

### **Beginning the day**

I get up very early in the morning. At five, I take my shower, I clean myself, then I go there [work on Monday, Wednesday and Friday]... usually at six-thirty... I cook for them [children]. I leave for them when they are preparing for themselves, they going to school. Then I leave them there. I just go. (Amina Abdul)

### **Waking up to start the day**

When feeling well the women get up in the morning, often before or as the sun rises, to begin their day. They get up early to prepare their children for school and themselves for their daily business and activities in the community.

Zuhura begins her day, "A usual day? When I'm fine, I'm just strong. I wake up very early. At five, five thirty because my children are going to school, I prepare them for school."

Sarah wakes to begin her day,

I'm wake up ... maybe five-thirty or six, early in the morning because my children she's [they're] going to school. Now sometimes, when I am not feeling well, I am wake up maybe at seven-thirty and then I do my job in my house.

Feeling well, Lucy gets up at quarter to six. She wakes the children and spends time with them making sure their school uniforms are clean and presentable and they have tea for breakfast before telling them to go to school. Then she leaves her house and is free to continue with her day. "I wake up the children. ... Then [I] cook for them. I tell [them] to go to school. And me, I go to the market to buy some potatoes to continue my business" (Appendix G).

Like the other women, Loise's days are long and busy, with the exception of Sundays when she goes to church and will not work selling consumables. She rises early to prepare for her day of delivering tomatoes and soap to customers,

When I ... wake up at fifteen minutes to six, prepare my girl to go to work. Then from there I set doing my housework. After that, I go in the market to bring some tomatoes and to whatever. At times, I don't do that. I go to sell my soap in the morning up to ten. Then I come, I pass in the market, get the vegetables now, tomatoes and whatever which I sell during the daytime.

Penninah rises from her bed a little later than some of the women, at seven o'clock. "When I wake up ... I prepared breakfast, then after that I pray for about ten minutes, then after that my time for medicine....then I ... go about my business."

Mama May does not have her own home in Kibera; she stays with friends and so her time of waking and getting up is determined by the daily schedules of those in whose home she stays. She describes staying with her present *rafiki*, "That woman wakes up around five because her children goes to school, even the woman, she's working ... Even there, I just prepared that child, when she wash ... I took her to the school."

### **A busy day**

Amina Bashir gets up exceptionally early. Like the others, her day is full, she says:

I normally get up; it's around four-thirty because my son has to prepare himself to go to school. So I wake up very early in the morning ... I will wake him. We take a thirty minute preps with him (to go over homework) ... for school. Maybe he has homework, he has something he wants me to help him, so I help him all – for about thirty minutes. And then at five, I leave him to prepare himself and I starts preparing tea for him. I prepare tea. At around six, he's gone. I wake the second born ... and then I prepare him. At around seven, he's gone. And then I wake

the last-born is in nursery school. I start preparing her because she's a girl. At seven-thirty ... I make sure I take her too, to school. From there, from school, I go back to the house ... Then I start preparing myself... There are some days that I have to go and wash clothes for people. ... At eight I go ... to somebody's house. I start washing ... Maybe I wash for ... about three hours or two, depending on their clothes. After washing, finishing the duty there, I come back to my house... then I will go to see what I have – clients who are waiting for me ... in the organization ... if there's problem, if there's an abused child. ... That time I settle with them the problem... if it's a case to be taken forward, I document and then I take forward. And then after that, it's around two, I make sure I take my ... lunch if there's lunch, or if there's porridge, I prepare some porridge. Then at around two, I start my duty in the house. I start ... washing my clothes, maybe washing the utensils... and then I have to take a rest for at least thirty minutes. ... I rest and then at four, my daughter comes back. When she comes back, I make sure she's O.K. in the house, give her each day something ... dress her. And then I leave if there is something I have to go and do, then I do. And that time, I come back, I prepare supper. After supper, my ... first-born comes back at around seven. We start reading again.

Zakia tells her story of a usual day in her life. Her narrative illustrates well the busyness of her day, from waking in the morning to closing her eyes in sleep at night.

How I spend my day? I wake in the morning first of all. I wake up, pray. After praying, preparing my boy for going to school ... make some tea for him ... to take and walk out to school. And then after that, I plan for my own things ... if I want to sell some soap, if I have some customers, I just go and distribute my soaps. If I have a customer who wants to plait ... we arrange and go, do whatever I do... if I don't have water in the house, I go and fetch some water, clean the house, prepare the house... if at lunch time, I prepare something to eat. Rest and pray again, the prayers of the afternoon. Just moving around doing some little, little work in the house.... Sometimes some programs come in between. ... I have my plans. If we have to go sometimes for meeting, we normally work with other people in the community, ... I Just wake up early, pray, prepare my boy, go to the centre, go to the facilities, go to the community ... and door to door campaign. ... My boy come at five, after

school at five. ... and he has his own keys. I've just already set him what he's supposed to do – come and change. Take a bit of – sometimes tea and sometimes he normally go to the mosque for prayers and sometimes, he go and read ... there's classes there for Islamic teaching. ... up to sometimes six-thirty. After coming back, we walk out there, go for prayers, we come and prepare our supper. So we eat... we pray and sleep, early.

### **A different busy day**

There are days the women are busy in different ways. When they go to the clinic or hospital for regular check-ups or with a sick child, they expect to be there for most of the day. Then they are unable to go about their usual business of the day and generate money. Loise explains,

Yeah. It's always busy. Now like to-day. I have woken up at that time, prepare the girl, now I want to do my housework. I want to go in the clinic. Now that's when I come. I think today, selling things, it's God who has brought me this to-day. ... I come from that place [clinic] and [not] be able to go to ... the market again, it will be difficult. Because always with the Kenyatta [hospital] you stay for almost a day.

### **An African woman**

When you are living as a woman ... you have to be strong. Because in Africa, you are supposed to be strong... a woman is there to stand for everything. When you don't ... give yourself courage ... every thing will go apart, because you are there for your children. ... If you don't advocate for your rights ... who will advocate ... for you? (Zakia)

These women currently live alone with their children. They tell stories of gender inequalities that have shaped and continue to shape their lives and the lives of their children.

### **Learnings from the past**

When Zakia was younger she lived with her mother in Nyeri, a rural area outside of Nairobi. She remembers that her mother had a job there on a coffee plantation and was “always busy, busy, busy.” Zakia witnessed the hard work the women did there; planting and harvesting coffee, fetching and carrying firewood on their backs, transporting water, taking the goats and cattle to fresh grazing land every morning and bringing them back at night to the safety of the compound, providing the men with buckets of water for a bathroom shower, serving tea, preparing and serving meals, and caring for the children. She silently watched and remembers the differences she saw in the roles of men and women,

They [women] are the one – to maintain the house, the children, the garden – to make sure everything is clear in the compound. The men doesn’t want, they wake up, ‘I want tea’. The tea is there on the table.

Although Zakia now lives in an urban area and is older, many of the gender traits and scripts she observed when younger are still re-enacted within Kibera’s communities by women and men. Zakia describes the strength of African women and their role,

Women in Africa are very strong. Because we know – we have already see the house which have no woman. The house is not stable. It’s not stable at all. ... they [men] want cattle there, cattle, because they know these cattle bring them money. ... if they [men] have money, getting to the hotel, eat and come and sleep. ... they are not caring even for the children. ... So if the woman gone, the children have to take over what the women do. (Appendix G)

Zakia knows from experience that women may be physically disciplined by some men for speaking out of turn too loudly in order to make their needs known,

A woman talking ... in front of a man? NO ! ... if you want something, you have to lie low, talk softly, ‘ I want this’.

Experience learning from this. But you are not there to talk loud. If you talk loud ... they will even cane you.

*This contrasts with Zakia's later comment when she talks of "walking like a lion."*

*The silencing of women's voices when younger may contribute to a reticence on the part of women to disclose their HIV+ status, especially to a male partner, and the promotion of keeping secrets.*

### **Boys and girls become men and women**

Mama May refers to the importance of the birth of boy children in the rural area where she lived with her husband on his family's land before he was killed. When her husband died, she was chased away from her husband's home and land because she had given birth to three daughters and no son. As she left that land, she remembers these words ringing in her ears; "What are you doing in this home? I don't want to see you. You don't have a baby boy. You only have ladies who cannot take care of the family." *Yet, it is the "ladies" who are taking responsibility for the care of their families in Kibera, as this study demonstrates.*

Children have traditionally been viewed as an investment in/for the future. It was the expectation that male children would, in time, take care of aging family members and the family property and land. Mama May's experience supports the importance given to the difference in worth of male and female children within some contexts. She talks of gender differences embedded in Kenyan societies with/by the use of a chicken metaphor:

They [men] don't cook or sell the chicken. Women know the insides of a chicken. It is the women who raise or buy the chickens, kill them, dress them, cook them and feed them to their families. Their families depend on the women for nourishment.

### **Left alone with the baby**

There is a gap of ten years between the birth of Zuhura's last daughter and her previous child. She spoke of the human need to be close to another human being, to be touched, and to share life with a man. Zuhura's commentary suggests that she feels responsible for transmission of HIV,

You see, the thing is that you need someone, that someone tells you, "I love you." Now you just come and stay together, where this person is staying. You get children. You get your children, this person ... hates you again and go. That's the life people live in Kibera. Men – most men ... even now, I don't trust any man. Since ... I got Miriam, you saw Miriam, and the baby, they are – duration of ten years, because I trusted also the father of the baby, ... before I know I was HIV positive ... I knew when I was pregnant with a small baby. When I went to the ... clinic, they go and diagnose me, they find I am HIV positive... but now I can't trust. ... I tried to talk to him, he could not – even he doesn't try to see me. ... Now we got this baby, but he just left the baby, like, that's now ... he did not care any more about the baby.

And Zuhura, like the other widow women, is left alone bearing the responsibility for the care and well-being of her children as well as coping with life as an HIV+ woman.

### **Women support women**

Amina Bashir's husband, a policeman, drank and had "started to be a bit violent" during her third pregnancy. He married another woman while she was in hospital giving birth to a daughter and left her with little money or provisions. Returning home, she was shocked by her husband's absence, yet had to quickly adjust to the hard fact that "my husband did not want to see me or even the children."

After becoming really sick and unable to meet the daily needs of caring for her children, she called a younger sister in her rural family village. The sister immediately

came to Kibera and provided money for food to feed the children while encouraging her to return to her family *boma* to recuperate. According to cultural tribal custom, consent was required from the husband even though he was no longer living with her and had taken a second wife. Amina Bashir was grateful for her sister's company and commented,

I found my sister being very good. She encouraged me and told me I was not going to die. ... She told me I have to have courage. And that's the thing – I thought maybe she would run away, but the ... first step she showed me, it was so nice. She came, we talked. She stayed with me for one week. ... She told me, 'Now I'm going to leave you money, and [when] the school is closed, you just come home with your children. We'll do anything and see whether you improve. And I told her, 'O.K.' Then she called my husband and told how bad [how sick his wife was], she's going back but when school was closed. Let him give me permission to go home, to go and rest a bit. Okay, when the school was closed. I went home. I packed my clothes and my children's' clothes, we went home. And we reach home, she was so good. She cared – she took care of me so much, so much. Every time I was getting food .... She was encouraging me. When I came back from home ... after one month ... I was changed completely. ... I was just like normal. (Appendix G)

Amina Bashir and her children were cared for by her sister and mother. She became stronger and was introduced to another HIV+ woman whom she remembers well,

[A]nother woman who was positive, even before me. And the woman talked to me, has told me that she has slaved even more, longer than me, and ' I still have years to live ahead of me and take care of my children.' So by that I had – I was sleeping nicely, I was – had no stress completely. So I came out when I – was – different.

*I find it interesting that Amina B. used the English word "slaved" in the context of talking about caring for children. Whether this was deliberate or a problem with language translation would require more research and I did not pursue it in this study.*

### **A witch to blame**

After Amina Bashir returned to Kibera and continued to feel well, she was told by a brother-in-law that her husband was now sick. She was also informed that his mother accused her of being a witch and putting a curse on him because she was jealous he had taken a second wife. Amina Bashir was held accountable for her husband's deteriorating condition by his family; she was spoken of very negatively by many in his family circle. She remembers that a brother-in-law visiting in Kibera told her, "Your husband is so sick and he's at home and ... they are going to Uganda to seek for medication from another witchcraft." *It is not uncommon for those who have had no exposure to HIV/AIDS community education to associate symptoms of the disease with practices of witchcraft, especially in rural areas.*

When she felt strong enough to travel again, Amina Bashir went to visit her husband to encourage him to go for HIV/AIDS testing and to talk with his mother. She reports,

I went there [her husband's homestead in rural Kenya]. ... I was told [by her mother-in-law] that I was the one killing my husband. The witchcraft told them that I was the one who bewitched my husband. ... So I was just a witch. ... The witchcraft told him that (I was) killing him because (he) has married another wife.

Yet it was Amina Bashir who nursed her husband and carried him on her back to the hospital when he was unable to walk and close to dying. At this time he apologized to her for infecting her with HIV; now she is caring for his second wife who is ill.

### **Keeping his secret**

Loise talked about her struggles to live positively after the death of her husband, and the shock of finding out that he had died of AIDS. She remembers,

[W]hen my husband died, every year I used to be demented. But with him, he knew he was HIV. He had already gone for the test. Even told the doctor, 'Don't tell that girl she will go away and leave me.' So the doctor was just telling me after his death.

Learning that the male doctor and her in-laws knew the cause of her husband's death, yet did not tell her, Loise became very upset. She comments, "I really felt bad, sister. I felt bad, that is why I have told you that I even went for the test and cancelled it. I was unable even to talk." In all probability, there was the very genuine fear on her husband's part that, should Loise learn the truth, she would abandon him as he became sicker and his need for care became greater. As it was, Loise and her children were put at risk because her husband, the father of her children, kept his "secret."

Amina Abdul lives with her children and two other women, her mother and sister. Like Amina Bashir she too received an apology from her husband for infecting her with HIV before he died. Amina Abdul remembers that her husband also refused to be tested "until the last time he was going to die." And then it was too late to begin the ARV treatment which might have saved his life.

Amina Abdul inferred that her husband suspected he may have been infected with HIV when he first began to feel sick, because he told her, "he was with another woman." By not telling her earlier about his suspicion regarding his weakening physical condition, Amina Abdul's husband put her and his children's future at risk. If she were to become sick and die, who would care for the children? Husbands' denial of the possibility of having contracted HIV is not unusual within communities where the number of people living with the disease is high; Kibera is one such community.

### **After telling her secret**

It was not until six months after living with a man that Penninah found out the man was already married. She had kept her HIV+ status a secret at first because she was afraid to tell him and she tried to persuade him to go for testing with her as a couple. He refused, so Penninah continued to keep her HIV+ status from him. She explains,

I continued with my process of taking medicine without telling him what I ... have been taught. Then one day ... [I] told him, 'Me, I'm positive.' When I told him that he ran away. He left me alone ... he disappeared and ran away.

*And Penninah, like other HIV+ women, was left by herself to care for four children. There was little evidence of support from men in the women's stories; this was not a focus of research.*

Sarah's mother is aware of her daughter's HIV+ status; she had another daughter and son-in-law who died of the disease, yet there is no in-depth discussion between mother and daughter regarding the subject. Sarah presently lives with another HIV+ woman and her two children. Five years ago, this woman disclosed to her husband that she was infected with HIV and he immediately left her and his children; he has not been seen or heard of since. *Husbands and fathers who leave their families because their wives or partners disclose their HIV+ status are a contributing factor in the overall breakdown of African family groupings within the HIV/AIDS context. These women have an incredible fear of being alone and it would appear that being with married men, those who are HIV+ or violent is better than being alone.*

### **No legal title to land**

Sarah is greatly concerned about where her children will live when she dies. Being a widow, she has no land to which she has legal title and comments, “I don’t have house in my place in my name.” It was not clear whether Sarah was referring to her living situation in Kibera or to her family land in rural Kenya. *The Kenyan Law of Succession Act legally provides for women to inherit land and property upon the death of their husbands. However, discrimination in Kenya on matters of inheritance takes many forms. Women often remain simply unaware of their rights to inherit property or are unable to redeem these rights in a court of law (Law of Succession Act, Revised, 2010).*

From the women’s stories, it becomes evident that each one is painfully aware of their sole responsibility for the care and well-being of their children.

### **If I die, who will take care of my children?**

Oh, my God, if I die, who will take care of my children?  
 Oh, my God, just give me strength to take care of my kids  
 because there is nobody else ... just give me life.... 'm  
 afraid of ... dying and leaving my children when they're  
 still very young. I'm praying so much ...so that I can stay  
 until they become big and then ... what comes after, at least  
 they know to support themselves outside there. (Amina  
 Bashir)

Whereas children may have traditionally been raised within the context of a multi-generational community, women in my study recounted stories of presently having little or no relationship with immediate or extended family members.

### **Shunned by mothers**

When Lucy was hospitalized, sick with tuberculosis and HIV+ complications, her mother shunned her and she remembers,

Yeah, I have TB first. First, I finish my medicine for TB, and then I take ARV medicine. ... my family, they don't know what to say to me. They throw me out, ... they told my daughter, 'If your mother die, I take these boys to the children's home and you go and find work for bar, ... I don't want to see your mother to buy your mother food.' ... I tell my mother to give a little money to pay the rent. My mother told me, 'ah, you know, I don't have money to waste.... You are – have AIDS and you die tomorrow. Every day you – you sleep, every day you don't work, every day you – you don't have the power to go and find your food'.

Lucy's story is similar to the stories of other women. Zakia's mother, upon learning that her daughter was HIV+, made efforts to alienate her and her son from the daily household routines and tried to segregate them from others when inside the home. As Zakia reports,

My Mama was the person who was telling me, 'Oh now, you see, you bring ... us a lot of problems.' ... She reacted very badly... 'No, I don't want you to touch ... anything in the house, just sit where you are. You have to sit here, don't want you touching things.' She went and give one cup, one plate, one small pot to cook my own things. ... 'I want you to move out of my house. ... you can go and live with other people who are HIV. I don't want to see you in my house.'

### **Taking my belongings**

Loise's parents and in-laws were aware that her husband had died of AIDS complications, and suspected that Loise was infected before she tested positively, yet they failed to inform her. When she was hospitalized for the first time, her husband's relatives expected her to die. Loise describes what happened,

Actually, they (in-laws) thought I was just going to die the very week. Even they had decided, taking my properties. ... Even the blankets, they were carrying – they saw me as I was just useless. (Appendix G)

### **Poor parents too**

Mama May's parents, like parents of the other women, have little money and are unable to support their daughters financially. Some do not support them emotionally either. As Mama May explains, "when I was home to my parents, my mum and dad didn't want to see me, they don't have money. ... Sometimes, I sleep without food."

*When asked who was presently caring for her two daughters, Mama May referred briefly to the fact that they were living in Machakos, her rural home.*

### **Mothers' support**

Zuhura's mother, also a widow, is not aware of her daughter's HIV+ status although she did know that Zuhura was nearing the end of a six-month treatment for tuberculosis. She knows her daughter is sick and has little money and so supports her and her grandchildren by cooking an evening meal. Without variation, the meal is basic, *ugali* and *sumawiki*, and, although appreciated, it does not provide the balanced nutrients necessary for the optimum benefit of ARV treatment. Zuhura comments,

It is not a balanced diet but I have to eat because I am hungry. I can't tell her, 'No, Mum. Please help me like this, like this.' I can't tell her because she can't also find. And I want her to love my children even if she doesn't have anything to give them but I still want her to love them. ... Now you fight for yourself to get what you want.

The stories of receiving no support from parents and/or siblings regarding their HIV+ status and their efforts to care for their children contrast with the experiences of Amina Bashir and Amina Abdul. When Amina Bashir was very sick, she made a call to her family in rural Kenya, and a sister came at once to offer financial and emotional support. Amina Bashir remembers,

I decided to call my sister, and ... I told her to come. She came from home. And I told her the truth. I told her, maybe, I'm positive, and this child I don't know. But if I die take care of my children. In that time, I found my sister being very good. She encouraged me and told me that I'm not going to die and I should not accept to die.

Amina Abdul is the only woman in the group who lives with close relatives since she tested positively almost ten years ago. She explains,

My father died a long time ago. ... And my mother is supporting me, and my sister. You know, oh, when you are going to start the drugs ... ARVs, you want ... the person who is going to guide you.

Amina Abdul was referring to the fact that her mother and sister took an active part in reminding her to take her medication regularly when she was first prescribed ARVs.

### **Fear of death**

As single mothers, these women fear death and leaving their children before the children are old enough to fend for themselves. The women speak of their fear of dying and leaving their children alone:

There was a time when I was crying on the bed saying that I will leave my children ... crying every now and then and saying, 'who is going to care for my children?' (Penninah, Appendix G)

Yeah. Because, if I die now, ma'am, my children will suffer and suffer. Because there is nobody to take care. (Loise)

*I wondered why Loise used the term "ma'am" when talking with me: she did this several times in our conversations. Was it because she was talking with a muzungu*

*(white person)? I felt uncomfortable in the moment when she addressed me so and wondered about her experienced perceptions of the power dynamics between us.*

What about these children... when I pass away? They are going to stay where? I don't have house in my home. I don't have anybody in my home who says they are going to help me. What can I do? So ... sometimes when I ...when I stay in my house ... my role is not feeling well. I'm feeling stress. ... When I am not, these children, they're going where? I don't have house in my place in my name. I can't take ... my children to my mum, my mum is somebody gone now ... so, sometimes, I'm feeling stressed. ... When I am not here, what about these children small? They're going to where? They're going to look like *chokora* in slums in Kibera. (Sarah)

Even if sometimes when I will be – you know, even when they [older children] get good education, even if I'm not around. They [older children] can take care of the baby. (Zuhura)

Let me change, I stay in God's hands, Let me pray to God, God will help me. Let me raise my sons, you see, my sons and grandsons, I want to see them. ... If I didn't take the drugs, I could died, I could passed away and left my son childrens. Yeah, and the children go to street to be a *chokora*. (Amina Abdul)

We are here because of our children. We can't say it, to throw in the things ... So ... the women are the ones who make things be. (Zakia)

These women meet the daily needs of their children as best they can. Their children go to them with requests and demands because there is no one else to go to.

### **They just come to you...**

And the children come with their problems because they don't have anybody else to tell their problem. They just come to you ... me who is responsible for them. (Zuhura)

*Each woman in this study is a mother. Each one of the women is the female head of a household. The stories told by the women speak to the responsibilities that go along*

*with the role of a single parent.* Mama May is presently responsible for the well-being of her grandson, while Sarah provides care for one grandson, her sister's four orphaned children, and her own five children. In all, the women are responsible for the care of 36 children (Table 2). Each woman struggles to cope with the demands of being a single parent every day.

**Days not able to work: Get up anyway**

If children are sick and cannot be left alone, mothers are unable to go into the community to work for money to buy food, water, and other necessary supplies. If there are days when a woman feels “down”, and is not strong enough to leave her home, again no income is generated, so her family may go hungry. There are days when these women wake up feeling ill and would like to stay on their beds sleeping, resting, restoring energy, yet they get up and face their single-parent responsibilities. In Loise's words,

Living with HIV and also just a widow ... you see, whenever you feel hurt, you must wake up because you are the only person home the children are looking to. Even at times you ... wake up feeling very bad; a child asks you, “Mum, how are you feeling?” You just say, “I'm O.K.,” because you don't want to make them worried. They know when Mum is not here, they cannot eat. So that gives me a very big challenge.

Children may become concerned and confused if their mother does not get up; they may wonder about the significance.

**Always being the one**

Zuhura talked of days when children arrive home from school with requests from the teachers for extra supplies or with a problem. It is at such times that she feels keenly the heavy burden of single-parenting, and says, “... when the children come with ... their problems, sometimes, I don't know what to do right when I am sick, down.”

## Disclosure

These mothers are protective of their children. *HIV+ mothers may wear a thicker child protective patina than those who are not HIV+.* They fear that their children may become victimized by stigma and discrimination within their local community contexts. They may experience unspeakable fears about their children contacting HIV which may account for no discussion with their children regarding their status. Trying to determine when to disclose their HIV+ status to their children poses a great deal of anxiety to these mothers. Some speak of choosing not to disclose their HIV+ status to their children, although children see their mothers regularly taking medication. Mothers do not want their children to worry, to become distracted from concentrating on their school work. Children are exposed to HIV/AIDS education as part of the curriculum in both primary and secondary schools and may be exposed to HIV/AIDS community-based education activities. Nevertheless, the stories of these women reflected a great deal of inner tumult when thinking about when to disclose their HIV+ status to their children. They worried about how best to disclose, when and how, and to which child. Zuhua describes her concerns about disclosing,

I'm waiting to tell the eldest, just the elder. I'm waiting to tell her because she's the elder – the others are young. I want them to become a little older. One day they understand, now they're young. Because, if I tell them now ... every time they are in class, they will start thinking, 'My mother is HIV, my mother is HIV,' – a very hard fear. Now we will miss our mother, she will die. ... now I can't tell them ... because they are still young and I want them to concentrate on their education. They are doing well in school and I don't want to stress them with anything. Right now, I'm thinking how to ... tell her [her oldest daughter] but, – no I don't think she will take it badly because she's also in puberty. (Appendix G).

*I do not know why Zuhura equated her daughter's development stage of puberty with being a good time to disclose her HIV+ status. Perhaps it has to do with the fact that puberty is generally related to sexual awakening and sexual activity is one method of the virus transference.*

Amina Bashir has not informed her children directly that she is HIV+, yet she is constantly vigilant in recognizing opportunities that arise in conversation to educate them on the subject. In her words,

You know now, you – you see, like in Kibera, there be a stigma still, for hide. And most of the people still believe that those people who are positive are going to die. ... the children have that idea, that HIV kills. I'm still taking them slowly. Every day in ... my house, sometimes I introduce topic of HIV ... because they are being educated like, the big boy sometimes come and ask me, 'Mama, we have been educated to-day about HIV,' so I go deeper, talking with him about HIV, just trying to prepare him for that, whenever I come and tell him, ... it not be like a shock. Or he will not see that I am going to die the next day. That's why.

Amina Bashir has not disclosed her HIV+ status directly to her children, as she does not want them to think that she is going to die every time she is sick and just needs a little rest. Nevertheless, she has alerted her elder son who is 13 as to what to do if he should find her sick on her bed. She has told him,

If you see I'm on my bed, very sick ... please run to Zakia ... he knows where my card is. ... I've shown him... the big boy, I told him, 'My card is here. If you see I become very sick, and Zakia is not there, please tell someone to take me to Amfry Hospital.'

*Each person diagnosed with HIV virus infection [sic] at a medical clinic or hospital receives an identification card that must be presented at each and every future visit to a clinic or hospital.*

The women who do not disclose their HIV+ status to their children may be reluctant to do so because they do not want to burden them with care-giving concerns or worry them unnecessarily. *And so I wonder what the balance is? Is it less stressful for HIV+ mothers to keep their HIV+ status a secret from their children than to worry about them if they are aware and the affect/effect this knowing has on their daily lives?*

#### **HIV+ status already disclosed**

Some children are openly aware of their mother's HIV+ status. When Loise was first diagnosed and began ARV treatment, she programmed her cellular phone to ring at a certain time to remind her to take the pills. The children heard the message on the phone, "Take dawa [drug or pill]! Take dawa," and became concerned. So Loise informed them of her status. Loise describes what happened when she first began her ARV treatment,

Now they are asking me. 'Mama, the 'phone is calling you, take dawa.' I take the dawa ... I know the olders go to school, being told. ... They know because, if – if someone does not see me taking drugs, I just hear, 'Eh Mum, nowadays, you don't take drugs.' Because they are worried, they know, the moment I don't take the drugs, I go down.

#### **A mother's role**

One of a mother's roles is to teach her children self-care skills for when they become independent, which is generally as adults. Older siblings often take on the parenting role and help out with chores in the home such as washing, cleaning, and cooking. Mothers purposefully teach their children how to cook and clean the house

which is important when the mother may be feeling unwell and unable to cook or do other necessary household activities. Lucy points out,

Yeah. I'm a good mother [laughs]. I want to teach my children you know this, you come and sit, you don't wake up. If your children, they don't know how to work in the house, you get trouble. ... So you have children, you must do work to teach them how to clean the house and how cook, how to clean their clothes. Yeah!

*Lucy knows well that if she is sick and unable to take care of the routine housework and prepare meals, there is no-one else to help out – so it is important that her children learn the necessary skills as soon as possible. However, if there is no food to cook, then all in the home may go hungry.*

### **Relationships with children**

Some women spoke specifically of relationships they had with their children especially concerning issues of medication, the need for rest and the necessity of immediate medical attention in the case of “being down” which refers to feeling unwell.

Zakia's narrative illustrates well the concern children have for their mothers; she moves in and out of the first and third person as she talks, beginning in the first person talking as/for her son who is 13,

I'm going to pray hard, you'll feel better. I don't want you to get sick, sleeping all the time.... if he come in the house and see me sleeping. 'Oh mama! Are you there?' If he see me sleeping over – 'Oh mama, are you sick? Have you gone to the hospital? Have you taken your medication? He just come and touch my head. 'Oh, you're not too hot. You're not too hot. No. Oh mama, what have you cooked? Is there any tea? Is there any porridge?' ... And he just talk to me, 'Mama, I – take care. If you are going to the hospital, don't walk until you get tired. Take this water and just drink some ... Go. If you are tired, sit down somewhere. Drink your water. Drink your water. Rest. And then go.' ...

‘Mama, and if you’re feeling bad, don’t – don’t clean the house! I help you – I’ll help you. Don’t touch even water. You’ll feel very cold and feel very bad.’ ... Mama, if you are not feeling good. I just put fire on, buy the paraffin, put on the stove, cook you some porridge. ... I know how to cook for you. ... I’m washing clothes, clean the house, bring some water.’ He go and bring water, to take water with these small, small jerry cans, five, five liters. I tell him, ‘You just carry the five – five and bring.’ ‘No, I’ll go, I’ll go two trips... Mummy, ... it will help us. I clean the house, clean the clothes, cook you some porridge. And you – you just rest. Take your medication and rest!’ Now ... he’s – if I wake up in the morning, [he] sees me praying, doing my own thing, ‘Oh Mummy, ...to-day you’re feeling very good. ... So me, I’m going to school. Bye-bye, see you.’ And he goes out.

*As Zakia tells me this story, I think about a role reversal of mother and child and wonder how this will impact on the child’s adult relationships in the future.*

Some children have an uncanny way of knowing when their mothers are not well and do the best they can to help out, especially during holidays. Loise draws attention to this fact,

Yeah, they always know [when I will be down]. Actually, when, when they are on holidays, they don’t want me to do anything. They say, “Mum, you leave – you leave. We will do’. Yeah [laughs].

*Children who know the HIV+ status of their mother may be hyper vigilant regarding her state of health. They worry about what will happen to them if their mother should become too sick to work and provide the basic necessities of life; who would care for them if she were to die?*

The nine women are responsible for meeting their own basic needs and those of their children. Providing minimal physical needs such as shelter that is safe, clothing, nutritious food, and a supply of fresh drinking water is paramount to the overall wellness

of any individual, and requires money to pay for the costs. The women work hard to generate money to meet their basic needs.

**If I sit there, that ten bob won't come.**

You also see people are selling many things on the roadside. You can even stay there for even a day without even selling. Maybe you sell what is not even enough for you for the day. So I always, as you see me going up and down, at times when you just call me, you want some tomatoes, this if it is for ten shilling, I just go. I don't care whether – because, if I sit there, that ten bob won't come. So I better take for you that. Yeah! (Loise)

The women in this study are poor, like most adults in Kibera, yet they are not destitute. *With the exception of Mama May, the women in this study all have a home in Kibera. When feeling well, they are able to work to generate money to buy the basic necessities of life.*

***Jua kali***

The women are casual workers within the informal sector of employed people known in Kibera as *Kibaru*. Within this sector is a sub-set of people who work in the hot sun, the *jua kali* (UN, 2002; 2004). These *jua kali* businesses are informal retail or hawking of goods.

Four of the women, Penninah, Zuhura, Lucy, and Sarah, have *jua kali* businesses and earn money by selling from a roadside kiosk or make-shift temporary construction. Penninah sells sweets. Zuhura makes and sells samosas (deep fried pastry filled with spiced vegetables and/or meat). Lucy makes and sells *bajia*. Sarah took out a small loan from one of the many moneylenders in Kibera to buy and sell chickens.

Amina Abdul has had a steady job for some time outside of her home in Kibera. She keeps house for another woman who is employed at a local hospital. Talking about how she makes money, she comments,

Me now ... I have another woman who is working at Kenyatta Hospital. I go there, I wash for her, her clothes, I clean her house. I go there Mondays, Wednesday and Friday. ... She give me some little money. (Appendix G)

Earning money honorably is important to Amina Bashir. She will not just take any work that may come her way and comments,

Myself, I am educated. And I normally make sure I don't choose any ... kind of job that comes across. ... if it is washing, I go for washing, washing for people's clothes, I get money. And I normally I do small ideas, like preparing ice – sometimes, I make ice.

*I was initially surprised to hear Amina Bashir talking about making ice which requires refrigeration. Being inside her home, I knew she had no refrigerator. Indeed, I have seen no refrigerator in any Kibera home I have been in. There may be units in some of the local eating places because the sodas and soft drinks are usually cold or at least chilled. However, trucks delivering large blocks of ice can be seen driving around inside Kibera throughout the day.*

One of Amina Bashir's small ideas is to make ice. She uses a neighbor's fridge at night to freeze the water and then in the morning crushes the ice and adds sweet flavoring. Selling ice is a good business; it is a good seller, very popular especially with the children who sometimes come to buy it directly from her house. Another one of Amina Bashir's small ideas is to make *mabuyu*. She sells both *mabuyu* and ice to local kiosks and stores and from her home. Amina Bashir also braids hair.

### **Work change due to HIV+ status**

Since becoming physically weakened by their illness and aware of their HIV+ status, there has been some variation in the work that some of these women now do. Penninah reports, “I decided to live with selling sweets because I was not able to ... carry heavy things. Business is ... nothing big. I am selling sweets. ...” Before becoming sick, Penninah would go to the local retail market in Nairobi very early in the morning and carry bundles of *sumawiki* on her shoulders back to Kibera to sell in one of the slum markets there.

Zuhura used to work in the formal sector. She was a professional cleaner and left a regular job at a well-known Nairobi hostel after working there for seven years. She now finds work in the informal sector and remembers, “Before I was working. I was a cleaner, I’m a professional cleaner. I do cleaning... I got a very good job, a good pay ... but when they wanted to grant test to me, now I decided to run away from there.” *It is illegal in Kenya for an employee to be fired because they are HIV+. However, many employers do fire HIV+ workers. Employers know that few employees can afford court costs to challenge dismissal; some employees are not informed of their legal rights.* Zuhura voluntarily left a position as a professional cleaner in a well-known Nairobi hostel that she had held for some time. Hearing the rumor that there was to be mandatory HIV+ testing for all employees, she was afraid that her positive status would be revealed and in her words,

My life was very different because I was working ... you find a good job... they want to take your blood and test you first so that they can pay you this good money to work there. And now you are afraid to continue the work... you come back and stay in the house.

When Zuhura has no work washing or cleaning and is feeling well, she makes samosas to sell from a make-shift kiosk she sets up at the side of the road, close to where she lives.

Loise no longer washes clothes for other people as a way to make money. Since learning of her HIV+ status, she has had two hospital stays because of respiratory complications. Believing that washing clothes in cold water affects her breathing, whenever possible she now avoids contact with too much cold water and comments,

I have to pay for them [the children]; I have to pay the house rent now. What is stressing me here is house rent, the children want examination money, ... with us who are HIV if you ... if you say that you go and work for somebody in the house, that water, that cold water, every day, it's not wanted. So you just say, 'God help.'

Loise now goes regularly to the industrial area of Nairobi where she buys reject soap that is prohibited from retail sales. She returns to her home and re-cycles it into another form of hardened soap which she sells in Kibera. She also sells tomatoes and onions. She explains how she makes money,

There is soap. ... I go to the Industrial where soap is made, original soap. ... I get the rejected. I come and put them in a small drum, also ... a big saucepan. I boil, then I pour it in a container. I start, after it is dry, I split it in two pieces. I sell that, ten bob apiece. Then I make also ground nuts (roasted peanuts). I sell tomatoes and onions.

Loise does not sell from the roadside because of experiencing frustration caused by sitting all day in one spot and not selling to a single customer. Therefore, six days a week with the exception of Sunday, she chooses to walk round villages in Kibera, making deliveries of soap, tomatoes and onions to customers who may call or text her on mobile phones asking for specific orders.

Before she became sick, Zakia, like Zuhura, had found employment in the formal sector: she worked in a fancy salon in Nairobi. She now works in her home, making all-purpose liquid soap to sell. She also braids hair, washes clothes, and custom makes crocheted table cloths and chair coverings for which the customers provide the cotton thread before she begins the work. She is paid a pre-determined amount once the customized crocheted piece is finished and delivered.

### **Networking**

Networking both inside and outside of Kibera provides work opportunities for the women. In the past, Zakia, Amina Bashir, and Amina Abdul have been paid for providing catering services for women's organizations that hold workshops within Kibera. Zakia speaks of the acceptance and support on the part of some organizations and their willingness to help HIV+ women by providing them paid work although it is only temporary and says, "I make good relationship with women outside because if they hear about good things, they come and inform me." Like the other women Zakia is constantly networking, listening for potential job opportunities and describes what happens when she networks,

[T]hey call me, they might call some other people, but because they know me, they just call me. ... 'there's good work to-day, come, ... you'll cook, get some amount of money and you'll get some things to take ... to your son.' So I just make a lot of relations.

Although Zuhura's preference is for cleaning, she does wash clothes for other people to make money. She cannot afford to be too choosy regarding the type of work she will accept as she is always in need of money. She explains,

People who know me, sometimes when I'm O.K., they call me even this washing, I go and wash for people and they

pay me. ... People who knows me, they call me, I go and do the cleaning, cleaning jobs. I'm a cleaner. ... A cleaner, a very good cleaner. ... But since ... I got this problem, I had to stay home, but people who knows me, they just call me. I go one day, I wash, I put on the line, they pay me, I come home.

Mama May no longer works as a barmaid since she became sick and she is not a permanent resident of Kibera. She is in Kibera looking for her daughter to give back her grandson. While in the slum, she and her grandson stay with different people. Therefore, she does not have to pay rent and returns the hospitality by caring for the children of the house and doing what she can to help out while there. Perhaps this is more in keeping with traditional African extended families when one member is being cared for by others. Mama May explains that she presently has no way of making money, "I don't have anything to make money. I don't." Later in the conversation she comments, "To make money, I educated my first child."

In all probability, Mama May had the expectation that she would be supported by her daughter's earnings from a secure job that paid well. To date, this has not happened. In fact, quite the reverse has taken place. Mama May presently has the responsibility for her grandson and is not currently in contact with her first-born daughter.

### **Being up, feeling down and stress-up**

You have AIDS, you have nothing to eat, you have a lot of stress. You have no medication, maybe the children are there, they are waiting for you, everyone's waiting for you, plus then you – you feel, you become so down, you feel stress-up, you become sick, you have nothing to eat. That's when you can die very easily but with AIDS, you can live for some times. (Amina Bashir)

The women in this study talk about their present lives; they all talk about experiences that cause them stress. Not only is stress due to the physical condition of their bodies, it is caused by the responsibilities of struggling each and every day to provide some quality of life for themselves and their children. They describe their emotional response to feelings of stress, of being unwell, as “feeling down” or “stress-up.” When they feel well and/or feel better, they describe themselves as “being up.”

### **ARV prescriptions**

The free antiretroviral drugs, ARVs, which the women take to keep them alive, are prescribed by a doctor after a medical examination and consultation. Each woman must return to the hospital doctor or clinic staff after a period of time for a medical check-up, blood work, and renewal of her prescription. Only then is she able to collect the next supply of ARV drugs.

Loise, who has been taking ARV drugs since 2005, was initially given drugs to last her only two weeks; now she collects three months’ supply at a time. She remembers, “At the beginning, it used to be two weeks, then from two weeks, one month. It grew like that, now it is just go and constant three months.” She refers to people becoming familiar with the drugs and beginning to go “up.” When medical staff observes an improvement in a woman’s health, they lengthen the time interval between required clinic or hospital visits. Individuals react differently when first introduced to ARV drugs. Loise alludes to possible side effects on the body as an initial reaction to the drug intake when she comments,

Maybe they just see that you are – you are now familiar with the medicine, you don’t have any problem. That is why you are given the rate, to avoid coming each and every

time to the hospital. Maybe when you have got a problem, you can just go – even if you have the medicine.

Loise may be referring to the introduction of new medicine in ARV treatment therapy. It is well to remember that, when these HIV+ women experience any unusual symptoms of sickness, they immediately seek out medical attention.

Loise has been “down and up, down and up” since 2005 and noticed a correlation between her “down and up” state and her CD4 count. When her CD4 count is low, she feels unwell and when it rises, she begins to feel better. Twice hospitalized when “down,” with respiratory complications and low CD4 count, she reflects, “that is when I can be at least frightened”. *I have no doubt that a stay in hospital is a reminder to Loise of her chronic illness, and there is the very real possibility that she could die, leaving her children with no-one to care for them; this must be a terrifying thought.*

Loise makes the point that there are days she wakes and feels unwell. However, she makes the effort to get up for the sake of her children because her children will become concerned if they do not see her on her feet, walking. She tries her best to get out of bed every morning and say; “I’m O.K. because you don’t want to make them worried. ... Eh Ma’am, nowadays, you don’t take drugs ... the moment I don’t take drugs, I go down.”

### **Too sick to work**

These HIV+ women are unlikely to make any money should they be unable to go about their daily business in the community. If they do not take their daily dosage of ARV drugs regularly, they will become sick and weak and, because they are unable to generate money for food, they and their children will most likely go hungry.

Loise believes that it is her strong belief in God and the power of prayer that keep her well. She says, “the prayers of the people keep me up.” She is grateful to wake up and to get up each day, and presently feels happy to be alive. “Yeah, me, I’m always a happy woman because, nowadays, waking up, if even the next day is not very easy, so thank God and when you’re – when you wake up normal, you must be happy.”

Amina Bashir talked of being “almost down” when she was unable to work because she was still bleeding after giving birth. Having no food or money to pay rent and support her children, she was near emotional and physical exhaustion and unable to get up from her bed. Experiencing a high degree of stress during this time, she reflects, “I don’t know if I am going to die, even, my baby is going to die. So I was so much stress-up.” Amina Bashir did not die. With support from her sister and mother and by taking the ARV drugs consistently as prescribed, she re-gained strength. Slowly, she came back “up,” and was once more able to work. Amina Bashir knows when a person is living with HIV, there is need to take ARVs on a regular basis; there is also need for extra attention to self-care and a balanced diet. As she explains,

What I think about the disease, AIDS? In my part like this now, it – what I can say that AIDS does not kill. If it kill, maybe I could have dead right now. But what kills people or what affects people so much is the problem. For example, you have – you have AIDS, you have nothing to eat, you have – you have a lot of stress. You have no medication. Maybe the children are there. They are waiting for you, everyone’s waiting for you, plus then you – you feel, you become so down, you feel stress up, you become sick, you have nothing to eat, that’s when you can die very easily but with AIDS, you can live for some time.

### **Not sick**

Like other women in the study, Amina Bashir does not consider herself sick because she is HIV+. She takes necessary precautions to keep herself healthy and able to work and attends immediately to any physical symptoms indicating the possibility of oncoming sickness, such as a headache or coughing, sweating and feeling cold. She explains,

Yeah, I know, I – when I am sick, I will dies of malaria, or I'll dies of another disease, but not AIDS. You know, AIDS can affect anybody. Doesn't matter whether it's – you're in a particular religion or you are small, you are old, it can affect anybody. But the thing is you can live for so long. There's a difference between AIDS and HIV. When you have HIV that means you – you can still live for so long. When it reaches the stage of AIDS, that's when opportunistic infections can over – overcomes your body, that's when you can die. But when you have HIV, you take care of yourself, you protect yourself, you eat properly. You can live more than any – like, just like any other person.

*Experiences of health and diagnosis of disease conceptually differ. The women in this study appear to associate being sick with lying on a hospital bed, or being incapacitated in some physical way. They do not appear to consider themselves as being sick because they are HIV+. This surprised me. I wonder if because their days are so full and so directed towards ways of generating money that they have little time to think of their medical condition. Or. Perhaps it has something to with an African definition of wellness?*

### **Being/going down**

Mama May, upon learning of her HIV+ status, was greatly shocked and at that moment thought of killing herself. At that time, she describes herself as “going down”

and “thinking that time of going in the coffin.” Mama May was very “up and down” for some time even after she began her ARV therapy, and before her body adjusted to the ARV treatment. Her body did not immediately respond to the ARV prescription. Because her CD4 count went down and remained low and her body weight continued to decrease at such a rate as to alarm her doctor, she was referred to an HIV/AIDS specialist.

There have been times when Mama May was hungry, had no money for food, and so chewed her drugs thinking she was putting something solid, in lieu of food, into her stomach. *Unless there is a particular concern on the part of the medical practitioner, patients are prescribed a three month's supply of ARV drugs at a hospital or clinic visit. Usually individuals are then weighed, and blood taken to check CD levels.* Mama May is still prescribed and receives only one month's supply of ARVs at a time. She was told by the specialist that chewing her drugs in lieu of food was not considered taking the ARVs properly. She remembers his words,

You are not using your tablets properly ... unless maybe you are not eating well. What is happening for you? Listen, we are going to change this medicine because this one is not working. But if you don't use your ... new medicines properly, Mama May, I'm telling you, there is no third life, if we put you on second life.

Mama May is well aware that, when taking ARVs, for optimum results, a balanced diet is necessary. However, to buy a constant supply of fresh fruit and vegetables costs money, of which these women have very little. Therefore, eating properly is great cause for “stress-up,” and for “going down.” Mama May could well be speaking for other women when she says; “Now to eat properly is when you have money. I don't have money.”

When Lucy went to the hospital in 2004 she was feeling “down” and remembers; “My CD4 count was down, it was 40, I, that day, I sleep in the hospital, the Kenyatta Hospital and that’s – I complete to sleep to hospital and I get TB. ... TB – before I start my ARV.” She sees herself only as sick when she is “down” on a bed, unable to walk. However, she does speak of being “down” because of stress and not always feeling “up” enough to make her *bajia* which means she has little money to buy food or pay the rent. Lucy remembers when the landlord sought her out wanting back-rent money immediately and threatening eviction. These are the times she becomes stressed and she says,

Stress, yeah, like that. You know ... somebody come to ask for the money when you don’t have money, that now – [I]... get stressed. You have ... to find how come to pay that house.

When Penninah took the HIV test and it proved positive, she was very “down.” It was the doctor who informed her how to live her life to stay alive, and not to get sick. To “stay up,” she was told to learn how to take care of herself, to remove as much stress from her life as possible and to eat a balanced diet. *The medical advice to Penninah and other HIV+ women who live in Kibera regarding the need to avoid stress and eat properly seems somehow “out of touch” with the realities of their lives. Perhaps this is indicative of gaps in service provider infrastructure for those infected with the disease. None of the women spoke of referrals to food distribution services, although some did refer to receiving counseling services particularly immediately after testing HIV+. However, the cold fact for the women in this study is that if they have NO money, they most likely will have NO food.*

For some time, after testing and at the beginning of her ARV treatment, Penninah remembers that she was always being sick and felt “down” when alone; especially that her “head [was] achy.” She says, “[I] was down before ... I was scared – hearing the peoples talking about it’s HIV, and I was not aware of it.”

When Zuhura and I talked, she was feeling “down.” She had tuberculosis and was taking medication for that as well as taking ARV drugs. Speaking specifically of living as an HIV+ woman, she says,

This [living with HIV+] is hard because if you can’t find anything you, O.K., you have to support yourself. ... Now you have to fight for yourself to get what you want. You can’t eat well, you can’t – you are taking your medication, you must eat well. And if you can’t eat well, you get side-effects. ... Sometimes ... you become very sick, you go to bed, you sleep in the day because you can’t eat well and you are taking this many [pills] – you must take the medications.

Zuhura, like other women, is appreciative that the ARV drugs are distributed free of charge, yet is often “stressed-up” because she requires a consistent supply of nourishing food to complement the drug treatment. She remains objective and expresses some of her frustration,

Because ... now I can get the medication to keep me alive, and if I can get food, food to eat, because it needs food to eat, I wouldn’t suffer, and do everything like other people are doing.

Zuhura stays home now much more than she used to before she became infected with the disease. She explains,

I stay alone a lot because I just stay home. You see ... HIV is very painful. When you are sick, all your body is very painful. Now when children come from school ... they need this and this, you start to stress, you become sick

again. ... Stress, I think stress is the biggest thing that – that make people go down.

Sarah speaks of the time when she was continually sick, actually lying on her bed suffering with symptoms of her body's distress – coughing, vomiting, and having diarrhea, before she finally consented to be tested, "Yes, [I] was sick. [I] was down. Every now and agains, [I] wake up... I am not feeling well." *When Sarah told her stories, she often referred to herself in the third or first person, switching back and forth. Her stories were long; at times she lapsed into her mother tongue or another African dialect. Being familiar only in hearing Kiswahili, I didn't recognize the language. I deliberately chose not to interrupt the conversation at these times; I did not want to stop her in the middle of her conversational flow as I thought this disrespectful. However, what was important was that I understood her meanings, and I certainly checked out my uncertainties with Winnie the mornings after Sarah and I met.*

Sarah talks of the stress of wondering what would happen to her children. She comments,

You are not staying two hundred years, no. ... when I'm not here, when I am not, what about these children?  
[They're] staying ... with who? ... that give me the stress-up for these children. (Appendix: G)

Amina Abdul has been receiving a three months' supply of ARVs for some time. She does not consider herself to be sick because she is HIV+. She knows very well that, if it were not for the drugs, she would become "down", then get sick, and most likely die. She takes a very pragmatic view of her viral infection,

[I] don't take it as, like a sentence of death. ... We live with AIDS until the day you are going [to die]. A day will reach, then God say, 'To-day you are going to die.' ... It's like life

... has to go on. ... you have to go on with life. ... it's better you know your status. ... Then you will change. ... You will start living ... like a ... born again.

*I am reminded of the term, "Born again Christian," and wonder what meaning these words have for Amina Abdul and, being a Muslim, where she heard them.*

Amina Abdul has been living as an HIV+ woman and taking the free ARV drugs that have most certainly kept her "up", alive, for almost ten years. She reports,

The medication is free. But the problem is, how will you get the food? ... The biggest stress is now the food, school fees, the house, the shelter, yeah.... This is the biggest problem. ... About HIV, it's not the big issue for me because I have the drugs, I am taking the drugs, yeah.

*Poverty, the lack of money, is a major source of stress for all these women who try so hard to make a "good life" for their children's future. They try their very best in desperate circumstances to provide the very basics of life.*

Amina Abdul is not alone in her concerns regarding the provision of the basic necessities of life for herself and her children within Kibera. This is an ongoing challenge and has increasingly presented hardships to those who depend on their ability to get up and work when and if work is available. For the HIV+ women in this study and, undoubtedly others infected with HIV, there are days when they are not feeling well, remaining in the morning lying on a bed, their own or in a hospital, and are unable to go about the business of their day. It is at these times that the struggle for survival becomes more acute.

### **Staying up**

Much has changed in Sarah's life since she accepted her positive status. She talked of seeing people in the community, and recognizing the looks on their faces as

being similar to how her face looked when she was “down”, had not been tested, and did not know she was HIV+. She is no longer so afraid and will now sometimes approach such a person telling them, “I want to take you to doctor. ... I want the doctor to help you. Even me, another time, [I] was down, like you.”

There are days or times in a day when Sarah is unable to sell her chickens in person because her HIV+ grandson is sick or she has to go to the clinic. However, her neighbors and friends sell for her and her business is slowly picking up. Most days she says she now feels well, not “stressed-up” because her chicken-selling business is showing a profit. She comments, “I am blessed because I am profit... she’s big to the business now, she’s going up. ... I say, thank-you, because I know I reshape.”

Since becoming a member of the Darajani Widows Living with HIV/AIDS group, Penninah has come to know that HIV/AIDS is not a death sentence; if she takes care of herself and takes her medication consistently, she is not likely to die. She finds support by being with other HIV+ women, has become stronger, accepted her status and is not “tearing so much.” She describes her present emotions regarding her HIV+ status,

Me – I can say that, when I know my status, I can say that,  
I am well because I am going on well – because nowadays  
I’m not sleepy ... I’m not sleeping at the bed that I am sick,  
... Now I’m taking ... that medication ... I’m now  
encouraging. I’m coming up.

Zakia knew little about HIV/AIDS before she was tested. For some time, she was reluctant to go for a test. She reflects, “I didn’t want to be get tested but, when I was just going up, down, up, down, every now and then, going sick, sometimes very good, sometimes sick.” Friends and a niece persuaded her to go to the clinic for an AIDS test

and, since living as an HIV+ woman, she acknowledges that, “Living with HIV is a challenge.”

Zakia, like others, does not think of herself as a sick person. She has educated herself regarding HIV. She knows how it affects people and what to do to remain healthy and strong, and to remain “up.” She acknowledges that initially the side-effects of the drugs were hard on her body, and she worked diligently and rigorously not to “go down.” She took, and continues to take, great personal interest in any information she can come by regarding HIV/AIDS and now presents herself as an advocate for HIV+ women in her local community and communities close by. She has learnt how to live with the disease and to keep herself “up.” She expresses her new knowledge concerning the disease this way,

Story about AIDS? The story about AIDS, HIV, and AIDS, this – I didn’t know anything about HIV but, when I went and be tested, I went to concentrate, wanted to know more about HIV and now I’m living positively since 2004. I’ve built my capacity in – on how I can live with HIV and AIDS.

Zakia was supported by her maternal grandmother, now dead, when she first learnt of her HIV+ status, was feeling very “down”, and had moved with her son into her mother’s house in Kibera. She was not made to feel welcome there and Zakia remembers it was her grandmother who “taught her ways to ... sit down and remove all stress you have in your – on your head.” Zakia learnt her lessons well; she learnt how to care for herself and to stay “up.” She now lives by the creed, “Forward ever, backward never,” and sees herself as an “up” person, who is “walking like a lion.” She explains,

Yeah, I’m empowered. I’m walking like a lion because I’m proud, I know what I’m going through – I know how to life.... Oh yeah, I – I’ve already gone to a lot of – through a

lot of training. ... I have that courage to even give – I, I'm ready to counsel even someone who is tested. Now, because I know, everybody gets that shock. If you test – if you come and the doctor test, you say, 'Noooo'. Samaya, to-day you are positive.' That shock come automatic and you get a lot of fear. You ... just shrink and get that cold, because you didn't expect something like that. ... at the time I was tested, I was not very happy ... I didn't shed my tears but I was having that cold inside. ... You have to accept your status. ... Because if you deny, how can you be helped? Oh, yes, I'm a human being, I have to accept.

*Hearing my name used caused me to change the direction of my listening process.*

*I had been intently listening to Zakia's talk and suddenly hearing my name brought the present context sharply into focus; Zakia was obviously conscious of my presence as a listening audience.*

When the women in my study are feeling “up”, they are outside of their homes, in the markets and participating in various local community-based activities. Going about their daily business, they may be exposed to stigma and many have already experienced discrimination because of their HIV+ status.

### **I am stigma**

[I] become sick because of stigma and that is what I don't want. The stigmas have come from, when I can afford to go out in the house, it is when I can become stigma from other peoples. (Penninah)

Many of the women participants in this study experienced stigmatization within their communities ranging from malicious gossip to actual threats. Although there is increased community-based information available regarding HIV/AIDS, there is still a great deal of ignorance surrounding the subject and a great deal of stigmatization within Kibera. Loise expresses well what many think when they hear that someone is HIV+,

[T]hey [husband's family] knew I'm HIV. Yet, myself I had not ...gone for the test. Even they had decided, they knew I was going to die. ... Maybe ... they will keep on spreading the news, 'That one got HIV, she takes big, big, drugs' you know. You see, they will start talking badly. ... So, they think that, when you have ... AIDS, you are not supposed to move near a friend or do something to somebody. You see, if I give somebody food and she or he knows that I am HIV, he thinks maybe [laughs] my disease is got ... in the food which I have given him. ... You see, when you have rashes, people will look at you as if you are no more, yeah? So – I think. Make people to eliminate you.

Amina Abdul has been on ARVs for almost ten years, the longest of the women in the study group, and recognizes that, if she had not been tested and had not started drug treatment, in all likelihood, she would have died. She now holds the belief that, because ARV medication is free, it is stigma that is causing the deaths of many individuals who are infected with HIV. She says,

I'm grateful. Because if I don't know my status until now, I could died. If I didn't take the drugs, I could died, I could passed away and left my son – childrens. And the thing that killing people is stigma, stigma.

### **Stigmatizing words**

When Lucy's mother became aware via a second-hand source, another daughter, that Lucy was diagnosed with HIV, she became verbally abusive to Lucy and her children, threatening to send the children to an orphanage if their mother were to die. Lucy, understandably, was very hurt by her mother's words and accused her mother of discriminating against her children because of stigma,

[M]y mother stigma my children ... even my children ... don't want to go and see my mother. ... So rude to them, to my children. And my children don't want to go and see her.

Interestingly, Lucy thinks that women are stigmatized more than men. She thinks this is so because women are out and about in the community more as they go about the daily business of generating income and feeding their children. She comments,

But women get stigma more, but men, no. ... but you, you are – if you have children, you get stigma – where you get to cook for children, money, when you go to school, but men, they can't get stigma, because they want to be – to drink, and come back in bed. They don't have the time to go and get stigma.

Penninah spoke of being greatly affected by the stigmatizing gossip that she hears when she is out in the community. Accepting and coming to terms with an HIV+ status is difficult enough; dealing with stigmatic wounding caused by words from others presents its own difficulties. Penninah used to be so affected by stigma that she spent a great deal of time crying alone in her room. Now she is learning from other HIV+ women how to cope and what she can do to help herself. She explains,

I'm life.... I'm not tearing so much. ... I will ... become sick because of stigma and that is what I don't want. The stigmas have come from, when I can afford to go out in the house, it is when I can become stigma from the other people's, I don't want, please. ... They [people close to her kiosk on the street in Kibera] can come and start speaking nonsense. ... My head is achy, when I am alone. ... I started staying, I can have something like a storybook, I can start reading, oh yeah, clapping, else I started singing, so that's the stigma gone, moved away.

In a similar vein, Zakia has learnt not to “open her ears” to words that can be hurtful. She and her son stayed with her mother when she was first diagnosed as HIV+, was seriously sick, and experienced stigma and discrimination. They were segregated from the family grouping, allocated separate utensils for personal use and their movement within the home was restricted. Receiving support from her grandmother, Zakia became

stronger and was able to resist “going down” by not listening to hurtful words that “people threw”, specifically words from her mother. However, her mother constantly reminded her and the community of the problems her presence presented. Zakia works hard to protect herself from “feeling down” because of hurtful words. She reflects,

... to hear whatever people are throwing, then you can go down. Because in the community there's a lot of people who died because of stigma. ... There's ... another lady who wanted to burn the houses... Look at you! You just go and get some problems... you bringing such a lot of problems.

### **Keeping secrets**

Within Kibera, women hear stories about violent acts of discrimination towards those whose HIV+ status becomes public knowledge and so they become secretive regarding their own HIV+ status. The women told cautionary tales of daily community interaction that allude to an underlying fear of their secret being found out.

Amina Bashir talks of avoiding situations in which she suspects she may be discriminated against and made to “feel bad” by the actions or words of others,

Maybe you go somewhere and ask for water to drink. You are being given ... not a good cup, because maybe people like me, they are going to infect him. So you see – if you go – if you know something that can stigmatize you, you better avoid it.

Sarah is afraid of being asked to leave her home by her neighbors should they learn of her HIV+ status. She spoke of keeping her “secret,” and choosing carefully where, when, and to whom she talks about HIV/AIDS in order to protect herself, her grandson, and the family’s present living environment. She describes her ongoing vigilance,

When you ... come to my house, talk with me in my house. When you are going outside, leave that topic. ... Even shamba [yard], when you wash your clothes, this is my secret in my shamba [land] ... and other children – once they know this boy, [Sarah's grandson] he's living with HIV+, they're going to tell their parents... Now this time when they know I'm living with HIV+, I can't stay this shamba [place]. They say, 'Move away.'

*Fear of being shamed and made to move from their home by neighbors are contributing factors to the reluctance on the part of some women to disclose their own HIV+ status as well as informing children that they too are HIV+.*

Zuhura keeps her status a secret from her mother, yet finds this difficult. "Because to live with what you have and to know that you can't tell your mother, it's really, it's hard." Zuhura has heard her mother speak badly of HIV-infected individuals and, because she is afraid of losing her mother's present, positive relationship, she has not disclosed her status. It is important to Zuhura too that her mother remains a prominent, benevolent figure in her children's lives and the children continue to have a strong bond with their grandmother. Therefore, striving to keep her small family together, she, like other women in the study, keeps her HIV+ status a "secret." *Zuhura's mother supports her by providing a daily meal for her and her children, and Zuhura desperately needs her mother's support in other areas of her life, yet is unable at this time to be truly honest for fear of losing the support she now receives. This is a terrible burden for Zuhura to live with.* She will only share her secret with others when she is assured that the environment is safe and there will be no negative ramifications for her or her children and they will not be hurt as a result of stigmatization. Zuhura knows that stigma and discrimination run rampant in Kibera and she fears for her children's safety should other parents find out that the mother of their child's friend is an HIV+ woman. She describes the situation,

This [discrimination] is the big problem in Kibera. ... Because if someone knows, even if a mother knows, she will start hating – hitting my children, [and saying] ‘You – even your mother is HIV positive.’ ... All this is stress.

### **What is stigma?**

In conversation with Mama May, I was surprised to learn that she had not heard of the word “stigma” and did not know its meaning. *Of the nine women in this study, Mama May had spent more time in a rural area than in an urban environment. She may have had less access to HIV/AIDS community-based education activities.* Given a brief definition of stigma, Mama May responds, “Maybe they talk ... behind ... You know, everybody cannot love you, everybody cannot hate you. ... Nowadays, I can see I have my friends and some other friends have disappeared” (Appendix G).

The women in the study narrated stories of how stigma has impacted their lives. Amina Bashir spoke of HIV/AIDS community-based information programs and referred to the fact that some people, even though personally well informed regarding the chronic disease, are just mean people, “But you know, nowadays, almost everybody had the information. Almost everybody has the information about AIDS, but some people do it for ugly. ... just ugly – they don’t care.”

### **Learning of HIV+ status**

It was a terrible shock for all the women to learn of their HIV+ status and they handled it in a variety of ways. The silence around their medical condition, pacts with others not to disclose, and vigilant caution in disclosing to children, family members, and/or neighbors, suggests they may voluntarily stigmatize themselves.

Ten years ago Amina Abdul tested positive for HIV infection and at that time people had to wait two weeks before being informed of the results. Now there is no

waiting for the results; adult individuals are active participants in the testing procedure and see the result immediately. On first learning of her HIV+ status, Amina Abdul cried. Then she dealt with the knowledge in a very realistic way, acknowledging the cold fact that her medical condition can never be reversed, “But I say, it was already happen. Nothing can be done.” Amina Abdul does not let her disease prevent her from having a positive social life in the community, yet keeps her status a secret in certain situations. Whenever she goes out to socialize, she takes her ARVs with her and keeps them hidden. She keeps her secret of being an HIV+ woman from some people she works for and refers to the difficulty she has sometimes asking for time off to go to the clinic for regular check-ups,

[I]t’s very hard to ask for them ...to let me go to clinic.  
They ask me, “What doing for?” You know, some people,  
they don’t want people who has HIV to work for them.

*Keeping their “secret” of being HIV+ close [sic] can be a double-edged sword. In attempts to avoid stigma and discrimination, the women may inadvertently miss opportunities for understanding, support and human kindness on the part of others. Disclosing an HIV+ status remains a huge personal risk especially in a climate where lack of HIV/AIDS education and ignorance is widespread.*

Mama May was prevented from jumping from the fourth floor of Kenyatta hospital by a woman who observed her distraught state after testing positive for HIV and had followed her. Mama May reflects back to that time, “I just wanted to go in my coffin. ... And I wanted to kill my – I wanted to throw myself down the stairs.” Although she admitted in conversation that she did not know the word “stigma,” her immediate reaction upon seeing the positive result of her AIDS test clearly demonstrated a form of

self-stigmatization. On some unconscious level Mama May immediately reacted in a very dramatic way, possibly indicating a deeply rooted fear of the disease, perhaps fueled by ignorance.

Learning of her positive status, Penninah was very shocked. “I... become shocked, for about three months. I was not happy on that day. Even I was crying. Then when I came back to home, I stay with no comfortable in my room.” When Penninah found the courage to disclose her HIV+ status to the man she was then living with, he immediately left her. She stayed in the same room with only her children and gradually became sicker. It was not until she became so weak and could no longer manage to care for herself that she called her oldest sister to ask for help. Keeping her secret for three months, Penninah isolated herself from her family and community, suffering alone with her children. With support from other HIV+ women she has become stronger, yet has still not disclosed her HIV+ status to her mother.

Amina Bashir initially kept her HIV+ status a secret from her mother, sisters and neighbors until she became physically and emotionally depleted. In her desperation to earn money to feed and house her family, she had returned to work too soon after the birth of her daughter. She remembers that she had thought she was “special” because she had a husband, and could not become infected with HIV and would “stay here” [not die]. Initially she did not inform her husband of her status and suggested they go as a couple to be tested. When he refused and left her, she became really distraught, discouraged, depressed, and suicidal,

I just end by cutting myself [off] because that time I had never told anybody. ... I didn't want even to stay close to my children, I was just crying doing everything. I felt like

killing myself. I stayed on, then carried myself, slowly by slowly.

Amina Bashir stigmatized herself; she did not ask for help or support until she was in such an extreme state of distress that she collapsed and could no longer care for herself or her children. Learning of her HIV+ status and being abandoned by her husband, she kept herself isolated and struggled with her children alone. Desperate, she finally reached out to a sister. She found the sister caring and understanding, as was her mother when Amina Bashir returned to the family *boma* to recuperate. The kindness and support shown to her by her family appears to have been unexpected, indicating that, on some level, Amina Bashir had thought that being diagnosed as an HIV+ woman would bring some sort of disgrace to her family. Perhaps she blamed herself for her HIV+ status, thinking she would no longer be accepted by her family. At the time of her diagnosis, Amina Bashir was not HIV/AIDS literate and knew little about the disease; she did know HIV could be transmitted through sexual intercourse. Trusting her husband and knowing that she had no marital relations outside of her marriage, she was at first confused as to how she had become infected. The realization that her husband had been unfaithful was shockingly devastating. *Many married African women think they are "safe" from HIV infection because they are married and assume the husband to be monogamous (UNAIDS, 2004).*

Zakia spoke of shock waves she experienced when she saw the two lines on the HIV/AIDS test kit, an indication of a positive status. "I... was not thinking of something like that will happen to me." So she requested a second test which again proved positive. At that time, because she was too sick to work and pay the rent or buy food, she took her son to stay with her mother in another house in Kibera. She was shocked again by the

unkind, discriminatory treatment they received and had not experienced any stigmatizing before. She describes the situation,

[M]y Mama was the first person to be told. I went in a very hushed situation because [she] was the first person to stigmatize me. ... my Mama was the person who was telling me, 'Oh now you see, you bring, you have just bring us a lot of problem. No, no, no. I don't want to hear about this.'

At this time, Zakia was adjusting to her HIV+ diagnosis while being responsible for the welfare of her son and remembers, "My boy was living just [in] fear because he ... didn't know what [was] happening." Zakia's son asked to go somewhere else yet at the time Zakia had few options; she had no money, was physically weak and so unable to generate any income for a while. So she disciplined her son to remain quiet, to draw as little attention as possible to their presence and to be patient. All the while, Zakia lived with the constant fear of being sent away; she was dependent on the hospitality of her mother. It was Zakia's maternal grandmother who encouraged her not to listen to her mother's negativity and to move with her son to a sister's home and finally into a home of her own. Only after she began to feel stronger ,and with her grandmother's support, was Zakia able to remove herself and her son from a toxic situation.

Sarah did not want to be tested for HIV. It was only after she became very sick and her oldest children encouraged her to see a doctor that she went. The doctor wanted Sarah to have an HIV/AIDS test which she refused. At that time she thought the doctor was merely being unkind to her. "That time, I can't talk with the doctor. ... she's mean. I'm so sad." Sarah returned home and became much sicker, returned to the doctor, and again refused to be tested.

It was as the result of much counseling, further support from her children, and becoming even sicker that Sarah finally did agree to be tested. The result was positive and Sarah was devastated. She rushed home immediately without relaying the information to her children; for two months she stayed inside her house, seldom venturing outside. In Sarah's words,

So I say, from that time, when I know my status ... I am stigma ... two months. ... when I stay in my house, I was sick. ... Now do you know that picture? When HIV arrive in Kenyan, 1984, that picture she's [be]come. ... she's tear-sharing because your picture, when you are living with HIV positive, you ... stay like a skeleton, that time. ... when you back to that, 1984, even me, I say, I come and look like skeleton ... so this is my secret for me alone. ... So – to our friends now – then you keep secrets.

Before Sarah began ARV treatment and re-gained weight and personal strength, she was caught in a bind. She did not want to die or to continue feeling so sick and weak. She was resistant to taking an HIV/AIDS test because there was the frightening possibility that the result might be positive – as it was. Given that she knew little then about current treatment for the disease, she had the belief that those infected with HIV became like skeletons and then died horrible deaths. She finally chose to have an AIDS test and now, with support from her children, medical practitioners, and other HIV+ women, lives a productive life as an HIV+ woman.

### **Living with HIV is a challenge**

My courage? – from other peoples, when we are talking, When I tell somebody, I am weak in this side, she tell me, “Do this,” and me, I find the way. ... They (other women in the group) help me and because we are in this support group, we are there, we are like twins, we are like friends, we are like the childrens of parents, one – one person. Because we share stories for helping. ... I feel happy when we are together.... we discuss more, without mens there ...

I have something that is hurting me, I tell them, then she tell me what I am going to do. ... that supporting group is helping me. (Penninah)

Day-to-day life in Kibera, a mega-slum, presents many challenges; living there as HIV+ women is just one of them. The nine women describe sources of support from which they draw hope, strength, and courage to cope and carry on.

All the women narrated stories of support groups specifically established for those who are HIV+.

### **Support groups**

Penninah finds it helpful to be with like-minded other HIV+ women who speak from experience of living positively with the disease; not feeling alone has become very important in her daily activities. She has forged friendships with other HIV+ women in support groups and, should her head begin to be “achy” when she is alone in her house, she calls or texts a woman she knows. They talk with her or go to make a home visit and she becomes calmer. Penninah has come to understand how HIV affects her body and how stigma can affect her thoughts and emotions. Since being enabled to comprehend more clearly that, with treatment, she can live a long time with HIV, she makes the comment that, in all likelihood, “... actually I won’t die.”

Penninah is a member of the Darajani Widows Living with HIV/AIDS group and has attended other support groups that are constantly springing up like new shoots in Kibera. Her network of new friends call or text her with information about a new group that appears in Kibera and want her to check it out. She finds courage, support, and “new tools” in many of these group meetings to cope with living as an HIV+ woman.

When attending HIV+ support groups Loise may speak to a specific challenge she is presently experiencing, “We talk – in case I have problem, I say, ‘I have done this and this.’ They will try to tell me, ‘you can do this and this, or go and see the doctor.’” However, Loise does not have much trust in the government and some local non-governmental organizations who arrange for trucks to enter Kibera with food for distribution to HIV+ individuals who present their identification cards. Loise has never received any free food and reports,

We don't from the government ... You can get here... there's food there, they give for people with HIV. Even if you go with the doctors' letter, if they says finish, nothing is there. Actually ... me have never got anything from – I always say it is a waste of time, because when you go to, ma'am, you go, there are always very many, even though who are not HIV.

Amina Bashir attends Post Test Clubs (PTC) and support groups and reveals that some help while others do not because, in some situations, it is only friends and relatives who are welcomed into the group. Amina Bashir comments,

Some are helpful, some. But some are not helpful because you get ...an individual person starting an organization then ... and some people comes in just become for his own family. He does not support other people.

The Darajani Widows Living with HIV/AIDS is one group that provides her with support from other women and she is appreciative of friendships that are initiated there and continue on into the community,

Like, in ideas, sharing of ideas. Becoming friends like us... so when I have problem, I can share. Zakia's close to me. I run to her. I tell her, 'I have this problem,' and she helps me.

Mama May spends most of her time now in her rural home and so does not regularly attend the Darajani Widows Living with HIV/AIDS meetings. Nevertheless, her commentary sheds light on the benefit she does receive from her participation. “And, with the women talk, when we talk ... even my head is pain me. Even when we started talking, yeah, we talk and the pains disappeared.”

It is hope for her children’s future that encourages Zuhura to remain strong and “keep up”. She is a founding member of the Darajani Widows Living with HIV/AIDS group and welcomes the time to relax with the other women when they meet. “We talk to each other... we talk freely when we are together; we are free, very free. We talk very nice.” Zuhura acknowledges the infancy of the Darajani Widows Living with HIV/AIDS group and recognizes the importance of feeling included in decision-making that affects all group members. This group meets every Saturday in the early hours so individuals can go about their money-making businesses the rest of the day. By actively participating in and with the group, Zuhura has made friends and appreciates home visits when she texts them if not feeling well; she finds these visits give her hope. Yet she remains wary of groups that come and go in Kibera,

It’s a very nice home visit. But this many, many support groups, they just use people. They use people. Because you are HIV positive, they put you together, they get money from you but this money – or any help they get from that doesn’t reach you. ... I become sick – no one is come – kind and support you and it is a support group. ... Because some people they just take you, they use you, your names, and they started getting money from somewhere, but you don’t get that money whenever – if you are sick. I decide I will only go to the Darajani, I need this – if I become O.K. Only Darajani because it’s what I started... and we will say – we will decide what to do at Darajani, and our group, how to help each other.

Zuhura was not well when I was collecting data; she had little energy and so was home much more than was usual. When she went to a local clinic in Kibera, a counselor tried to persuade her to join another support group there. She refused, even though she was informed that she would be provided with food if she joined the group. She still refused and was not overly impressed with the tactics of coercion used by staff. She makes this observation, “Now, when you are very sick, you can’t eat anything. If you bring me food and... I can’t eat any of them. Who is going to eat this food?”

As an HIV+ positive woman, Zuhura advocates for those whose voices are still unheard. She thinks that there are times, when the food offered, it is too late to be of help; more to the point, if someone is alone, too weak to work or get off the bed, and out of their home, who is going to cook the food and provide the cooking fuel?

Sarah received much support from her oldest children, counselors, and doctors prior to being tested. Initially reluctant to attend support groups, she has come to depend on the mutual exchange of stories, the emotional support she receives there, and the privacy she has come to expect. In her words,

[I]n group, you are here now, like me ... [I] was feeling well. Anybody you talk, anything you want to talk, your status, your disclosure ... anything you are free to talk, but in outside, leave that chatter.

Sarah goes to the hospital once a month for her CD4 blood count to be checked and to get a month’s supply of ARV drugs, and attends a support group there. At first somewhat cautious, she now welcomes participating in the support group there and remembers,

And when I go to that room, so many persons I know! But I don’t know what [that] she is living with HIV because she’s helped and she’s free. She’s feeling like anybody.

You can know – you can understand this person is living with HIV positive. So many peoples I know here. But now that time – sasa, [O.K.] – she [other HIV+ women in group] – she give me *moyo, moyo*. ... And Sarah now, I feel well now. After now, I like support group. ... morality in hearts.

Sarah chooses to keep her HIV+ status a secret from those whom she fears may stigmatize and discriminate against her. Knowing from experience that women in the support groups she has attended share the same concern and the same secret provides her with comfort and incentive to explore new groups and venture out further in her community. She now participates in three support groups in Kibera, including a group that facilitates the merry-go-round financial scheme of a micro-economic project that finances her chicken-selling business.

Lucy regularly attends two support groups a week. Like Zuhura, she is leery of government-sponsored groups because she thinks they engage in nepotism and support only their own relations, tribal members, and friends. She comments, “The government, bad people. ... they come through people, like leaders, they don’t – they can’t give us.”

Amina Abdul’s friends inform her of groups and workshops that are relevant to those living with HIV. Participating in such groups provides her with a “safe place” to talk about the challenges of living as an HIV+ woman. She welcomes the freedom to talk openly without fear of discrimination and stigma and says,

I go to groups for, I go and – there to chat with my friends. ... sometimes, you don’t know some of the – way of coping with HIV. If you go there, you talk, you learn something from them. I got support groups ... when you go to support groups you have – you feel comfortable, you feel very nice, you feel free talking to the other people like you. They have others like you. You see? You are free.

Amina Abdul is proud of the certificate she received for participating in a three-day treatment-literacy working group. She is a strong believer in personal confidence and believes that support groups supply information and education that can empower those who listen and learn. Yet, she astutely recognizes that it is the individual who empowers themselves,

You have to empower yourself first. Nobody is going to come out, say that, 'we empower you.' No. You are the one who is going to empower yourself – if you want to raise your son, you want to do the things you see in front of you. ... You start with yourself first, then you go outside to the other people.

Since accepting her HIV+ status, Zakia has availed herself of every opportunity to learn from an array of community-based information sharing efforts, inclusive of support groups; now she “walks like a lion.” She feels empowered, has developed pride in the preventative work she does “round, round and round” in the community, around issues relating to HIV/AIDS, HIV+ women’s rights, family violence, and child protection. All of her work is voluntary, as she describes, “The volunteer? We just – now the people who are just – now we see there’s a need... you just feel from your heart.”

Zakia lives by example; it is important to her that she is seen within the community as a strong woman, a role model, who is very capable of caring for her son and taking responsibility for her own life. She knows from personal experience that, with early treatment and adequate self-care, testing positively for HIV/AIDS does not preclude life ahead, it is not an emissary of imminent death. “Forward ever, backward never” is a motto which shapes her daily activities and she works hard not to be judged as weak by others. She encourages those who live as HIV+ women to live full lives, “because if you – if you show them that you are weak, they’ll see how if I live with this virus, I will die

soon.” Zakia is a very strong community member, and believes she learns from her community,

I think that ... if the community was not there ... my mind will just say [sic] simple; I couldn't open up my mind. Because the community is opening up my mind, because ... if I walk out in the community, ... I get a lot of information. I get some people who want help. ... I'm part of community and they give me more strength because I know I have to work with my – the community – with other people. It's not me, alone, I have to work for them and they are – they're here to give me – ever the community also, you get – you go and get a lot of information in that community.

### **Being community**

All the women in this study are active participants in community group initiatives that promote raising public awareness of the need for HIV/AIDS testing, other health issues such as tuberculosis, child and family violence, and women's rights. The impetus may come from an actual support group consensus or be initiated by the will of an individual.

As “an educated lady”, it is important to Amina Bashir that she makes every effort to attend as many workshops and training sessions as possible to remain current with all issues related to individual and community health. She passes on this information where and when applicable and says,

I am a volunteer, especially right now – I am a paralegal...I volunteer for – seeing the rights of women, the rights of people who are living with HIV. ... so that they are not being exploited. The rights of children, especially yesterday, I was ... in a training for three days of the right of children and completed yesterday. So – I also train people and groups. ... they form groups, I train how you can pick your ten shillings in group set, give one person – business and he returns his loan. When ... one of the member becomes broke, he comes to the group, ‘please, I

have a problem, help me.' You are being given two hundred to assist your children, maybe for lunch, or for supper.

It was not until after she was tested and began to learn about HIV and its possible effects on individual bodies that Amina Bashir had the realization that her sister and her father had died of the infection some years before. Now she works hard participating in community-based HIV/AIDS programs to prevent people dying because of ignorance and before it is too late to get medical treatment. She says, "But it was too late [to help her sister and father] .... From there, I have to help other people. ... even if my sister is dead, I have to help the community, so I decided to get into the community and volunteer."

As well as conducting the community work involved with protecting the human rights of children and HIV-infected people, Amina Bashir walks in the company of like-minded others among community villages, talking to those who will listen about the disease and encouraging individuals, especially pregnant women, to go and get tested.

Mama May accompanies members of the Darajani Widows Living with HIV/AIDS when they go out into the community to talk about specific subjects such as the importance of being tested. She also attends workshops in Kibera that have the potential to provide her with skills to make money or to save money. For example, she learned how to transform paper into fuel suitable for cooking.

When Penninah goes about in the community advocating the need for HIV/AIDS testing or other related health self-care issues, she never goes alone as it is not safe. It is not safe for any individual woman to walk around Kibera speaking to groups about HIV/AIDS or any other subject, for that matter. There is strength and safety in numbers as Penninah reports,

Because when we go, be alone, they will abuse you. ...  
 When we go, and when you are alone they started abusing,  
 But when we are in our group, we discuss ... about raping,  
 about HIV, feeling what we can do. But ... some others are  
 not willing. ... They don't want to hear that. And they're  
 the ignores, they are ignoring.

Taking part in "drama," is one way that Lucy contributes to the well-being of the  
 local community,

We go to – to community to educate, ... to go to the house  
 to ...educate about some – not HIV, about TB,  
 tuberculosis. ... sometimes, they choose me. They tell me  
 'Now go and act.' So today, you act like you are sick, in  
 TB and I do it. ... I know, because I don't want ... people  
 to suffer like me, so I must ... go first to tell her, You have  
 to know this, this and this because TB is dangerous.

### **Belief in God**

All the women without exception spoke of a trust and a belief in a God. Not one  
 woman made reference to African Indigenous cultural beliefs regarding deities; they  
 spoke of ritualistic practices more associated with western and Islamic religious beliefs  
 from which they find comfort and strength.

There are four Muslim women in this study group of nine African women. They  
 are Zakia, Amina Bashir, Amina Abdul, and Zuhura. Muslim practices are taken up daily  
 by these women, in their homes and in one of the local mosques.

When being stigmatized by her mother, Zakia remembers her grandmother  
 reminded her to pray,

Life doesn't go smooth way you think. You've been living  
 your own life very good, doing your own job. Now, God  
 have just bring this, just to test your heart and mind, to see  
 how strong you are. You have to live and know – live and  
 think about your life. Talk to your God. Go to your knees  
 every now and then to give [you] courage, to ... cope with

the situation ... you are living on. One day, one time, change will come.

Zakia listened to her grandmother and prays five times a day, as is the Muslim custom. She prays hard for God to give her strength, to give her courage, “to fight whatever I’m going through.” She recognizes that there are those in both the Christian and Islamic faiths who will not accept HIV as a sickness and discriminate against those who are infected: “some people... doesn’t want to hear about HIV – if you are HIV, they just – they just put it on like you are a sinner.” According to Zakia, people who think of those who are HIV+ as sinners are the people who stigmatize and discriminate against those who are sick with the disease. She distinguishes between faith and the followers. “Faith is big, but the people, they are the ones who are complicating the things. ... God doesn’t want to know who are you. We are all one people.”

Amina Bashir prays to God in her home and regularly attends the mosque. She is not afraid to stand up in her community with her friend and neighbor, Zakia, another Muslim woman, to talk publicly about HIV/AIDS. She wants to be seen as a living example that HIV/AIDS does not kill if treated early enough.

Amina Abdul, the third of the four Muslim women in the group, lives with a strong belief in God. She believes in the creed that God is in charge of her life: “I stay in God’s hands, let me pray to God. God will help me.” She expresses a very realistic view of life and mortality,

Because death is there. ... if you have HIV, if you don’t have HIV, death is there. Yeah. You will die, one day, one time, yeah. [Laughs]. Yeah. ... When time is ready, when the day – ah me, I’m praying to God, I’m telling my God, help me to raise my children to get good ... education, to get to college, to get work to get their wives, to get their grandchildren. I have to succeed them, yeah, yeah.

Being a devout Muslim woman, Zuhura prays five times a day and attends a local mosque. She prays to God for practical things such as work so she can send her three-year-old daughter to nursery school. Educating her children from an early age is important to Zuhura and she hopes in the future to feel well enough to work and make money as she used to do before she was diagnosed with the virus. She wants to feel strong again and prays to God, “to be strong and do my work.”

Loise is an active member of the Mother’s Union in her local Anglican church and teaches Bible Study to children on Sunday in the church compound. This is the church compound in which the Darajani Widows meet every Saturday in one of the other buildings. It was Loise who made the initial request to use the room for meetings without cost from the powers that be within the church. She never works on a Sunday, as she goes to church that day with her children. When hospitalized, it was church members who supported her financially so she was able to continue with necessary rent payments and her children did not go hungry. She narrates a story,

Now I have been using drugs since 2005 up to now. I have been down and up, down and up but support groups, and church member, plus – my God first, they have been helping me up to date. ... and it is the church members who, up to now, it’s only church members who are helping to pay for my children.

Social workers, counselors and doctors have been a big part of Mama May’s life since she became sick and tested positively as an HIV+ woman. She lost so much weight before her body adjusted to the ARV treatment that she spent much time talking with HIV/AIDS professionals regarding the circumstances of her present life. She is prescribed only one month’s supply of the drugs at a time which necessitates a return trip to Nairobi should she be in her family’s *boma* at such a time; finding money for

transportation can be cause for “stress-up.” Mama May acknowledges that the drugs are keeping her alive and for that she thanks God and is thankful. She comments, “My life? Then before, it was only danger but now I really pray a lot and I thank God for that.” Mama May practices the Catholic faith, at times seeking support from the Guadalupe Nuns in Kibera and prays at night, saying, “Even at late, I have to lay down, I pray.”

Penninah prays every day. She believes that it is because of God’s personal care that she continues to get up every day and continues to live,

God is the one who will make me to be – now. I am going to pray Him – pray. [He] is always caring about me. And I always make sure I will go to church on Sunday, and I always ... pray in my house. ... I always pray for God, asking Him to help me and wake up. And now I can say God is with – with me.

Prayer, God, and her pastor provide Sarah with encouragement, courage and strength to continue living each day and do her best to provide for the ten children in her care. At the time of our conversations, she announced that she was feeling well and prays to God to live longer, “[I am] feeling well, but I say, God is help me. I need another twenty years, I need another more years.” Sarah talks privately with her pastor about her fears of dying before all her children are adults and can be responsible for making their own way in the world. She and the pastor pray together and she strongly believes that it is God’s will that she is still alive now. Sarah confides,

Then you say, ‘God look me.’ God, he can’t leave you. When I talk with [God] Love – God ... can’t leave [me]. I know I am staying like this ... because of God. ... He kind of give me stay. ... Because when I talk to God, I’m feeling well ... my body is ... feeling well, My house is feeling well. ... Even now, I feel well [laughs]. I say, ‘God help me, and keep me another time.’ Yes.

Lucy goes to church every day and comments,

Every day I go to church. I'm a Catholic. I wake up, I pray, I take my medicine. ... Every Sunday, you go to church. ... I went to church... before I know my status. I can't start now. I went before my status. Even now we go, we continue at that church, even now.

By going to church regularly Lucy finds hope and encouragement. When she is feeling unwell or has a particular challenge that is cause for stress, she stands up at the appropriate time in the church and requests support from the congregation. She describes the circumstances,

The father, [church priest] they give you hope. If you are sick, then you go to church ... and you stand up and you take the [stand]... I'm O.K. I see the miracle in God. ... They do me well, because I'm walk – the other people, [who remain sick], they sleep in the hospital, they don't work. But you in life, you get work, you grow and you find ... what you want, and God you pray for – and you pray from God to help you more.

The days are long and busy for these HIV+ women as they go about their daily lives in Kibera. They go to sleep after a hard day of work, often as or after the sun sets.

### **Ending the day**

Maybe sometimes when I – body she's not feeling well ... even seven, I'm going to sleep ... Na, maybe sometimes when I am good, at even ... nine I'm going to sleep. (Sarah)

After a full day of work, attending support groups, participating in community activities, exchanging news when talking with friends, and going for medical check-ups, these mothers generally return to their homes to have an evening meal with their children, help with homework in some households, and then to sleep.

### **Cooking supper**

Penninah's children cook the evening meal and care for themselves when she is feeling sick or her head is achy. Bending low as is required while preparing some food items on a *jiko* (round heavy metal cooking utensil that uses charcoal fuel for cooking) which is located close to the ground can become uncomfortable at times. Penninah is usually in asleep between eight-thirty and nine o'clock every night. She reflects, "When I become sick, my children simply prepare their... meal, they care for their own... So I can tell the older one to prepare the meal... for the whole."

Sarah's older children help her in cooking the evening meal. Those children not in high school arrive home around five o'clock and the one in high school arrives home close to six-thirty. She likes to eat with all her children and the usual sleeping time is nine o'clock. However, if Sarah is feeling unwell, she goes to bed earlier.

### **Time to sleep**

Amina Bashir goes to bed normally around ten o'clock after she has finished preparing the *mabuya* and ice, and taking the ice to a neighbor's fridge for the night. She describes the staggered bedtime routine for those in her house, "The girl goes first at around eight. ... the first-born was (is) very late because he studies. When I'm closing my eyes, he's from the table studying."

Lucy goes to bed at approximately nine o'clock and her children go at the same time. Her oldest daughter comes home from making some money at around seven-thirty and helps with preparing the evening meal. Lucy eats with her children, oversees the homework of those children still in school, and "must watch the news first" before going to bed. After watching the news on a small television she has in her home, she cleans up

and then goes to bed. Lucy reports, “My children, they finish first their homework and I prepare supper. After eating, I wash my dishes, even my children help.”

Zuhura’s mother cooks and provides the last meal of the day for her daughter and grandchildren. When they have eaten, they return home to sleep, and Zuhura likes to go to bed early at eight-thirty. She says, “I like going to bed early because it is also good when you sleep, the sleep is also like medicine in our body.”

The three days a week Amina Abdul works outside of Kibera, she may not return home until between five-thirty and seven o’clock; it depends on when she finishes the assigned workload and how quickly she can walk. The walk to work usually takes one hour. She prefers to walk because she can save the cost of the fares for the two *matatus* it takes for the journey. Once home, Amina Abdul prepares the meal while her children do their homework. They all go to bed at the same time, approximately around nine o’clock to half past that hour,

They go [to bed] at the same time because they have to do their homework. When they come from the school, they have to clean, sometime, they clean their uniform, if it’s really dirty ... I cook, then they at ...we go to bed.

The nine storylines teased from the meta-narratives of the nine women in this study speak to their participation in community activities and how they experience and story their daily lives. The women live in one of the world’s mega slums, Kibera; they have no husbands, little support from extended family members, and are responsible for the care of their dependent children. Rising early each day, they struggle to generate enough money to buy clean water, food, pay the rent, and supply themselves and their children with whatever else is urgently needed in their daily lives. They all believe in a

God, and participate in at least one support group. By attending HIV+ support groups their circle of friends has become wider. They make new friends by listening and sharing resonating stories of living positively with the chronic disease and they go to sleep after a long, full day.

In the next chapter, Chapter 6, Discussion and Conclusion, I discuss my findings, and draw some conclusions. I suggest foci for future research within the HIV/AIDS context.

## Chapter 6: Discussion and Conclusion

How do HIV+ women living in Kibera, Kenya experience and story their daily lives and participate in community? In this dissertation I explored the lives of nine HIV+ women who are widows, responsible for the care of children, and presently live in Kibera, recognized internationally as a mega slum.

These women live in a country in sub-Saharan Africa, a region of the world that is more heavily affected by HIV/AIDS than any other. However, as a result of antiretroviral treatment scale-up, they are among those who now live longer with the disease. In 2006, free antiretroviral drugs provided in public hospitals and health centers contributed to the 29% decrease in HIV/AIDS-related deaths between 2002 and 2006 (UNGASS, 2010). Although fewer people are dying, the disease has radically reshaped demographics and none of the interventions can replace what has been lost in terms of human capacity and resources (Commission on HIV/AIDS and Governance in Africa (CHGA), 2004; UNAIDS, 1998, 2006). It is difficult to imagine how generations to come will cope and manage with the changes in social landscapes as has happened in the past after major catastrophes (Sánchez, 2008). The lives of the women in this study changed dramatically when they were diagnosed with HIV/AIDS.

Women in Africa are already all too familiar with many aspects of personal and collective loss on many levels. They experienced loss associated with colonial rule when collective freedom to move at will was terminated. Individuals from past and present no longer work land from which they sustained an economy which fed and supported them, their children, and other family members (Payne, 2005). Thirty years ago the HIV/AIDS pandemic presented African peoples with one more loss to compound the daily struggle

to live and support family. They lost their overall health, an essential resource in their everyday lives. Many died; extended families were disrupted or lost. The fabric of community life was torn in pieces. If it were not for the antiretroviral drugs, many more women would now die. It is well to remember that, while easier access to antiretroviral drug therapies may prolong life, life is not necessarily made any easier.

It has often been that women's histories are written by men whose perceptions and written records do not correspond to the reality of women's lived experience (Gordon, 1986). Feminist scholars challenged this notion of patriarchal importance and continue to be diligent in efforts to balance the scales, to quiet the cacophony of men's voices, and to raise the voices of women (Belenky, Clinchy, Goldberger, & Tarukte, 1986; Gilligan, 1982; Gottlieb, 1995, Harding, 1991). The convergence of narrative, feminist and Indigenous methodologies within this research study provided a venue in which Amina Abdul, Amina Bashir, Loise, Lucy, Mama May, Penninah, Sarah, Zakia and Zuhura speak loudly with their own voices on standpoints that intersect with many aspects of their lives today.

Life is more difficult for HIV+ women in Kibera than it is for those who are not chronically ill; the grinding reality of poverty is realized in all aspects of their daily struggles to survive. Their lives are far more complex than may be assumed by an apparent normalcy of waking up each morning in their respective homes to begin their days. Every day the women cope with the balancing of multi-faceted challenges and living with HIV is just one of these challenges. These women have an intimate knowledge of poverty, gender inequality, concern for the future of their children, and stigma in a post-colonial context that shapes their everyday activities.

This final chapter includes five topics of discussion: poverty, women and their children, stigma, shared community, and limitations of the study. This is followed by narrative reflections on the study and then the conclusion, “Where to from here?”

### **Poverty**

The magnitude of poverty in Kibera cannot be overstated. The fact that poverty affects every aspect of living is revealed in the many layers of each story. The face of poverty becomes illuminated in the pragmatic, concrete, stark, day-to-day accounts of the lives of the women in this study. This research explored the lives of impoverished HIV+ women living in miserable conditions where the lack of infrastructure is a key contributor to sickness. Every day the women, living in homes with earthen floors, must fetch and pay for water. Before they can drink it, they must boil or chemically treat it to safeguard against waterborne diseases. Access to essential resources to support health is frequently non-existent and appropriate services for dealing with family violence, child abuse, and legal issues are inadequate. The women sometimes find themselves dependent on the goodwill of others for a meal and, at times, for somewhere to sleep. Infected with HIV, they often did not seek medical attention until the need for antiretroviral treatment was urgent (Marston & De Cook, 2004). Although Unge et al. (2008) reported that HIV+ individuals receiving ARV treatment in Kibera are now in receipt of government food supplements, not one woman in my study reported receiving any such food supplement. The women in my study were not asked specifically whether they had ever received government or other agency food supplements because they were HIV+. However, several of them reported they had received “nothing” in the past. One woman drew

attention to the futility of lining up for food supplements from trucks that entered Kibera: they were turned away before they got to the front of the queue as there was no food left.

The lives of HIV+ individuals living in poverty have been affected by access to cheaper ARV medications. The combination of medical advancement and recognition of human rights that once were on the periphery is making differences in the lives of HIV+ individuals. “Today, the vast majority of countries (89%) explicitly acknowledge or address human rights in their national AIDS strategies, with 92% of countries reporting that they have programmes in place to reduce HIV-related stigma and discrimination” (UNAIDS, 2010, p. 10). That being acknowledged, my study revealed alarmingly that the nine HIV+ women in Kibera live each day in conditions that continue to infringe on their human right to a quality of life that offers personal health, dignity, choice, and hope for the future for themselves and their children, qualities of life that so many others take for granted. These women live in desperate poverty.

Every waking day these women confront social justice issues because they live in an environment of poverty. They struggle with the profound impacts of social determinants of health that impinge on their well-being and their chances of living a flourishing life (WHO, 2008). They lack access to work, affordable health care, schools, and education for their children. They lack the financial resources to live in adequate houses. As a result they must live in houses where the roof leaks during the rainy season, where the light is constantly dim because there is no electricity and the one window – if there is one – is only big enough to allow inside a small amount of daylight. The air is dusty and human and animal waste litter the ground outside; on hot days, the stench may become unbearable. Generating money to buy food and pay rent is the main

preoccupation of daily life for these HIV+ women who have little time for relaxation and leisure pursuits (Bodewes, 2005; Davis, 2006).

Living conditions shape everyone's life. Deep inequities are the result of a combination of toxic national and international policies, economics, and politics. For those living in extreme poverty, this is a matter of life and death (WHO, 2008). The social and political conditions in Kibera, social determinants of health, are such that it is astonishing people survive, let alone expect to be well or to thrive, and this is especially true for women who are HIV+. If it can be said that health is a fundamental human right and that every human being is entitled to the enjoyment of the highest attainable standard of health (WHO 1999), that human right is denied to residents of Kibera. It remains imperative to address the needs of those who live in such appalling conditions to prevent further unnecessary suffering and early death.

Poverty creates the conditions for diseases, such as malaria, and tuberculosis, which then further erode the health of HIV+ individuals. Michael Kazatchkine, executive director of the Global Fund, announced that the HIV/AIDS crisis heralded a paradigmatic shift in the global response to health (BBC, 2011). Acknowledging health to be a basic human right, he stated that health should be viewed as an investment, not just an expenditure, in matters of global development. When poverty-related illnesses – those directly linked to poor diet, inadequate housing, and unsanitary conditions – are allowed to continue, people are unable to contribute to economic growth in the community and the nation. For the women in this study, the need for a balanced diet and healthy living environment illustrates this point. One woman living in one windowless room with her four children had tuberculosis. One of her children was absent from school due to

malaria. When women are sick, have little energy or need to care for sick children, they are unable to work and the home economy becomes even more desperate. If there is a need to purchase medication, financial resources are further drained.

### **Women and their children**

Like women in many global communities, the HIV+ mothers in this study struggle to survive. HIV/AIDS in the African context, where access to ARVs is relatively new and sometimes tenuous, affects the everyday life of these women in a social and political environment that does little to promote their health or soothe and heal them when they are sick. It is well known that HIV/AIDS strikes productive adults in the prime of life. Much has been written about grandmothers who raise orphaned grandchildren in crowded and impoverished conditions (Dane & Levine, 1994; UNAIDS, UNICEF & USAIDS, 2004; UNAIDS, 2010; UNICEF, 2003). Relatively little has been documented regarding widows who are the female heads of households and who care for children in just such conditions. This study helps to address this gap in the literature.

All the women spoke of their relationships with children, especially of their anguish when thinking what would happen if they were to die before the children were capable of fending for themselves. They are frightened their children may gravitate to the streets and join the legions of orphans who have no alternative because nobody is left in their immediate family and no one in their extended family has the means or sometimes the willingness to support them (UNAIDS et al., 2004).

The women spoke of interactions with their children regarding issues of medication, their need for rest, and the necessity of immediate medical attention should it be required. Attention was drawn to concrete ways children helped with household

chores such as fetching water and cooking meals, behaviors which are consistent with the phenomenon of child-headed households that has become a reality in the African HIV/AIDS context. There is little available research but increasing urgency regarding the psychological well-being of vulnerable children such as these. Their swelling numbers will continue to contribute to grave psychosocial and cultural challenges and distress in countries where the disease has claimed millions of parents (Beuman & Germann, 2005; Cluver & Gardner, 2007). Little is known about how vulnerable children, those whose lives are touched in diverse ways by HIV/AIDS, adjust to adulthood. The interlinkages between children in the context of HIV/AIDS and the implications of these factors merit further investigation.

### **Stigma**

Stigma directed towards those who are HIV+ is profound in Kibera; eight of the nine women reported having experienced stigma in one form or another. Amina Abdul speaks of the seriousness of stigma attached to being infected with HIV, “And the thing that killing people is stigma, stigma.” She is alluding to the fact that some people do not access treatment because fear of stigma prevents them from being tested. While ARV treatment may prolong life for those infected with HIV, there is no treatment that curbs or prevents stigma, although programs are in place to address the issue. Stigma permeates all communities in which HIV+ people live and is gaining attention from those in positions of power at community, national, and international levels.

The most prevalent public image of HIV/AIDS in a globalizing world is one of desolation and despair (BBC, 2011); it is a disease that used to be widely considered a death sentence and is feared by many as something to hide. Many faces of those who test

positively for the disease are lost in statistical columns. A diagnosis of being HIV+ brings to mind a social death before a possible physical death due to the progression of AIDS and the stigma attached to diseases commonly associated as being transmitted sexually (Sontag, 1989). Stigma due to ignorance continues to compound the struggles of daily living for HIV+ women around the globe.

There is an increasing amount of literature regarding stigma written from a western perspective. There is a need to know more about stigma written from non-western worldviews. I found no literature that addresses possible effects of Indigenous philosophies relating to the interdependency of individuals within the collective and how this may determine underlying thoughts and actions of those who experience HIV/AIDS stigma and discrimination. For that matter, I found no reading material either that addresses motivation on the part of those who commit acts of HIV-related stigma and discrimination from the perspective of an Indigenous worldview. However, my study data did isolate instances whereby two HIV+ women were perceived as liabilities by their own mothers. More research in the area of HIV/AIDS-related stigma in family groupings is needed to better understand the phenomenon.

Although stigma was not the focus of my study, in my data I found disjuncture and disconnects in conversations relating to stigma and issues of HIV+ status disclosure. Women spoke of learning to cope with stigma in support groups, and then confided to not disclosing their HIV+ status to children because they thought the children too young to understand. One woman had not informed her young grandson that he is HIV+ because she was afraid he would inform neighbors' children who would report to their parents and thus she may eventually be shunned or chased away from her home.

Cudd (2006) and Alavi (2008, 2010) have written about voluntary oppression or self-blaming by those who have experienced some form of oppression by others in their past, such as Holocaust victims and those who experience racial discrimination. In a similar vein, several women in this study, upon receiving their HIV+ diagnosis, self-stigmatized and suffered silently by keeping their status a secret. One woman tried to kill herself. Another mother did not discuss HIV/AIDS openly with her children, yet they knew of her condition and reminded her to take the ARV medication regularly. Another woman's older children were aware of their mother's HIV status, as they were the ones who initially persuaded her to have an HIV/AIDS test and had spoken with the doctor. Some mothers referred to the fact that HIV/AIDS was part of the school curriculum and so children were most likely to be already informed about the disease. This may be compared to sex education in Western schools; some parents rely on the school to broach what they consider a sensitive topic, while other families insist on teaching their values as they have "the talk."

Deciding when and how to disclose their HIV+ status not only to their children but to others must be a difficult decision, as one must consider the impact of stigma on the collectives of family, ethnic group, and other close community groups. These HIV+ women were referred to support groups after their diagnosis and only then did they discuss "officially" issues relating to HIV/AIDS-related stigma. To prevent more deaths by those infected with HIV, there is a desperate need for more in-depth research in the area of HIV/AIDS-related stigma, particularly as it pertains to disclosure to children.

### **Shared community**

The HIV+ women in Kibera live community (refer to Definition of Terms, p. viii above), and they share a vibrant economic activity motivated by their quest for survival. They wake up early on most days to care for children; they make saleable items and take them to markets or to customers; they wash clothes, braid hair, and some clean and cook for others outside of Kibera. They are always alert to opportunities for generating income. Loise tried selling tomatoes by the roadside but no one bought from her stand, so she decided to try another way; she now sells tomatoes as she walks around the community and takes orders via text phone messages. Income earned by each woman is used to pay rent, buy food, water, household items, and to educate children, and yet it is never enough. Their earned income is insufficient to purchase a quality of life that offers personal dignity, choice, and freedom from stress and sickness.

The women attend several groups, post-positive groups for those who have tested positive for HIV, and micro-economic groups that support individual enterprise. Sarah was able to begin her chicken-selling business using small loans from several such “round robin” groups. Actively participating in community efforts to prevent the spread of HIV/AIDS, women spoke of walking in twos, threes, or more around local villages speaking about HIV/AIDS-related issues: their actions spoke to a collective responsibility, kindness and a willingness to help others, especially other HIV+ women.

Community was also evident through attending religious community groups and practicing religious rituals of choice, such as prayer, in the privacy of their homes. Active participation afforded women comfort and provided them with some strength when they woke each morning to face another day.

In search of ways to generate money, women tend to spend a good part of their days moving around local communities inside the villages of Kibera as well as other locations in and close to the city of Nairobi. Participation in daily activities to earn money, attend support groups, receive medical treatment, and participate in religious community groups may require the women to move a distance from their homes. This necessity to move away from home, and local familiar communities, in efforts to survive contrasts sharply with an Indigenous idea of a collective interdependency.

### **Limitations of the study**

Given the scope, depth and diversity of the HIV/AIDS phenomenon worldwide, and specifically in Africa, the research design meant that the sample size of this study is small. Nevertheless, it is adequate within a narrative inquiry where the depth of data is significant (Morse, 1991; Riessman, 2008). The sampling strategy was purposeful rather than random and, as with most qualitative research, the findings are not intended to be generalizable for other populations (Morse, 1991). Nonetheless, the findings may fund theory development (Morse, 1991; Thorne, Kirkham, & O'Flynn-Magee, 2004) and could be used by practitioners, policy makers, and community development workers who see that the paradigm cases represent situations that they recognize (Sheilds, 2007).

In Kibera I was a visible minority. My role as a western, white, non-Indigenous, female research interviewer undoubtedly affected the stories I was told. In telling their stories, the women engaged in a synthesis of their past, present, and future and presented themselves in a certain way. The process became “in part a shared narrative construction and reconstruction through the inquiry” (Connelly & Clandinin, 1990, p. 5; Reissman, 2008). Bruner (1987) wrote that “A life led is inseparable from a life as told – or – a life

is not 'how it was' but how it is interpreted and re-interpreted, told and retold" (p. 137).

The women and I collaborated in the co-construction of a new narrative about living with HIV/AIDS. Consistent with narrative, the women told me stories in a moment in time and I acknowledge that I never heard their whole stories.

The use of English when conducting the interviews was a limitation that I must acknowledge. English is not the first language of the women in the study, it is mine. All of the women selected for participation in the study were required to be able to converse in English in the interviews. Many of the women speak three languages.

Limitations of language restricted what the women could and did share with me. Acknowledging the diversity of Indigenous languages, I remained diligent in listening for meaning regarding pronoun use and reference to time in the analysis of interviews. For example, as I listened to Sarah's stories, I realized she consistently moved back and forth in her use of first- and third-person voices; Zakia told me stories of the past using present tense verbs. Although I had made previous trips to Kenya and listened to Kenyan women speak, I found it took some time to again become accustomed to listening and hearing the sound of their voices. In retrospect, I would have preferred a longer interval between my arrival in Nairobi and the first of my interviews in Kibera. As it was, Winnie and the women were eager to begin, and I made the decision to start the conversations for data collecting when invited.

There are also some limitations, gaps in the data which are surprising and of which I am aware. For example, the concept of death reoccurs several times in the narratives of the women, yet only one woman reported attending a funeral. This was her husband's funeral and it took place in the rural village of his birth and not in Kibera.

Funerals are a big part of African communities and have become very frequent due to the HIV/AIDS pandemic. Although HIV/AIDS death was not the focus of my research, it is surprising that the narratives the HIV+ women told of life in Kibera do not touch more on the issues of HIV/AIDS-related deaths or funerals.

This study was constrained by costs and time; international studies cost more than local studies. With the exception of a reimbursement from the University of Victoria graduate department paid out under a “special request” on my part to cover the cost of a Kenyan research permit, I have received no funding.

### **Narrative reflections of the study**

The use of a convergence of methodologies, narrative, feminist and Indigenous, gave me license to engage fully in conversations with nine HIV+ women living in a mega slum in an African country, Kenya. It was not until I began to analyze my data that I realized how deeply affected I had been by my experience. To tell this part of the story, and to reflect on my experience, I found myself shifting from a purely formal academic style of writing to a creative one with poetic renderings in some places.

*Despite the hardships of squalid living conditions and ongoing challenges of providing for children, the women told me stories of courage about their present and past life experiences. In voices once silent and invisible in meta-narratives of dominant western discourse, each woman shared her own separate tales of a collective heritage. Non-western voices spoke out in unison, blending and wrapping synchronized words in sounds that were initially new to me, a westerner. As I listened to hear the women speak, my conscious definition of a “me” became blurred. There were moments when I lost touch with time and space and experienced the notion that “Silence is our listening openness”*

*(Levin, 1988, p. 232). In hindsight, this emergent temporality in the loss of personal boundary, this visceral encounter with something larger than the me/you divide, participant/researcher in this context, and individual detailed narrative plots served as a segue, a connector to other realms of reality. And I began to sense something exceptional.*

*I silently listened generously to hear more intently and my balance in the role of a western academic on a research standpoint teetered, causing me to totter and plunge into something nebulous, somewhere unfamiliar; I knew not the here of a where in the now of then. These African women openly talked with me, an English woman, another woman, yet a stranger. They told me stories of many forms of abuse in their lives, stories too of abandonment by those closest to them. They told me of struggles in maintaining personal dignity; they spoke of their fear for the future of their children if they were to become sick and die leaving their children alone. These nine women confided in me, and the open details of their lives ate away at our flesh exposing the raw bones of vulnerability.*

*It is well documented that those who live in poverty are disproportionately vulnerable to the dark side of life; these women face enormous challenges every day. Yet not only do they find ways of caring for children, they carry with them an ongoing concern for the well-being of others and I sensed an inherent quality in the lives of these women. As if it were perfectly natural, they performed regular acts of human kindness towards others who live in similar circumstances.*

*And so I began to wander in wonder, calling up past stories of my own life's experiences. I invoked information gained from the hallowed halls of university. I recalled words written in books and other wordy records and I listened to people from Africa*

*speak of things at first unintelligible to my western thinking. I came to understand that "trauma shatters old structures of consciousness, both in the individual and collective psyches and provides an opportunity for the development of either healing and the creation of imaginative new structures or pathological and rigidified reaction" (Wall & Louchakova, 2002, p. 263). As I witnessed the tales nine women recounted of many experiences of personal trauma, including hearing for the first time that they were infected with HIV and will live the rest of their lives as HIV+ women taking antiretroviral drugs, I remembered "not to overlook the phoenix for the ashes" (Higgins, 1994, p. 323). Resilience and hope, wings of the phoenix, are human traits for coping with stress and catastrophe. In brief, hope is a belief in positive outcomes related to life situations that generate stress and implies a certain amount of perseverance. Having hope provides the means, the energy by which negative thinking may transform into resilience. Briefly, resilience is the capacity to bend successfully without breaking while adapting and nurturing personal transformation despite risk or adversity (Bonnie, 1996).*

*Yet western explanations do not satisfy me, there is more. I read of an old African philosophy, Ubuntu (Chilisa, 2012). This African philosophy gives voice to what I experienced as a researcher in Kibera; to some of the things that I have experienced by exploring the experiences of African women in community. It is a philosophy that connects human beings in an undercurrent of interdependency and flows steadily in the mainstream of modernity. The concept of Ubuntu which in the Zulu maxim, "umuntu ngumuntu ngabantu" translates to "a person is a person through other persons," and*

*differs from the Cartesian maxim of "I think therefore I am" which defines the individual as a solitary self. The Ubuntu philosophy defines the individual in terms of relationships to others in community and as relationships change so do individuals.*

*Ubuntu promotes a worldview that envisions humanity as an essential component in the cosmology and eco-systems that exist interdependently in the universe. Beliefs based on Ubuntu stress the importance of a communal responsibility for sustaining life and human value is determined by the interplay of social, cultural and spiritual criteria. This philosophy acknowledges a principle of equity among and between generations which regulates the sharing of natural resources and everyone works in a collective, individual interdependence towards a common good (Chilisa, 2012; Ubuntu, 2003).*

*Colonialism on the African continent brought with it a capitulation to dogmatic fixation with power and control at the expense of Indigenous insights into nature and different ways of acquiring knowledge. During the colonization process, Indigenous knowledge and ways of knowing were disrespected, prohibited, silenced and replaced by ways foreign to peoples who connected strongly with the land. Religious dogma, often with good intent slowly yet determinedly dismantled and pushed underground traditional beliefs, values and practices. African peoples became inculturated to varying degrees by contact with others who came from lands far away. Many African people were forced to adapt and find alternative ways of living and being, at least on the surface in the public eye of the colonizer. As I write this, I am acutely aware and remember that I, too, come from a far away land.*

*More recently, the HIV/AIDS pandemic further compelled individuals and whole communities to further depart from traditional ways in order to cope with the devastation caused by HIV. Although change is constant and dramatic change is part of an African landscape, all Indigenous covenants have not been completely lost, obliterated or become obsolete like do-do birds. They lay, like seeds dormant in the ground, waiting for the positive touch of anger, the flow of healing tears, the warmth of the human spirit and the ripeness of time to swell, rise and push through the richness of the earth, ready to blossom once more.*

*Amina Abdul, Amina Bashir, Loise, Lucy, Mama May, Penninah, Sarah, Zakia and Zuhura live very differently now in Kibera than their venerated ancestors did in rural settings. Their ethnic roots go deep into the earth, grounding them in ancestral networks which may sustain them in hard times such as these. Perhaps they tap into invisible, ancient, rooted systemic sources of being that defy an imperial rule of divide and conquer and colonial ways that have little or no relevance to an African sense of humanity's place in the universe. Perhaps it is a deep belief, an ingrained value in the Ubuntu philosophy that advances the capacity of these women to remain empowered as they live every day as HIV+ women in one of the biggest slums in the world.*

*Ubuntu, say it enough times and the residue of sound vibrates through the universe like echoes released to eternity. Ubuntu, repeat it slowly, opening a mouth to let out sounds from deep within you and there is a sense of opening-up to something bigger than the containment of a solitary self. Ubuntu, say it loudly in the presence of others who join in chorus and veiled forces begin to shift the shrouded, rigid layers of human*

*separation. Ubuntu, Ubuntu, say it loudly, say it softly, say it many times and, like the raw pulsating rhythm of a moyo, the steady beat of a drum, a resonance begins to fill the air, connecting one's life force with the life force of human kind.*

*As I read and re-read the transcriptions of the stories the women told me, especially references to stigma, I found myself emotional and crafted the following poem.*

### STIGMA

*Human kindness forgotten,  
Side-stepped, stepped on or over  
In nasty, messy shows of ignorance.  
Energy conjured up by one other, others or one's self to  
separate,  
Isolate, alienate within the wholeness of humanity.  
Hurtful words spoken,  
Harmful deeds done,  
Like spears, take aim.  
Let go, they find their mark  
Piercing the heart of the one  
Who silently, perhaps in secret, is suffering already.*

### **Where to from here**

The HIV+ women in my study have lived many days in a place of despair and hunger within a world of great promise and hope. Nelson Mandela pointed out that more money is spent annually on weapons than for the support of the millions infected by HIV. “Overcoming poverty is not a gesture of charity; it is an act of justice” (Nolen, 2007, p. 353).

Hunger and despair affect individual health. Health has become a social justice issue and a human right. To remain healthy requires that people live in healthy environments, to eat regularly, and drink clean water. These women live in poverty conditions where the balance between those who are receiving ARVs, the lack of food,

and food supplement programs are incommensurate. Those in charge of government health service delivery of food programs for HIV+ individuals have a moral responsibility to explore alternative ways to ensure those in most need are indeed the recipients of food supplements. HIV+ individuals who live in slum environments have the right to access opportunities to thrive economically, socially, and educationally as does everyone.

This study exposes the vulnerability of women in the patriarchal government systems in which they live. Financially poor women need ready access to information regarding their rights for freedom from gender-based violence; they must have easier access to legal resources if necessary, and they must be assured that corruption at any level will not impede their daily struggles for survival.

A new vision is required in programming for women; programming more suited to and reflective of the realities of their daily lives. The objective of so many programs for marginalized women living in borderlands on or below the poverty line is empowerment. Women such as these in my study are already empowered; they are already in possession of many transferable skills demonstrated by their capability in providing for children in environments where poverty conditions are dire. To focus only on the empowerment of women is to ignore the larger problem – the abusive and repressive men in their lives. Something must be done to protect them from continued exploitation and further abuse. The generalization that women need empowering is to keep them in a place of helplessness while diverting attention away from the underlying challenge of gender inequality in a world that has lost its balance. Tallis (2002) reminds us that empowerment has no influence on gender inequality if gender relations at a

personal, collective, institutional, and broader societal level are not addressed. Kako (2008) and Carpenter (2002) emphasize that men and women are socially-culturally interdependent in an African context. What is needed is an in-depth examination of gender in both politics and health “to understand sex-specific outcomes of all types exposing the manner in which patriarchy oppresses all human beings in various ways” (Kako, 2008, p. 35). What many poor women lack is opportunity, not empowerment.

Much has been written about the vulnerability of women within the context of HIV/AIDS, yet little attention has been given to the inevitability of change – men’s tenuous hold on power in a changing world where the male colonial pedestal is crumbling. Inequality between the genders straddles all social strata, not only in African contexts, and cannot be separated from the wider issues of human liberation (O’ Kelly & Carney, 1986). HIV/AIDS research adds to the already sizeable body of literature, yet HIV continues to spread. The door remains open for further research in the complex and interdependent area of dual responsibility on the part of men and women for HIV prevention (Pisani, 2006).

There remains a demand for continued clinical research to understand and arrest the spread of the HIV/AIDS pandemic. In this study, the women’s narratives reflect a need to mend holes in the cloth of human relations, to the ways in which people interact and communicate. The lack of basic respect and compassion for fellow human beings, the human factor, appears absent in many situations where people relate as genders, where people trade with each other, and where individuals deal with each other on private, governance, and political issues (Adjibobosoo 1995).

The magnitude of the HIV/AIDS pandemic is unprecedented. The virus has already taken the lives of millions of people around the globe, and has affected the lives of millions more. The human tragedy of HIV/AIDS has resulted in an impetus for change, forcing individuals and whole communities to adapt and find alternative ways of living in order to survive.

It would be important to follow over time a group of HIV+ women, as little is presently known about long term survival issues. Findings from such a study would contribute to a realistic view and understanding of how the global face of HIV/AIDS changes over time in relationship with a particular context.

### **Closing**

Amina Abdul, Amina Bashir, Loise, Lucy, Mama May, Penninah, Sarah, Zakia, and Zuhura continue to live in Kibera, one of the biggest slums in the world. As single HIV+ mothers caring for children with little support from families or government services, they display enormous personal courage in the face of incredible challenges. Factors such as poverty, gender inequality, and the impacts of colonialism and corruption have pushed or nudged them into the margins of society from where they bravely struggle each day to survive and provide a quality of life for their children and themselves.

Their generosity of spirit touched my heart and stimulated my intellect. I was humbled by the interconnectedness of the women's struggles to thrive as I listened to their stories of courage, strength, and power. And I am aware too that the voices of these nine women may speak for millions of other women who live in similar circumstances around the globe. I admire Amina Abdul, Amina Bashir, Loise, Lucy, Mama May,

Penninah, Sarah, Zakia, and Zuhura tremendously; they remain in my memories and in my heart.

## References

- Abdo, N. (2004). Honour killing, patriarchy, and the state: Women in Israel. In S. Mojab, & N. Abdo (Eds.), *Violence in the name of honour* (pp. 57–91). Istanbul: Istanbul Bilgi University Press.
- Abdo, N. (Ed.). (1996). *Sociological thought: Beyond Eurocentric theory*. Toronto: Canadian Scholars' Press.
- Achebe, C. (1958). *Things fall apart*. New York: Anchor Books.
- Achola, M. A. (2002). Colonial policy and urban heath: The case of colonial Nairobi. In A. Burton (Ed.), *The urban experience in eastern Africa, c. 1750–2000* (pp. 119–137). Nairobi: The British Institute in Eastern Africa.
- Adjibolosoo, S.-B. K. (1995). *The human factor in developing Africa*. Westport, CT, London: Praeger.
- Adu-Febiri, F. (2003). Facilitating cultural diversity in a monolithic global economy: The role of human factor education. *International Journal of the Humanities*, 1, 885–908.
- Adu-Febiri, F. (2008). Triumph of the commons: Human factor and the building of sustainable communities. *Review of Human Factor Studies*, 14(1), 8–44.
- Akinsola, H., & Popovich, J. (2002). The quality of life in families of female-headed households in Botswana: A secondary analysis of case studies. *Health Care for Women International*, 23, 761–772.
- Alavi, R. (2008). *Race and oppression: Philosophical issues in voluntary oppression* (Doctoral dissertation). Retrieved from [http://kuscholarworks.ku.edu/dispace/bitstream/1808/3941/llumi-ku-2404\\_1.pdf](http://kuscholarworks.ku.edu/dispace/bitstream/1808/3941/llumi-ku-2404_1.pdf)
- Alavi, R. (2010). Race, identity, stereotyping and voluntary oppression. *Global Virtue Ethics Review*, 6(1) 13–27.
- Alligood, M. R. (2010). *Nursing theory: Utilization and application*. St. Louis: Mosby-Elsevier.
- Alma-Ata Declaration. (1978). Proceedings of the International Conference on Primary Health Care (PHC), 6–12 September 1978, formerly Alma-Ata, Kazakhstan. Retrieved from [http://www.who.int/hpr/NPH/docs/declaration\\_almaata.pdf](http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf)

- Amadiume, I. (1997). *Re-inventing Africa: Matriarchy, religion and culture*. New York: Zen Books Ltd.
- Amnesty International. (2010). *Insecurity and indignity: Women's experiences in the slums of Nairobi, Kenya*. London: Amnesty International Publications.
- Amis, P. (1984). Commercialized rental housing in Nairobi, Kenya. In C. V. Patton (Ed.), *Spontaneous shelter: International perspectives and prospects* (pp. 235–357). Philadelphia, PA: Temple University Press.
- Amuyunzu-Nyamongo, M., & Taffa, N. (2004). The triad of poverty, environment and child health in Nairobi informal settlements. *Journal of Health & Population in Developing Countries*, 1–14. Retrieved from <http://www.jhpdc.unc.edu/>
- Anderson, K. (2008). Notokue Opikitreet – “old-lady raised”: Aboriginal women's reflection on ethics and methodologies in health research. In K. Anderson, P. Doyle-Bodwell, E. Hatley, B. Jacobs, C. Leclair, T. Lindberg, S. Maracle, M. C. McKay, & P. Monture (Eds.), *Canadian Woman Studies* (pp. 6–14). York, Ontario, Canada: York University.
- Anderson, J., & Reimer-Kirkham, S. (1998). Constructing nation: The gendering and racializing of the Canadian health care system. In V. Strong-Boag, S. Grace, A. Eisenberg, & J. Anderson (Eds.), *Painting the maple: Essays on race, gender, and the construction of Canada* (pp. 242–261). Vancouver: University of British Columbia Press.
- Andrews, M. (2007). Exploring cross-cultural boundaries. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 489–511). Thousand Oaks, CA; London: SAGE Publications.
- Appadurai, A. (2004). The capacity to aspire: Culture and the terms of recognition. In V. Rao & M. Walton (Eds.), *Culture and public action* (pp. 59–84). Stanford, CA: Stanford University Press.
- Arntsen, H. (1997). *The battle of the mind: International new media elements of the new religious political right in Zimbabwe*. Oslo: University of Oslo.
- Arslanian-Engoren, C. (2002). Feminist poststructuralism: A methodological paradigm for examining clinical decision-making. *Journal of Advanced Nursing*, 37(6), pp. 512–516.

- Aukot, E. (2008). *Northern Kenya: A legal-political scar*. Retrieved from Africa InfoServ website: <http://www.pambazuka.org>.
- Authenticity. (2011). In Wikipedia. Retrieved from [http://www.en.wikipedia.org/wiki/Authenticity\\_\(philosophy\)](http://www.en.wikipedia.org/wiki/Authenticity_(philosophy))
- Aveggio, M. T. (2011). *Reduce gender inequalities: reduce poverty*. Retrieved from <http://www.undp-povertycentre.org/pub/1PCOnePager73.pdf>
- Awang, S. S. (2000). Indigenous nations and the human genome diversity project. In G. Sefa Dei, B. L. Hall & D. G. Rosenberg (Eds.), *Indigenous knowledges in global contexts: Multiple readings of our world* (pp. 120–136). Toronto: University of Toronto Press.
- Ayisi, E. O. (1972). *An introduction to the study of African culture*. Nairobi: East African Educational Publishers.
- Babbie, E. (1989). *The practice of social research* (5<sup>th</sup> ed.). Belmont, CA: Wadsworth.
- Bakhtin, M. M. (1975). *The dialogic imagination: Four essays* (C. Emerson & M. Holquist, Trans.). Austin, TX: University of Texas Press.
- Bamberg, M. G. W., & McCabe, A. (1998). Editorial. *Narrative Inquiry*, 8, iii–v.
- Barthes, R. (1996). Introduction to the structured analysis of narrative. In S. Oneya & J. A. G. London (Eds.) (1997), *Narratology* (pp. 45–60) New York: Longman.
- Bangkok Charter of Health Promotion in a Globalized World. (2005). The 6th Global Conference on Health Promotion. August, 2005. Bangkok, Thailand. Retrieved from [http://www.who.int/healthpromotion/conference/6gchp/hpr\\_050829\\_%2520BCHP.pdf](http://www.who.int/healthpromotion/conference/6gchp/hpr_050829_%2520BCHP.pdf)
- Bartky, S. L. (1997). Foucault, femininity, and the modernization of power. In K. Conboy, N. Medina, & S. Stanbury (Eds.), *Writing on the body: Female embodiment and feminist theory* (pp. 129–154). New York: California University Press.
- Battiste, M. (1999). *Reclaiming indigenous voice and vision*. Vancouver, BC, Canada: University of British Columbia Press.
- Battiste, M. (2008). Research ethics and protecting indigenous knowledge and heritage: Institutional and researcher responsibility. In N. Denzin, Y. Lincoln, & L. Smith

- (Eds.), *Handbook of critical and indigenous methodologies* (pp. 497–510). Los Angeles; London; New Delhi; Singapore: SAGE.
- Battiste, M., & Henderson, Y. (2000). *Protecting indigenous knowledge and heritage: A global challenge*. Saskatoon, SK, Canada: Purich Publishing Ltd.
- Beauman, L. (with Germann, S.) (2005). Psychological impact of the HIV/AIDS epidemic on children and youth, In G. Foster, C. Levine, & J. Williamson (Eds.), *A generation at risk* (pp. 93–134). New York: Cambridge University Press.
- Becker, G. (1997). *Disputed lives: How people create meaning in a chaotic world*. Berkeley: University of California.
- Beetham, G., & Demetriades, J. (2007). Feminist research methodologies and development: Overview and practical application. *Gender and Development*, 15(2), 199–216.
- Behar, R. (2008). *China storms Africa*. Retrieved from <http://www.fastcom/magazine/126/special-report-china-in-africa-html>
- Belenky, M. F., Clinchy, B. M., Goldberger, N. R., & Tarukte, J. M. (1986). *Women's ways of knowing : The development of self, voice, and mind*. New York: Basic Books.
- Benham, M. P. (2007). Mo' ōlelo: On culturally relevant story making from an indigenous perspective. In D.J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 512–533). London: SAGE.
- Benini, A. (2000). *Construction of knowledge*. Rome: Gnome.
- Besio, K. (2003). Steppin' in it: Postcoloniality in Northern Pakistan. *Area*, 35(1), 24–33.
- Black, P. (1994). *Mega cities and mega slums in the 21st century*. Retrieved from <http://www.itt.com/waterbook/page80.pdf>
- Black, P. (1996). *Thirsty cities: Water, sanitation and the urban poor*. Retrieved from <http://wateraid.org/documents/plugin-documents/thirstycities.pdf>
- Blaikie, N. (1993). *Approaches to social inquiry*. Cambridge: Polity.
- Bodewes, C. (2005). *Parish transformation in urban slums: Voices of Kibera, Kenya*. Nairobi, Kenya: Paulines Publications.
- Bongaarts, J. (2001). Household size and composition in the developing world in the 1990s. *Population Studies: A Journal of Demography*, 55(3), 263–279.

- Bonnie, B. (1996). *Fostering resilience in children*. Retrieved from <http://www.ericdigests.org/1996-2/fostering.html>
- Bourdillion, M. F. C. (1990). *Religion and society: A text for Africa*. Gweru: Mambo Press.
- Bourdillion, M. F. C. (1993). *Where are the ancestors? Changing culture in Zimbabwe*. Zimbabwe: University of Zimbabwe Publications.
- Bova, C. (2000). Women with HIV Infections: The three waves of scientific inquiry. *Journal of the Association of Nurses in AIDS Care*, 11(5), 19–28.
- Bradshaw, T. K. (2005). *Theories of poverty and anti-poverty programs in community development*. Retrieved from <http://www.rupi.org/Forms/wp06-05.pdf>
- Brahm, E. (2004). *Trauma healing: Beyond intractability*. Retrieved from [http://www.beyondintractability.org/essay/development\\_conflict\\_theory/](http://www.beyondintractability.org/essay/development_conflict_theory/)
- Brand-Castellano, M. (2004). Ethics of Aboriginal research. *Journal of Aboriginal Health* 1, 98–114.
- Brayton, J. (1997). *What makes feminist research feminist? The structure of feminist research within the social sciences*. Retrieved from <http://www.unb.ca/PAR-L/win/feminmethod,htm>
- British Broadcasting Corporation. (2006, June 2). Kenya to provide free AIDS drugs [Television broadcast]. Retrieved from <http://www.news.bbc.co.uk/2/hi/Africa/5040240>.
- British Broadcasting Corporation. (2008, March 11). In pictures: Flying toilets [One minute world news]. Retrieved from [http://www.news.bbc.co.uk/2/shared/spl/hi/picture\\_gallery/07/africa\\_flying\\_toilets/html/1stm](http://www.news.bbc.co.uk/2/shared/spl/hi/picture_gallery/07/africa_flying_toilets/html/1stm)
- British Broadcasting Corporation. (2011, March 27). One planet: The disease and development trap [Radio broadcast]. Retrieved from <http://www.bbc.co.uk/programmes/p00ffsny>
- Brown, L., & Strega, S. (Eds.). (2005). *Research as resistance: Critical, indigenous & anti-oppressive approaches*. Toronto: Canadian Scholars' Press.
- Bruner, J. (1987). Life as narrative. *Social Research*, 54(1), 11–32.
- Bruner, J. S. C. (1990). *Acts of meaning*. Cambridge: Harvard University Press.

- Brunner, E. (1997). Socioeconomic determinants of health: Stress and the biology of inequity. *British Medical Journal*, 314, 1472–1477.
- Burns, D. (2005). Feminist methodologies. In B. Somekh & C. Lewin (Eds.), *Research methods in the social sciences* (pp. 66–73). London: Sage.
- Cairncross, S., Hardoy, J. E., & Satterthwaite, D. (1990). *The poor die young: Housing and health in Third World countries*. London: Earthscan Publications.
- Cajete, G. (2004). Philosophy of native science. In A. Waters (Ed.), *American Indian thought: Philosophical essays* (pp. 45–57). Malden: Blackwell.
- Campbell, V., Meseyton, H., & Propp, C. (2004). (2<sup>nd</sup> ed.). Reliable as written or true as told?: The history of attempts at annihilating Canada's First Nations. In F. Adu-Febiri (Ed.), *First Nations students talk back* (pp. 119–128). Victoria, B.C., Canada: Camosun College.
- Canadian Institutes of Health Research (CIHR). (2007). *CIHR guidelines for health research involving aboriginal people*. Ottawa, ON, Canada: CIHR.
- Canadian International Development Agency (CIDA). (2009). *CIDA and gender equality*. Ottawa, ON, Canada: Government of Canada.
- Canales, M. K. (2000). Othering: Toward an understanding of difference. *Advanced Nursing Science*, 22(4), 16–31.
- Cane, P. (2005). *Trauma healing and transformation: Awakening a new heart with body, mind, spirit practices* (2<sup>nd</sup> ed.). California: Capacitar International Inc.
- Carpenter, C. (2002). Gendered theory in world politics: Contributions of a non-feminist standpoint. *International Studies Review* 4(33), 153–165.
- Caruth, C. (1995). *Trauma: Explorations in memory*. Baltimore: John Hopkins University Press.
- Casper, L. M., McLanahan, S. S., & Garfinkel, I. (1994). The gender-poverty gap: What we can learn from other countries. *American Sociological Review*, 59, 594–605.
- Central Intelligence Agency, (2009). *The world factbook*. Washington: Central Intelligence Agency Publisher.
- Centre on Housing Rights and Evictions (COHRE). 2004. *Listening to the poor? Housing rights in Nairobi, Kenya*. Retrieved from website [www.cohre.org](http://www.cohre.org)

- Chakravarti, D. (2006). Voices unheard: The psychology of consumption, poverty and development. *Journal of Consumer Psychology* 16(4), 363–376.
- Chant, S. (2003). *Female household headship and the feminization of poverty: Facts, fictions and forward strategies*. Retrieved from <http://www.eprints.lse.ac.uk/574>
- Chant, S. (2006). Re-thinking the feminization of poverty in relation to aggregate gender indices. *Journal of Human Development*, 7(2), 202–20.
- Chase, S. E. (2005). Narrative inquiry: multiple lenses, approaches, voices. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3<sup>rd</sup> ed.). (pp. 651–679). Thousand Oaks, CA: Sage.
- Commission on HIV/AIDS and Governance in Africa (CHGA). (2004). *The impacts of HIV/AIDS on families and communities in Africa*. Index No. CHGA-B-11-0001. Retrieved from [www.un.org/esa/population/pubsarchive/hivmtg/hivmtg.htm](http://www.un.org/esa/population/pubsarchive/hivmtg/hivmtg.htm)
- Chen, M., Vanek, J., Lund, F., Heintz, J., Jhabvala, R., & Bonner, C. (2005). *Women, work and poverty*. United Nations Development Fund for Women: United Nations.
- Chikwanhe, A. B. (2008). *A culture of violence or a violent culture?* Retrieved from Africa InfoServ website: <http://www.africfiles.org>
- Chilisa, B. (2012). *Indigenous research methodologies*. Los Angeles, London, New Delhi, Singapore, Washington DC: SAGE.
- Church, D. (Ed.). (2005). *Einstein's business: Engaging soul, imagination and excellence in the workforce*. Santa Rosa, CA: Elite Books.
- Clark, D. (1978/9). Unregulated housing, vested interest and the development of community identity in Nairobi. *African Urban Studies*, 3(Winter), 33–46.
- Clark, Marie H. (1984). Women-headed households and poverty: Insights from Kenya. *Signs*, 10(2), 338–354.
- Clandinin, D. J. (Ed.). (2007). *Handbook of narrative inquiry: Mapping a methodology*. Thousand Oaks, CA: Sage.
- Clandinin, D., & Connelly, F. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.

- Clark, J. P., Feldberg, G. D., & Rochon, P. A. (2002). *Representation of women's health in general medical versus women's health specialty journals: A content analysis*. BioMed Central, 2. Retrieved from <http://www.biomedcentral.com/1472-6874/2/5>
- Cluver, L., & Gardner, F. (2007) Risk and protective factors for psychological well-being of children orphaned by AIDS in Cape Town: A qualitative study of children and caregivers' perspective. *AIDS Care*, 19(3), 318–325.
- Cockburn, C. (1991). *In the way of women: Men's resistance to sex equality in organizations*. Ithaca, New York: ILR Press.
- Collins, P. (1990). *Black feminist thought: Knowledge, consciousness and the politics of empowerment*. New York: Routledge, Chapman & Hall.
- Connell, R. W. (1987). *Gender and power: Society, the person, and sexual politics*. Cambridge, UK: Polity Press.
- Connelly, F. M., & Clandinin, D. J. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2–14.
- Cook, J. A., & Fonow, M. M. (1990). Knowledge and women's interests: Issues of epistemology in feminist sociological research. In J. M. Nielson (Ed.), *Feminist research methods: Exemplary readings in social science* (pp. 69–93). London: Westview.
- Coombe, R. (1993). The properties of culture and the politics of possessing identity: Native claims to the cultural appropriation controversy. *Canadian Journal of Law and Jurisprudence*, 6, 249.
- Cott, N. F. (1987). *The grounding of modern feminism*. London: Yale University Press.
- Cudd, A. E. (2006). *Analyzing oppression*. New York: Oxford University Press.
- Dane, B. O., & Levine, C. (Eds.). (1994), *AIDS and the new orphans: Coping with death*. Westport, Connecticut, London: Auburn House.
- Davis, M. (2006). *Planet of Slums*. London: Verso.
- Davis, B., & Gannan, S. (Eds.). (2006). *Doing collective biography*. Berkshire, U.K. Open University Press.
- Day, S., & Brodsky, G. (1998). *Women and the equality deficit: The impact of restructuring Canada's social programs*. Ottawa: Status of Women.

- de Kruijff, G. J., & Chana, T. S. (1980). *Case studies of site and services in Kenya*. Nairobi: University of Nairobi Housing Research and Development Unit.
- De Smedt, J. (2009a). "Kill me quick": A history of Nubian Gin in Kibera. *International Journal of African Historical Studies*, 42(2), 201–220.
- de Vault, M. L. (1996). Talking back to sociology: Distinctive contribution of feminist methodology. *Annual Review of Sociology*, 22, 29–50.
- Dean, R. G. (1995). The use of narratives as an approach to understanding in an AIDS support group. *Clinical Social Work Journal*, 23(3), 287–304.
- Deleeck, H., & Van den Bosch, K. (Eds.). (1992). *Poverty and the adequacy of social security in the E. C.: A comparative analysis*. Aldershot, UK: Avebury.
- Dentith, S. (1995). *Bakhtinian thought: An introductory reader*. New York: Routledge.
- Denzin, N., & Lincoln, Y. (2008). Preface. In N. Denzin, Y. Lincoln, & L. Smith (Eds.), *Handbook of critical and indigenous methodologies* (pp. ix–xv). Los Angeles: SAGE.
- DeWalt, D. A., Berkman, N., Sheridan, S., Lohr, K., & Pignone, M. (2004). Literacy and health outcomes: A systemic review of the literature. *Journal of General Internal Medicine*, 19(12), 1228–39.
- Donner, L. (2002). *Women, income and health in Manitoba: An overview and ideas for action*. Winnipeg: Women's Health Clinic.
- Donner, L. (2003). *Including gender in health planning: A guide for regional health authorities*. Winnipeg: Prairie Women's Health Centre of Excellence.
- Douard, J., & Durham, J. (1993). HIV-infected women and children: Social and ethical perspectives. In F. L. Cohen & J. D. Durham (Eds.), *Women, children and HIV/AIDS* (pp. 228–240). New York: Springer Publishing Company.
- Doyal, L. (2009). Challenges in researching life with HIV/AIDS: an intersectional analysis of black African migrants in London. *Culture, Health and Sexuality*, 11(2), 173–188.
- Dunn, J. R., & Dyck, I. (2000). Social determinant of health in Canada's immigrant population: Results from the national population health survey. *Social Science Medicine* 2000; 51(11), 1573–1593.

- Duran, E., & Duran, B. (1995). *Native American postcolonial psychology*. Albany: State University of New York Press.
- Duran, E. (2006). *Healing the soul wound: Counselling with American Indians and other Native Peoples*. New York: Teachers College Press.
- Ehrenprels, D. (Ed.). (2008). *Poverty in focus: Gender equality*. International Poverty Centre (IPC).
- Ehrenreich, B., & English, D. (1978). *For her own good: 150 years of the experts' advice to women*. New York: Doubleday.
- Edries, S., & Triegaardt, M. (2004). The feminization of HIV/AIDS. *The African Renaissance, 2004, 1(2)*, 121–124.
- Ekdale, B. (2011). *Kibera's history*. Retrieved from [www.brianekdale.com/?=kiberas-history](http://www.brianekdale.com/?=kiberas-history)
- Elabor-Idemudia, P. (2000). The retention of knowledges of folkways as a basis for resistance. In G. Sefa Dei, B. L. Hall, & D. G. Rosenberg (Eds.), *Indigenous knowledges in global contexts: multiple readings of our world* (pp. 102–119). Toronto: University of Toronto Press.
- Ellington, L. L. (2006). Embodied knowledge: Writing researchers' bodies into qualitative health research. *Qualitative Health Research, 16(2)*. 298–310.
- Elliot, J. (2005). *Using narrative in social research: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.
- Ellsworth, E. (1989). "Why doesn't this feel empowering?" Working through the repressive myths of critical pedagogy. *Harvard Education Review, 59*. 297–324.
- Elkins, C. (2005). *Imperial reckoning: The untold story of Britain's gulag in Kenya*. New York: Henry Holt and Company.
- Ertürk, Y. (2004). Violence in the name of honor within the context of international regimes. In S. Mojab, & N. Abdo (Eds.), *Violence in the name of honor: Theoretical and political challenges* (pp. 163–176). Istanbul: Istanbul Bilgi University.
- Estrella, K., & Forinash, M. (2007). Narrative and arts-based inquiry: Multinarrative approaches. *Journal of Humanistic Psychology, 47*, 376–383.

- Etherton, D. (1971). *Mathare Valley: A case study of controlled settlement in Nairobi*. Housing Research and Development Unit: University of Nairobi.
- Eyaa-keen Centre (2005). *Post traumatic stress disorder* [Brochure]. Retrieved from [www.eyaa-keen.org/Pages/PTSD%20Brochure%Aug%202005pdf](http://www.eyaa-keen.org/Pages/PTSD%20Brochure%Aug%202005pdf)
- Fanon, F. (1965). *A dying colonialism*. (H. Chevalier, Trans.). New York: Grove Press.
- Fanon, F. (1967). *Black skin, white masks*. New York: Grove Press.
- Farber, W. (2001). *Kunstlehre der erklärung* [Explanation of the teaching art]. Graz: Selbstverlag.
- Ferro, G. P. (1978/9). Nairobi: Overview of an east African city. *African Urban Studies*, 3(Winter), 1–14.
- Fixico, D. (2003). *The American Indian mind in a linear world: America studies and traditional knowledge*. New York: Routledge.
- Forsyth, B., Vaudermael, A., Kershaw, T., & Grobbelaar, L. (2008). The political context of AIDS-related stigma and knowledge in a South Africa township community. *Journal of Social Aspects of HIV/AIDS*, 5(2), 74–82.
- Foster, G., Levine, C., & Williamson, J. (Eds.). (2005). *A generation at risk: The global impact of HIV/AIDS on orphans and vulnerable children*. London: Cambridge University Press.
- Foucault, M. (1977). [A. Sheridan, Trans.]. *Discipline and punish: The birth of the prison*. New York: Vintage Books.
- Frank, A. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago and London: University of Chicago Press.
- Frank, A. (2000). The standpoint of the storyteller, *Qualitative Health Research*, 10(3), 354–365.
- Frank, A. (2003). *How stories remake what pain unmakes*. Seattle, WA: ASP Press.
- Frank, A. (2004). *The renewal of generosity: Illness, medicine and how to heal*. London: The University of Chicago Press.
- Frank, A. (2004c). Health stories as connectors and subjectifiers. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine*, 10, 421–40.

- Frank, A. (2009). The necessity and dangers of illness narratives, especially at the end of life. In Y. Gunaratnam & D. Oliviere (Eds.), *Narrative & stories in health care: Illness, dying and bereavement* (pp. 160–175). New York, Oxford: Oxford University Press.
- Freeman, M. (2002). The presence of what is missing: Memory, poetry and the ride home. In R. J. Pellegrine & T. R. Sarbin (Eds.), *Critical incident narratives in the development of men's lives* (pp. 165–176). Binghamton, NY: Haworth Clinical Practice Press.
- Fukuda-Parr, S. (1999). What does feminization of poverty mean? It isn't just lack of income. *Feminist Economics*, 5(2), 99–103.
- Gandhi, L. (1998). *Postcolonial theory: A critical introduction*. New York: Columbia University Press.
- Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA Journal*, 14 (3) Fall, 1–32.
- Gee, J. P. (1999). *An introduction to discourse analysis: Theory and method*. New York: Routledge.
- Geertz, C. (1973). *The interpretation of cultures*. London: Fontana.
- Gellar, S. (2006). *Religion and democratization in colonial and post-colonial Africa: Parallels in the evolution of religious of religions and political governance structures*. Retrieved from [http://www.indiana.edu/~workshop/papers/gellar\\_conf.pdf](http://www.indiana.edu/~workshop/papers/gellar_conf.pdf)
- Gergen, M. (2001). *Feminist reconstruction in psychology: Narrative, gender and performances*. Thousand Oaks, CA: Sage.
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Boston: Harvard University Press.
- Gitau, S. & Washington, O. (2002). *Land tenure and tenancy concerns and issues in Kibera*. Kenya: University of Nairobi, Department of Land Development.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago: Aldine Publishing Co.
- Glaeser, E. (1997). Ghettos: The changing consequences of ethnic isolation. *Regional Review*, 7(2), Spring, 18–24.

- Goffman, E. (1974). *Frame analysis: An essay on the organization of experience*. New York: Harper, Colophon Books.
- Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity*. New York: Touchstone.
- Gordon, C. (Ed.). (1980). *Power/knowledge, selected interviews and other writings, 1972–1977 by Michel Foucault*. Hertfordshire: Harvester Wheatsheaf.
- Gordon, D. (2005). *Indicators of poverty and hunger*. Expert Group Meeting of Youth Development Indicators, 12th–14th December, 2005. United Nations Headquarters: New York. Retrieved from [http://www.org/esa/socdev/unyin/documents/ydDavidGordon\\_poverty.pdf](http://www.org/esa/socdev/unyin/documents/ydDavidGordon_poverty.pdf)
- Gordon, L. (1986). What's new in women's history? In T. de Laurentis (Ed.), *Feminist studies: Critical studies* (pp. 20–30). Bloomington, IN: Indiana University Press.
- Gottlieb, L. (1995). *She who dwells within: A feminist vision of a renewed Judaism*. San Francisco: Harper.
- Government of the Republic of Kenya. (2008). *Kenya Vision 2030: A globally competitive and prosperous Kenya*. Retrieved from <http://www.planning.go.ke>
- Green, M. (2006). Representing poverty and attacking representation: Perspectives on poverty from social anthropology. *Journal of Development Studies* 42(7), 1108–1129.
- Gruskin, S., & Tarantola, D. (2000). Health and human rights: In R. Detels, J. McEwan, R. Beaglehole, & H. Tanaka (Eds.), *The Oxford textbook of public health* (4<sup>th</sup> ed.) (pp. 311–336). USA: Oxford University Press.
- Gruskin, S., & Tarantola, D. (2001). HIV/AIDS, health and human rights. In P. Lampley, H. Gayle, & P. Mane (Eds.), *HIV/AIDS prevention and care programs in resource- constrained settings: A handbook for the design and management of programs*. (pp. 661–678). Arlington, VA: Family Health International.
- Gruskin, S., & Tarantola, D. (2002). Human rights and HIV/AIDS. In M. Essex, S. Mboup, P. Kanki, R. Marlinck, & S. Tlou (Eds.), *AIDS in Africa* (2<sup>nd</sup> ed.) (pp. 641–653). New York: Academic/Plenum Publishers.
- Gruskin, S., & Tarantola, D. (2005). Human rights and children affected with HIV/AIDS. In G. Foster, C. Levine, & S. Williamson (Eds.), *A generation at risk: The global*

- impact of HIV/AIDS on orphans and vulnerable children* (pp. 134–156). New York: Cambridge University Press.
- Gugler, J. (Ed.). (1982). *Overurbanization reconsidered in cities in the developing world: Issues, theory, and policy* (pp. 114–123). London: Oxford University Press.
- Gullia, G. (2004). Health status of people of slums in Nairobi, Kenya. *Environmental Research*, 36, 219–217.
- Guy-Sheftall, B. (1998). Engaging difference: Racial and global perspectives in graduated women's studies education. *Feminist Studies*, 24(2), 327–333.
- Gvekve, K. (1996). *African cultural values: An introduction*. Philadelphia, Ghana: Sankofa Publishing Company.
- Haig, B. D. (1997). Feminist research methodology. In J. P. Keeves (Ed.), *Educational research methodology, and measurement: An international handbook* (pp. 180–5). Oxford: Elsevier.
- Harding, S. (1987). Is there a feminist method? In Harding, S. (Ed.), *Feminism and methodology* (pp. 1–14). Bloomington, IN: Indiana University Press.
- Harding, S. (1991). *Whose science? Whose knowledge? Thinking from women's lives*. Ithaca: Cornell University Press.
- Hardoy, L. E., & Satterthwaite, D. (1989). *Squatter citizen: Life in the urban third world*. London: Earthscan Publications Ltd.
- Harnard, D. (1991). *Back to the oral tradition: Through skywriting at the speed of thought*. Retrieved from <http://www.cogsci.soton.ac.uk/%7Eharnad/Papers/harnadskyteaching.html>
- Hartstock, N. (1987). *The science question in feminism*. Ithaca, NY: Cornell University Press.
- Harvey, L. (1990). *Critical social research*. London: Unwin Hyman.
- Harvey, D. (2005). The transformational speculative logic of capitol. In A. Silca (Ed.), *Social thought: From the enlightenment to the present* (pp. 718–723). London: Pearson.
- Higgins, G. O. C. (1994). *Resilient adults: Overcoming a cruel past*. San Francisco: Jossey-Bass Inc.

- Holzemer, W. L., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Dlamini, P. S., ... & Naidoo, J. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541–551.
- hooks, b. (1984). *Feminist theory: From margin to center*. Boston: South End Press.
- Horrell, S., & Krishnan, P. (2007). Poverty and productivity in female-headed households in Zimbabwe. *The Journal of Development Studies*, 43(8), 1351–1380.
- Human Rights Watch. (2001). *2001 Human Rights Watch World Report*. New York: Human Rights Watch Publishing.
- Human Rights Watch. (2003). *Policy analysis: A call for action on HIV/AIDS – related human rights abuses against women and girls in Africa*. Washington: Human Rights Watch Publishing.
- Human Rights Watch. (2008). *A question of life or death*. Retrieved from <http://www.hrs.org/en/reports/2008/12/16/question-on-life-or-death?print>
- Human Rights Watch. (2009). *World report 2009: Events of 2008*. Retrieved from [http://www.hrw.org/sites/default/files/reports/wr2009\\_web.pdf](http://www.hrw.org/sites/default/files/reports/wr2009_web.pdf)
- Integrated Regional Information Networks (IRIN). (2009). *Urban poverty and vulnerability in Kenya*. Retrieved from [http://www.jvinn.es.org/pd/Urban\\_Poverty\\_and\\_Vulnerability\\_in-Kenya.pdf](http://www.jvinn.es.org/pd/Urban_Poverty_and_Vulnerability_in-Kenya.pdf)
- International Monetary Fund. (2005). *Kenya: Poverty Reduction Strategy Paper*. Retrieved from <http://www.imf.org/external/pubs/ft/scr/2005/cr0511.pdf>
- Johnson, J., Bottoff, J., Brown, A., Grewel, S., Hilton, B.A., & Clarke, H. (2004). Othering and being othered in the context of health care services. *Health Community*, 16(2), 253–271.
- Kako, P. M. (2008). *Health needs of HIV-infected women in Kenya*. (Unpublished doctoral dissertation). University of Wisconsin, Milwaukee, WI.
- Kanter, E. R. (1992). *Challenge of organized change: How companies experience it and leaders guide it*. New York: Free Press.
- Karombo, T. (2011). *Analysts dismayed at China's Zimbabwe 'invasion'*. Retrieved from [www.businesslive.co.za/...2011/analysts-dismayed-at-china-s-zim](http://www.businesslive.co.za/...2011/analysts-dismayed-at-china-s-zim)
- Kaure, A. (2008). *Africa at large: The new scramble for Africa*. Retrieved from African InfoServe website: <http://www.africafiles.org>

- Kawachi, I., & Kennedy, B. (1997). Socioeconomic determinants of health: health and social cohesion. Why care about income inequality? *British Medical Journal*, 314, 1037–1045.
- Kawachi, I., Levine, S., Miller, S., Lasch, K., & Amick, B. (1994). *Income inequality and life expectancy – theory, research and policy*. Boston: Harvard School of Public Health.
- Kelly, A. (2004). The scent of positive lives: (Re) memorializing our loved ones. *Qualitative Inquiry*, 10(5), 767–787
- Kenya AIDS Watch Institute (KAWI). (2008). *2008 Report*. Retrieved from <http://www.kenyaaidssinstitute.org/prescolomn.html>
- Kenya Joint Staff Advisory. *Poverty reduction strategy paper 2003/2004*. (IMR. Country Report No. 07/60). Retrieved from <http://www.imfo.org/external/puns/ft/sc/2007/cr07160.pdf>
- Kenya Ministry of State for Planning National Development (2007). *Kenya vision 2030: Transforming national development*. Retrieved from <http://nairobi.iom.int/Country%20Information/kenya/Vision%25202030-Kenya.pdf>
- Kenya Society of International Development (2007). *Kenya's vision 2030*. Retrieved from [http://www.kenyaembassy.com/pdfs/Vision2030\\_Abridged%20version.pdf](http://www.kenyaembassy.com/pdfs/Vision2030_Abridged%20version.pdf)
- Kipp, W., Timdyebwa, D., Rubaale, T., Karamagi, E., & Bajenga, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International*, 28, 856–871.
- Kincheloe, J. (2001). Describing the bricolage: Conceptualizing a new rigor in qualitative research. *Qualitative Inquiry*, 7, 679–692.
- King, K. (1996). *Jua kali Kenya, 1970–95: Change and development in an informal economy 1970–95*. Athens, OH: Ohio University Press.
- Kippax, S. C., Holt, M., & Friedman, S. R. (2011). Bridging the social and the biomedical: Engaging the social and political sciences in HIV research. *Journal of the International AIDS Society*, 14(supp. 2), 1–3.
- Kirwen, M. (2005). *African cultural knowledge: Themes and embedded beliefs*. Nairobi: Mias Books.

- Kirwen, M. (2008). *African cultural domains: Life cycle of an individual*. Nairobi: Mias Books.
- Klot, J., & Nguyen, V. (Eds.). (2009). *The fourth wave: Violence, gender, culture and HIV in the 21st century*. UNESCO.
- Konadu, K. (2007). *Indigenous medicine and knowledge in African society*. New York: Routledge.
- Kovach, M. (2009). *Indigenous methodologies: Characteristics, conversations, and contexts*. Toronto: University of Toronto Press.
- Kvale, S. (1996). Ten standard objections to qualitative research interviews. *Journal of Phenomenological Psychology, 25*, 147–173.
- Kreiger, N. (2001). A glossary of social epidemiology. *Journal of Epidemiology and Community Health, 55*(10), 693–700.
- La Chapelle, D. (2001). *Negotiating the tides of change*. Toronto: New Society Publications.
- Landman, M. (2006). Getting quality in qualitative research: A short introduction to feminist methodology and methods. *Proceedings of the Nutrition Society, 65*(4), 429–433. New York: Routledge.
- Lather, P., & Smithies, C. (1997). *Troubling the angels: Women living with AIDS*. Boulder, CO: Westview Press.
- Law of Succession Act. (2010/1981). Retrieved from [www.kenyalaw.org/klr/fileadmin/pdfdownloads/Acts/LawsofSucessionActCap160.pdf](http://www.kenyalaw.org/klr/fileadmin/pdfdownloads/Acts/LawsofSucessionActCap160.pdf)
- Lennon, K., & Whitford, M. (Eds.) (1994). *Knowing the difference: Feminist perspectives in epistemology*. London: Routledge.
- Leon, D. A., & Walt, G. (2001). International perspective on health inequalities and policy. *British Medical Journal, 32*(7286), 591–594.
- Levin, D. M. (1989). *The listening self: Personal growth, social change, and the closure of metaphysics*. New York: Routledge.
- Levine, C. (1994). The new orphans and grieving in the time of AIDS. In B. O. Dane & C. Levine (Eds.), *AIDS and the new orphans: Coping with death* (pp. 1–12). Westport, Connecticut, London: Auburn House.

- Levine, P. A., & Frederick, A. (1999). *Waking the tiger: Healing trauma*. Berkeley, California: North Atlantic Books.
- Lewis, S. (2006). *Stephen Lewis to continue fight against AIDS after UN envoy term ends*. Retrieved from [http://www.stephenlewisfoundation.org.new\\_item?news=1760](http://www.stephenlewisfoundation.org.new_item?news=1760)
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Link, B., & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385.
- Locke, L. F., Silverman, S. J., & Spirduso, W. W. (2004). *Reading and understanding research* (2<sup>nd</sup> ed.). Thousand Oaks, CA: SAGE.
- Lugano, E., & Ngundo, J. (2001). *A participatory urban appraisal study of Mashimoni, Kambi, Muru, Lindi and Silonyo villages – Kibera informal settlement*. Nairobi: Oxfam Publishing.
- Luginaah, I., Elkins, D., Maticka-Tyndale, E., Landry, T., & Mathui, M. (2005). Challenges of a pandemic: HIV/AIDS-related problems affecting Kenyan widows. *Social Sciences & Medicine*, 60, 1219–1228.
- Macharia, K. (1992). Slum clearance and the informal economy in Nairobi. *The Journal of Modern African Studies*, 30(2), 221–236.
- Maguire, P. (1987). *Doing participatory research: A feminist approach*. University of Massachusetts: Center for International Education.
- Makwana, R. (2007). *International aid and economy still failing sub-Saharan Africa*. Retrieved from [www.zmag.org/content/showarticle.cfm?section10=27ITEMID=13061](http://www.zmag.org/content/showarticle.cfm?section10=27ITEMID=13061)
- Mann, J., & Tarantola, D. (1996). *AIDS in the world 11*. New York: Oxford University Press.
- Marcoux, A. (1998). The feminization of poverty: Claims, facts and data needs. *Population and Development Review*, 24(1), 131–139.
- Marmot, M. G., & Wilkinson, R. G. (Eds.). (1999). *Social determinants of health*. Oxford: Oxford University Press.

- Marmot, M. G., & Wilkinson, R.G. (2001). Psychological and material pathways in relation between income and health: A response to Lynch et al. *British Medical Journal*, 322(7296), 1233–1238.
- Marston, B., & De Cock, D. (2004). Multivitamins, nutrition and antiretroviral therapy for HIV disease in Africa. Retrieved from <http://www.nejm.org>
- Matrix Development Consultants. (2002). *An overview of informal settlements in Nairobi*. Kenya: Matrix Development Consultants.
- Mbiti, J. (1990). *African religion and philosophy* (2<sup>nd</sup> ed.). Oxford: Heinemann Education Books.
- McDonald, K., & McIntyre, M. (2002). Women's health, women's health care: Complicating experience, language and ideologies. *Nursing Philosophy*, 3(3), 260–267.
- McIntosh, P. (1990). White privilege: Unpacking the invisible knapsack. *Independent School*, 49(2), Winter, 31–36.
- McIsaac, E. (2000). Oral narratives in a site of resistance: Indigenous knowledge, colonization and western discourse. In G. Sefa Dei, B. L. Hall, & D. G. Rosenberg (Eds.), *Indigenous Knowledges in global contexts: Multiple readings of our world* (pp. 89–101). Toronto: University of Toronto Press.
- Mehl-Madrona, L. (2007). *Narrative medicine: The use of history and story in the healing process*. Rochester, Vermont: Bear & Company.
- Mereghetti, E., & Mensa, M. (Producers/Directors). (2004). *Eyes wide open*. Ethnos Merriam-Webster Online Dictionary. (2011). Retrieved from <http://www.merriman-webster.com/dictionary/ghetto>
- Mikell, G. (1997). *African feminism: The politics of survival in sub-Saharan Africa*. Philadelphia, PA: University Pennsylvania Press.
- Mills, J. E., Edwards, N., Jackson, R. C., MacLean, L., & Chaw-Kant, J. (2010). Stigmatization as a social control mechanism for persons living with HIV and AIDS. *Qualitative Health Research*, 20, 1469–1483.
- Minh-ha, T. T. (1987). *Woman, native, other*. Indianapolis, IN: Indiana University Press.
- Mishler, E. (1979). Meaning in context: Is there any other kind? *Harvard Educational Review*, 49, 1–19.

- Mitchell, M., & Egudo, M. (2003). *A review of narrative methodology*. Australian Government, Department of Defence: Systems Sciences Laboratory.
- Moatti, J., Souteyrand, Y. (2000). HIV/AIDS social and behavioral research: Past advances and thoughts about the future. *Journal of Social Science and Medicine*, 50(11), 1519–1532.
- Moghadam, V. (2005). *The feminization of poverty and women's human rights*. Retrieved from <http://www.unesco.org/shs/gender>
- Mohanty, C. T. (2003). *Feminism without borders: Decolonizing theory, practicing solidarity*. London: Duke University Press.
- Mojab, S. (2004). The particularity of “honor” and the universality of “killing”. In S. Mojab & N. Abdu (Eds.), *Violence in the name of honor: Theoretical and political challenges* (pp. 15–38). Istanbul: Istanbul Bilgi University Press.
- Momsen, J. H. (2002). Myth or math: The waxing and waning of the female-headed household. *Progress in Development Studies*, 2(2), 145–151.
- Morgan, J. (2003). *Long life: Positive HIV stories*. Cape Town: Double Story Books.
- Morrison, A., Raju, D., & Sinha, N. (2007). *Gender equality is good for the poor*. Policy Research Working Paper 4349. The World Bank.
- Morse, J. M. (Ed.). (1991). *Critical issues in qualitative research methods*. Thousand Oaks, CA: SAGE.
- Muindi, B. (2010). *Kenya: Gap between poor-rich widening*. Retrieved from <http://allafrica.com/stories/201001281106.html>
- Murphy, D. (1995). *The Ukimi road: From Kenya to Zimbabwe*. New York: The Overlook Press.
- Muwonge, J. W. (1980). Urban policy and patterns of low-income settlement in Nairobi, Kenya. *Population and Development Review*, 6(4), 595–613.
- Nandy, A. (1989). *The intimate enemy: Loss and recovery of self under colonization*. Delhi: Oxford University Press.
- Neader, K., & Skott, C. (2006). Important meeting with important persons: Narratives from families facing adversity and their key figures. *Qualitative Social Work: Research and Practices*, 5, 295–311

- Ngua, P. (1995). *Informal settlements in Nairobi: A baseline survey of slums and squatter settlement and inventory of NGOs and CBOs*. Toronto: University of Toronto Press.
- Nkrumah, K.(1965).(D. Tweedle, Trans.). *Neo-colonialism. The last stage of imperialism*. London: Thomas Nelson & Sons, Ltd.
- Noddings, N. (1986). *Caring: A feminine approach to ethics & moral education*. Berkeley, CA: University of California Press.
- Nolen, S. (2007). *28 Stories of AIDS in Africa*. Toronto: Knopf Canada.
- Nosotro, R. (2004). *Europe's colonization of Africa*. Retrieved from [www.hyperhistory.net/apwh/essays/comp/cw25colonizationafrica.htm](http://www.hyperhistory.net/apwh/essays/comp/cw25colonizationafrica.htm)
- Oakley, A. (1998). Gender, methodology and people's way of knowing: Some problems with feminism and the paradigm debate in social science. *Sociology*, 32, 307–331.
- Obbo, C. (1995). What women can do: AIDS crisis management in Uganda. In D. F. Bryceson (Ed.), *Women wielding the hoe: Lessons from rural Africa for feminist theory and development practice* (pp. 151–178). Washington, DC: Berg Publishers.
- Obudho, R. A., & Aduwo, G. O. (1989). Slum and squatter settlements in urban centres of Kenya: Towards a planning strategy. *Journal of Housing and Built Environment*, 4(1), 17–30.
- Odimegwu, C. O. (2002/2003). *Prevalence and predictors of HIV-related stigma and Knowledge in Nigeria: Implications for HIV/AIDS prevention initiatives*. Research Report submitted to the 2002/2003 Takem Program in International Health. Retrieved from: [www.hsph.harvard.edu/research/takemi/files/RP210.pdf](http://www.hsph.harvard.edu/research/takemi/files/RP210.pdf)
- Ogburn, W. F. (1957). Cultural lag as theory. *Sociology and Social Research*, 41, 167–174.
- O'Kelly, C., & Carney, L. S. (1986). *Women and men in society*. Belmont, CA: Wadsworth Publishing Company.
- Okin, S. (Ed.). (1999). *Is multiculturalism bad for women?* Princeton: Princeton University Press.

- Olesen, V. (2000). Feminisms and qualitative research at and into the millennium. In N. Denzin, & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (2<sup>nd</sup> ed.). (pp. 215–56). London: Sage.
- Oloo, O. (2008). *The political economy of ethnic identities in Kenya – part 1 of 3*. Retrieved from Africa Info Serve website: <http://www.africafiles.org>
- Ottawa Charter for Health Promotion. (1986). Retrieved from [http://www.who.int/hpr/NPH/docs/ottawa\\_charter\\_hp.pdf](http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf)
- Palmer, G. (2007). *Relative poverty, absolute poverty and social exclusion*. Retrieved from <http://www.poverty.org.uk>
- Parker, R. (2001). Sexuality, culture, and power in HIV/AIDS research. *Annual Review of Anthropology*, 30, 163–79.
- Parsons, T. (1997). Kibera is our blood: The Sudanese military legacy in Nairobi's Kibera Location, 1902–1968. *International Journal of African Historical Studies*, 30(1), 87–122.
- Patton, M. (1990). *Qualitative evaluation and research methods* (2<sup>nd</sup> ed.). Newbury Park, CA: SAGE.
- Payne, R. K. (2005). *Framework for understanding poverty*. (4<sup>th</sup> ed.). Highlands, Texas: aha! Process, Inc.
- Payne, R. K., DeVol, P., & Smith, T. D. (2001). *Bridges out of poverty: Strategies for professionals and communities*. Highlands, TX: aha! Process, Inc.
- Pendakur, K., Pendakur, R., & Woodcock, S. (2008). A representation index: Measuring the representation of minorities in the income distribution. *The B.E. Journal of Economic Analysis and Policy*, 8(1), 1–21.
- Pheifer, L. (2000). *Sachverhalte, konstruktion und wirklichkeit*. Wien: Selbstverlag.
- Pisani, E. (2008). *The wisdom of whores: Bureaucrats, brothels, and the business of AIDS*. Canada: Penguin Canada.
- Powers, J. (2202). *Converting a savage mind: Conversion and civilization*. Retrieved from [http://www.suite101.com/article.cfm/african\\_history/88514](http://www.suite101.com/article.cfm/african_history/88514)
- Pratt, M. L. (1992). *Imperial eyes: travel writing and transculturation*. London: Routledge.
- Punch, P. D. (2000). *Developing effective research proposals*. London: SAGE.

- Quigley, W.P. (2003). *Ending poverty as we know it*. Philadelphia, PA: Temple University.
- Radley, A., & Chamberlain, K. (2001). Health psychology and the study of the case: From method to analytic concern. *Social Science & Medicine*, 53, 321–332.
- Ravallion, M., & Chen, S. (2008). *The developing world is poorer than we thought but no less successful in the fight against poverty*. The World Bank.
- Reid, C., & Tom, A. (2006). Poor women's health discourses of legitimacy, poverty, and health. *Gender and Society*, 20(3), 402–420.
- Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.
- Richardson, C. L. (2004). *Becoming Métis: The relationship between the senses of Métis self and culture of self*. (Unpublished doctoral dissertation). University of Victoria, Victoria, BC, Canada.
- Riessman, C. K. (1993). *Narrative analysis*. Newbury Park, CA: Sage.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. London: Sage.
- Rootman, L., Frankish, J., & Kaszap, M. (2007). Health literacy: A new frontier. In M. O' Neill, A. Pederson, & S. Dupere (Eds.), *Health promotion in Canada* (pp. 61–74). Toronto: Canadian Scholars' Press.
- Rootman, L., & Gordon-El-Bihbety, D. (2008). *A vision of a health literate Canada: Report of the expert panel on health literacy*. Ottawa, ON, Canada: Canadian Public Health Association.
- Rosenberg, D. G. (2000). Toward indigenous wholeness: Feminist praxis in transformative learning on health and environment. In G. Sefa Dei, B.L. Hall, & D. G. Rosenberg, (Eds.), *Indigenous knowledges in global contexts: Multiple readings of our world* (pp. 137–154). Toronto: University of Toronto Press.
- Rosser, S. (1994). Gender bias in clinical research: The difference it makes. In A. Dan (Ed.), *Reframing women's health: Multidisciplinary research and practice* (pp. 253–265). London: Sage.
- Said, E. W. (1991). *Orientalism: Western concepts of the orient* (3<sup>rd</sup> ed.). Hamondsworth: Penguin.
- Said, E. W. (1993). *Culture and imperialism*. London: Chatto & Windus.

- Sanchez, J. M. (Ed.). (2008). *Droughts: Causes, effects and predictions*. New York: Nova Publications.
- Sarantakos, S. (2005). *Social research* (3<sup>rd</sup> ed.). London: Palgrave.
- Schaefer, R.T., & Smith, E. (2005). *Sociology: First Canadian edition*. Toronto: McGraw Hill.
- Schatz, E., Madhaven, S., & Williams, J. (2011). Female-headed household contending with AIDS-related hardship in rural South Africa. *Health Place* 17(2), 598–605.
- Schwartz, J. E. (2005). *Freedom reclaimed: Rediscovering the American vision*. Baltimore: Johns Hopkins University,
- Schwartz-Barcotte, R. (2001). *Youth, culture, NGO involvement and collective violence in Kibera, Nairobi – East Africa's largest slum* (Unpublished doctoral dissertation). Chapel Hill, NC: University of North Carolina.
- Seale, C. (1995). Dying Alone. *Sociology of Health and Illness*, 17(3), 376–392.
- Sehmi, A. (2009). *Elderly women denied dignified life*. Retrieved from Africa InfoService website: <http://www.africafiles.org/article.asp?ID=21216>
- Scandlyn, J. (2000). When AIDS became a chronic disease. *Western Journal of Medicine*, 172(2), 103–133.
- Seidman, I. (2006). *Interviewing as qualitative research* (3<sup>rd</sup> ed.). New York: Teachers College Press.
- Sen, G., Östlin, P., & George, A. (2007). *Unequal, unfair, ineffective and inefficient gender inequality in health: Why it exists and how we can change it*. Final Report to the WHO Commission on Social Determinants of Health. Retrieved from [http://www.who.int/social\\_determinants/.../wgekn\\_final\\_report\\_07.pdf](http://www.who.int/social_determinants/.../wgekn_final_report_07.pdf)
- Servan-Schreiber, D. (2003). *The instinct to heal: Curing depression, anxiety, and stress without drugs and without talk therapy*. Texas: Holtzbrinck Publishers.
- Shaw, C. M. (1995). *Colonial inscriptions: Race, sex, and class in Kenya*. Minneapolis, MN: University of Minnesota Press.
- Sheilds, L. (2007). Re-stor(y)ing life within life-threatening illnesses: (Research proposal). School of Nursing: University of Victoria, BC, Canada.
- Sheldrake, R. (1988). *The presence of the past: Morphic resonance and the habits of nature* (2<sup>nd</sup> ed.). Rochester, VT: Park Street Press.

- Silver, H. (1994). Social exclusion and social solidarity. *International Labour Review*, 133(5/6), 531–579.
- Simich, L. (2009). *Health literacy and immigrant populations*. Retrieved from [www.canada.metropolis.net/pdfs/health\\_literacy\\_policy\\_brief\\_jun15\\_e.pdf](http://www.canada.metropolis.net/pdfs/health_literacy_policy_brief_jun15_e.pdf)
- Simmel, G., & Jacobson, J. (1965). The poor. *Social Problems*, 13,(2), 118–140.
- Singer, P. (2009). *The life you can save: Acting now to end world poverty*. New York: Random House.
- Slattery, P. (2001). The educational researcher as artist working within. *Qualitative Inquiry*, 7(3), 370–398.
- Smith, L. T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. New York: Palgrave.
- Smith, M. (2009). *Poverty is hazardous to women's health* (Unpublished master's thesis). University of Victoria, Victoria, British Columbia, Canada.
- Somekh, B., & Lewin, C. (2005). *Research methods in the social sciences*. Thousand Oaks, CA: Sage.
- Somekh, B., Stronach, I., Lewin, C., Nolan, M., & Stake, J. (2005). Participating in the research community. In B. Somekh & C. Lewin (Eds.), *Research methods in the social sciences* (pp. 335–343). Thousand Oaks, CA: Sage.
- Somerville, M. (2006). *The ethical imagination: Journeys of the human spirit*. Toronto: House of Anansi Press Ltd.
- Sontag, S. (1989). *Illness as metaphor and AIDS and its metaphors*. New York: Farrar, Straus & Giroux.
- Spagnoli, F. (2009, January 8). Human rights facts (94): What is poverty? (Different definitions of poverty and an attempt to make some order) [Web blog comment]. Retrieved from <http://filipspagnoli.wordpress.com/2009/01/08/human-rights-facts-94-what>
- Spelman, E. (1988). *Inessential woman: Problems of exclusion in feminist thought*. Boston: Beacon Press.
- Spender, D. (1982). *Invisible women: The schooling scandal*. London: Writers and Readers.

- Spiker, P., Alvarez Leguizamon, S., & Gordon, D. (Eds.). (2007). *Poverty: An International Glossary* (2<sup>nd</sup> ed.). London: Zen Books.
- Stanley, L., & Wise, S. (1993). *Breaking out again: Female ontology and epistemology*. London: Routledge.
- Stevenson, W. (2000). *Decolonizing tribal histories* (Unpublished doctoral dissertation). University of California: Berkeley, CA.
- Storeburner, R. L., & Low-Beer, D. (2004). Population-level HIV advances and behavioral risk avoidance in Uganda. *Science*, 304(5671), 714–718.
- Stringer, J. S., Zulu, I., Levy, J., Stringer, E. M., Mwangi, A., Chi, B. H., ... Sinkala, M. (2006). Rapid scale-up of antiretroviral therapy at primary care sites in Zambia: feasibility and early outcomes. *Journal of the American Medical Association*, 296(7), 782–93.
- Sutcliff, P., Sarsfield, P., & Gardner, C. (2007). *Social inequities in health and Ontario public health*. Retrieved from <http://.sdhu.com/uploads/content/listings/SocialInequitiesInHealthOntarioPublicHealth>
- Tan, S.-H. (Ed.). (2005). *Challenging citizenship: Group membership and cultural identity in a global age*. Aldershot, England: Ashgate.
- Tallis, V. (2002). *Gender and HIV/AIDS*. Retrieved from <http://www.bridge.ids.ac.uk>
- Tarantola, D. (2006). Now you see it ... now you don't! Or the elusiveness of health and human rights in governance. *Human Rights Defender* 15(3), 14–26.
- Thayer-Bacon, B. (2003). *Relational (e)epistemologies*. New York, NY: Peter Lang Publishers.
- Thibos, M., Lavin-Loucks, D., & Martin, M. (2007). *The feminization of poverty*. Retrieved from [http://thewilliaminstitute.com/Portals/10/Poverty\\_Di...](http://thewilliaminstitute.com/Portals/10/Poverty_Di...)
- Thiong'o, N. wa. (1986). *Decolonizing the mind: The politics of language in African literature*. London: Heineman.
- Thomas, W. (1995). Kiss the baby goodbye. 'Kowhaiwhai' and aesthetics in Aotearōa, New Zealand. *Critical Inquiry*, 22(1), 90–121.

- Thomas, R. A. (2005). Honoring the oral traditions of my ancestors. In L. Brown & S. Strega (Eds.), *Research as Resistance: critical, indigenous, & anti-oppressive approaches* (pp. 237–254). Toronto: Canadian Scholars' Press.
- Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytical challenge in Interpretive description. *International Journal of Qualitative Methods*, 3(1), 1–11.
- Todaro, M., P. (1989). *Economic development in the third world*. London: Longman.
- Townsend, P. (1979). *Poverty in the United Kingdom: A survey of household resources and standards of living*. Harmondsworth: Penguin Books.
- Torpy, J. M., Lynn, C., & Glass, R. M. (2003). Men and women are different. *The Journal of the American Medical Association*, 289(4), 510.
- Tripp, A. M. (2002). The politics of women's rights and cultural diversity in Uganda. In M. Molyneux & S. Razau (Eds.), *Gender, justice, development and rights* (pp. 413–444). New York: University Press.
- Turner, J. (2003). *The structure of sociological theory* (7<sup>th</sup> ed.). Toronto: Thomson/Wadsworth.
- UBUNTU. (2003). Retrieved from <http://www.ivow.net/ubuntu.html>
- UNAIDS. (1998). *The demographic impact of HIV/AIDS*. Retrieved from [www.un.org/esa/population/pubsarchive/hivmtg/hivmtg/htm](http://www.un.org/esa/population/pubsarchive/hivmtg/hivmtg/htm)
- UNAIDS. (2004). *The global coalition on women and AIDS*. Retrieved from <http://www.womenandaids.unaids.org>
- UNAIDS. (2004). *2004 Report on the global AIDS epidemic* (4<sup>th</sup> ed.). Geneva: Switzerland: UNAIDS.
- UNAIDS, UNICEF, & USAID. (2004). *Children on the brink 2004: A joint report of new orphan estimate and a framework for action*. Geneva, Switzerland.
- UNAIDS, UNTPA, & UNIFEM. (2004). *Women & HIV/AIDS: Confronting the crisis*. Geneva, Switzerland.
- UNAIDS. (2006). *Report on the global AIDS epidemic*. Geneva, Switzerland: UNAIDS.
- UNAIDS/WHO. (2007). *Worldview HIV/AIDS*. Retrieved from <http://www.avert.org/worldstats.htm>
- UNAIDS. (2008). *Report on the global AIDS epidemic*. Geneva, Switzerland: UNAIDS.

- UNAIDS. (2009). *Annual Report*. Retrieved from [http://www.unaids.org/en.../unaids.../report/.../2009\\_annual\\_report\\_en.pdf](http://www.unaids.org/en.../unaids.../report/.../2009_annual_report_en.pdf)
- UNAIDS. (2010). *Global Report: UNAIDS Report on the Global AIDS Epidemic*. Geneva, Switzerland: UNAIDS.
- UNAIDS. (2011). *AIDS at 30: Nations at the crossroads*. Geneva, Switzerland: UNAIDS.
- UNFPA. (2006). *Annual Report*. Retrieved from <http://www.unfpa.org/public/publications/pd/413>
- UNGASS. (2008). *Country report – Kenya*. Nairobi, Kenya: Kenya Office of the President, Ministry of Special Programmes.
- UNGASS. (2010). *HIV and AIDS in Kenya*. Retrieved from <http://www.avert.org/hiv-aids-kenya.htm>
- Unge, C., Johansson, A., Zachariah, R., Some, D., Van Engelgem, I., & Ekstrom, A.M. (2008). Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kibera. *AIDS Care*, 20(2), 146–149.
- UNICEF. (2003). *Africa's orphaned generations*. New York: UNICEF Publishing.
- UNICEF. (2005). *Gender equality: The big picture*. Geneva: UNICEF Publishing.
- United Nations. (1995b). *Report of the World Summit for Social Development, Copenhagen, Denmark, March 6–12, 1995*. Sales No. E. 96.IV.8.
- United Nations. (1995b). *Second review and appraisal of the implementation of the Nairobi forward-taking strategies for the achievement of women*. Report of the Secretary General. New York: United Nations.
- United Nations. (2009). *The millennium development goals report – 2009*. Retrieved from [http://www.un.org/millenniumgoals/pdf/MDG\\_report](http://www.un.org/millenniumgoals/pdf/MDG_report)
- United Nations. (2010). *Rethinking poverty: Report on the world social situation*. New York: United Nations Department of Economic and Social Affairs.
- United Nations Habitat. (2004). *Housing rights, land & tenure, land and housing*. Geneva, Switzerland.
- United Nations Habitat. (2004). *Dialogues: Second World Urban Forum*. Barcelona, Spain.

- United Nations Population Fund Association. (2006). *Ending the increased feminization of AIDS*. Retrieved from <http://www.unda.org/news/news.cfm?ID=805>
- United Nations Population Fund Association (2008). Update regional survey – Sub-Saharan Africa. In UNAIDS (2008), *The changing HIV/AIDS landscape: Selected papers for the AIDS epidemic*. Retrieved from <http://www.hivinsite.ucsf.edu/global%3Fpage%3Dcr09-00-00>
- UN Statement. (1998). *Definition of poverty*. Retrieved from [www.va.org/osa/socdev/unyin/documents/yd.DavidGordon\\_poverty.pdf](http://www.va.org/osa/socdev/unyin/documents/yd.DavidGordon_poverty.pdf)
- USAID. (2009). *HIV/AIDS*. Retrieved from [http://www.usais.gov/our\\_work/global\\_health/aids/News/aidsfaq.html](http://www.usais.gov/our_work/global_health/aids/News/aidsfaq.html)
- Valaskakis, G. G., Stout, M. D., & Guimond, E. (Eds.). (2009). *Restoring the balance: First Nations women, community, and culture*. Manitoba: University of Manitoba Press.
- van Brakel, W. H. (2005). Measuring health related stigma – a literature review. Retrieved from [www.kitpublishers.nl/-/2543/measuring-health-related-stigma --- a-literature-review.pdf](http://www.kitpublishers.nl/-/2543/measuring-health-related-stigma---a-literature-review.pdf)
- Vinyard, A. (1998). Agenda for interdisciplinary and international women's studies. In K. Conway (Ed.). *Women's studies in transition: The pursuit of interdisciplinarity* (pp. 92–101). Newark: University of Delaware.
- Walby, S. (2001). Against epistemological chasms: The science question in feminism revisited. *Sages*, 26( 2), Winter, 485–509.
- Walker, M. (2005). Feminist methodologies. In B. Somekh & C. Lewin (Eds.). *Research methods in the social sciences*. (pp. 66–73). Thousand Oaks, CA: Sage.
- Wall, K. & Louchakova, O. (2002). Evolution of consciousness in responses to terrorist attacks: Toward a transpersonal theory of cultural transformation. *Humanistic Psychologist*, 30(3), 252–273.
- Wangui, E. E., & Darkoh, M. B. K. (1992). A geographical study of Kibera as an example of an uncontrolled settlement. *Journal of East African Research and Development*, 22, 75–91.




- Weber, S. (2008). Visual images in research. In J. G. Knowles and A. L. Cole (Eds.). *Handbook of the arts in qualitative research* (pp. 41–54). Thousand Oaks, CA: Sage.
- Wells, K. (2010). *Narrative inquiry*. USA: Oxford University Press.
- Wilkinson, R., & Marmot, M. (2003). *Social determinants of health: The solid facts*. Geneva: World Health Organization.
- Wilson, J. B. (1988). Women and poverty: A democratic overview. *Women and Health*, 12(3 & 4), 21–40.
- Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Halifax & Winnipeg: Fernwood Publishing Company Ltd.
- Wolcott, H. (1994). *Transforming qualitative data: Description, analysis, and interpretation*. Thousand Oaks, CA: Sage.
- World Bank. (2007). *Global economic prospects: managing the next wave of globalization*. Retrieved from <http://www.kenyaaidsinstitute.org/index.htm>
- World Economic Forum. (2005). *Women's empowerment: Measuring the global gender gap*. Geneva, Switzerland. Retrieved from [www.weforum.org](http://www.weforum.org)
- World Health Organization. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–20 June, 1946: signed on July 22, 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7th April 1948.
- World Health Organization. (1998). *Gender and health: Technical paper*. Geneva, Switzerland: WHO.
- World Health Organization. (1999). *World health report: Making a difference*. Geneva, Switzerland: WHO.
- World Health Organization. (2004). *Republic of Kenya: Investment programme for the economic recovery strategy for wealth and employment. creation, 2003–2007*. Retrieved from <http://apps.who.int/hdp/database/print.aspx>
- World Health Organization. (2005). *Social determinants of health*. Retrieved from [http://www.who.int/social\\_determinants/en/](http://www.who.int/social_determinants/en/)


World Health Organization. (2007). *A safer future: Global public health security in the 21st century*. Geneva, Switzerland: WHO.

World Health Organization. (2008). *Closing the gap in a generation: health equality through action on the social determinants of health*. Geneva, Switzerland: WHO.

World Health Organization. (2011). *Health policy*. Retrieved from [http://www.who.int/topics/health\\_policy/en/](http://www.who.int/topics/health_policy/en/)

## Appendix A Republic of Kenya Research Clearance Permit

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p style="text-align: center;">PAGE 2</p> <p>THIS IS TO CERTIFY THAT:</p> <p>Prof./Dr./Mr./Mrs./Miss <u>SAMAYA</u><br/><u>WANTYLER</u></p> <p>of (Address) <u>P.O BOX 1700 STN CSC</u><br/><u>VICTORIA BRITISH COLUMBIA CANADA</u></p> <p>has been permitted to conduct research in.....<br/>.....Location,<br/><u>NALROBI WEST</u> District,<br/><u>NALROBI</u> Province,<br/>on the topic <u>HOW DO AFRICAN INDEGENOUS</u><br/><u>WOMEN WHO ARE HIV POSTIVE &amp; ARE</u><br/><u>LIVING IN KIBERA, KENYA EXPERIENCE</u><br/><u>STORY THEIR DAILY LIVES AND</u><br/><u>PARTICIPATE IN COMMUNITY</u></p> <p>for a period ending <u>31ST MARCH</u> <u>11</u><br/><u>20</u></p> | <p style="text-align: center;">PAGE 3</p> <p>Research Permit No. <u>NCST/5/002/R/915</u></p> <p>Date of issue <u>01.10.2009</u></p> <p>Fee received <u>USD 400</u></p> <div style="text-align: center;">  </div> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <div style="text-align: center;"> <br/> <i>Applicant's<br/>Signature</i> </div> <div style="text-align: center;"> <br/> <i>Secretary<br/>National Council for<br/>Science and Technology</i> </div> </div> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p style="text-align: center;">CONDITIONS</p> <ol style="list-style-type: none"> <li>1. You must report to the District Commissioner and the District Education Officer of the area before embarking on your research. Failure to do that may lead to the cancellation of your permit</li> <li>2. Government Officers will not be interviewed with-out prior appointment.</li> <li>3. No questionnaire will be used unless it has been approved.</li> <li>4. Excavation, filming and collection of biological specimens are subject to further permission from the relevant Government Ministries.</li> <li>5. You are required to submit at least two(2)/four(4) bound copies of your final report for Kenyans and non-Kenyans respectively.</li> <li>6. The Government of Kenya reserves the right to modify the conditions of this permit including its cancellation without notice</li> </ol> <p style="margin-top: 20px;"><u>GPK605543m/10/2009</u></p> |  <p><b>REPUBLIC OF KENYA</b></p> <hr style="width: 50%; margin: auto;"/> <p><b>RESEARCH CLEARANCE PERMIT</b></p> <p style="margin-top: 20px;">(CONDITIONS— see back page)</p> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

## Appendix B Research Authorization

REPUBLIC OF KENYA



### NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telegrams: "SCIENCETECH", Nairobi  
Telephone: 254-020-241349, 2213102  
254-020-310571, 2213123  
Fax: 254-020-2213215, 318245, 318249  
When replying please quote

P. O. Box 30623-00100  
NAIROBI-KENYA  
Website: www.ncst.go.ke

Our Ref: **NCST/5/002/R/372/5**

**1<sup>st</sup> October, 2009**

**Samaya Vantylor  
3-144 Dallas Road  
Victoria, BC, V8V 1A3  
CANADA**

#### RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on "*How do African indigenous women who are HIV positive and are living in Kibera, Kenya experience/story, their daily lives and participate in community?*" I am pleased to inform you that you have been authorized to undertake your research in *Kibera, Nairobi West District* for a period ending *31<sup>st</sup> March 2011*.

You are advised to report to *the District Commissioner and the District Education Officer, Nairobi West District* before embarking on your research project.

Upon completion of your research project, you are expected to submit two copies of your research report/thesis to our office.

  
**PROF. S. A. ABDULRAZAK Ph.D, MBS  
SECRETARY**

Copy to:  
The District Commissioner  
Nairobi West District

The District Education Officer  
Nairobi West District

## Appendix C

### Community Contact Letter of Agreement

#### COMMUNITY CONTACT LETTER of AGREEMENT

Date:

I voluntarily agree to identify some women who have been living with HIV/AIDS for over 12 months, can speak and understand English and have access to a cell 'phone and are living in Kibera for recruitment purpose for a research study to be conducted by Samaya VanTyler. I also agree to be available for on-going consultations related to enacting this research in a culturally sensitive manner.

I will receive an honorarium of \$5 in Kenyan shillings in acknowledgement of my willingness to engage in the recruitment process and will receive this honorarium once all participants have been selected. I will receive the set amount regardless of the number of participants recruited.

I understand that I may withdraw at any time and receive the full honorarium.

I also agree to keep any knowledge that I have regarding the names of participants in the study confidential.

---

Signature

## Appendix D Intake Form

INTAKE FORM  
Date:

Name: Use this name or another.

Cell number:

Age:

Tribe:

Year of HIV+ status:

Year husband died:

Number, names and sex of children:

Willing to talk with me openly about HIV+ status:

Willing to be a participant in the study:

Date, time and place of Interview/conversation #1.

Date, time and place of Interview/conversation #2.

## Appendix E

### Sample Guiding Questions

#### Sample Questions for Interviews

*Conversation #1*

##### Interview #1

[The intention is to build rapport and invite stories and experiences of living as HIV+ women]

- Tell me your story of living with HIV.
- How do you talk about living with HIV?
- How has having HIV affected who you are? Have you felt more vulnerable (different) since learning that you are HIV+?
- Where do you get your strength from?
- How are you treated by your family, friends, others in the community?
- Do you do things differently now than you did before you knew you were HIV?  
Tell me about them.

*Conversation*

##### Interview #2

[The intention <sup>is</sup> ~~was~~ to explore further the narratives of the HIV+ women living in Kibera, and to clarify information from <sup>conversation</sup> Interview #1]

- How do you spend your day- from the time you get up?
- What do you know now that you didn't know before you became infected with the HIV virus?
- What else would you like me to know about living your life as an HIV+ woman?

## Appendix F Participant Consent Form

### PARTICIPANT CONSENT FORM

Jambo! My name is Samaya VanTyler: I am a PHD candidate research student from the University of Victoria, British Columbia, Canada. My research question is "How do Indigenous African women who are HIV+ and are living in Kibera, Kenya experience/story their daily lives and participate in community?"

I am inviting you to be part of my research because you live n Kibera, have known of your HIV/AIDS status for over one year, speak and understand English, have access to a cell 'phone and are willing to talk with me about your life now, Your participation is COMPLETELY VOLUNTARY; you can choose NOT to be part of this study.

If you decide to take part in the study we will have two conversations. Being seen with me in the community may identify you as a woman who is HIV+. To help safeguard and respect your confidentiality you will choose the time and place of our conversation. These conversations will be recorded, will be about two hours each, and you will receive 100KSh at the end of each conversation. You can decide to withdraw from the study at any time, in the middle of a conversation, without taking part in the second conversation and without explanation.

In Nairobi, I will keep all my notes and recordings locked in my room at the Flora Hostel and locked in a filing cabinet when back in Canada, I will keep notes and recordings for five years and then shred the paper and destroy the recordings. Unless you give me permission to use your name, I will not use your name when writing up my findings; I will use other names.

Talking with me openly about your HIV/AIDS status and your present life may cause you to feel uncomfortable or distressed. If this happens, adequate time and support will be provided to deal with concerns. WOFAK provides free counseling services and \_\_\_\_\_. our community contact is available to suggest culturally sensitive resources. At any time, you can contact me at (cell #) or \_\_\_\_\_, our community contact at (cell #) to answer questions or express concerns.

I will listen closely to you as you tell me your stories about living with HIV/AIDS and your present community life in Kibera. Sharing your stories and providing me the opportunity to write about them in an academic way may encourage others to speak out about their experiences of living with the disease. In this way, information can be used to develop service delivery programs that better meet the community and individual needs of those who are HIV+.

I will present findings in a Kibera community setting that meets your privacy needs and will talk with \_\_\_\_\_, our community contact, as to the location. You can choose to attend or not.

I \_\_\_\_\_ agree to be part if this research study and understand fully what is expected of me.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix G Exact Quotations

The original conversation is identified by bold, italic font.

1. Lucy: I wake up the children. ... Then [I] cook for them. I tell [them] to go to school.

And me, I go to the market to buy some potatoes to continue my business.

*I wake up with children – to – to – to watch how to prepare her school – her school uniform. Then we – we cook for them tea – then we go- the – I tell her to go to school.*

*And me, I go to market to buy some potatoes to continue my business.*

2. Zakia: Women in Africa are very strong. Because we know – we have already see the house which have no woman. The house is not stable. It's not stable at all. ... they [men] want cattle there, cattle, because they know these cattle bring them money. ... if they [men] have money, getting to the hotel, eat and come and sleep. ... they are not caring even for the children. ... So if the woman gone, the children have to take over what the women do.

*Women in Africa are very strong. Because we know– we have already see the house which have no women. The – the house is not stable. It's not stable at all because something is missing. Because if the woman is not here – everything –everything just stand the way it is. The man says, 'No.' There's nobody because they just want cattles there, cattles because they know these cattles, it will bring us money. They just go and look– if they have money, getting to the hotel, eat, and come and sleep. ... they are not caring even for the children because everybody – they – children are there sitting, they all, the children over the – the other side, they normally know – no – sometimes they*

*always – always get the – they know how even to milk the cows. They just go milk and take the milk and go to sleep. They are not there to ask, ‘Father, this – we want this.’ ‘No, no, no, no. Because your mama is not there. No, no. Go and take milk, go and sleep.’ Sometimes they are those – there’s more boys than the girls, they’re the one who send the cattles of the – river no – is there – there’s rivers. They go, take water, go and take grass, bring them back. They don’t care about the children.*

3. Amina Bashir: I found my sister being very good. She encouraged me and told me I was not going to die. ... She told me I have to have courage. And that’s the thing – I thought maybe she would run away, but the ... first step she showed me, it was so nice. She came, we talked. She stayed with me for one week. ... She told me, ‘Now I’m going to leave you money, and [when] the school is closed, you just come home with your children. We’ll do anything and see whether you improve. And I told her, ‘O.K.’ Then she called my husband and told how bad, [how sick his wife was], she’s going back but when school was closed. Let him give me permission to go home, to go and rest a bit. Okay, when the school was closed. I went home. I packed my clothes and my children’s’ clothes, we went home. And we reach home, she was so good. She cared – she took care of me so much, so much. Every time I was getting food .... She was encouraging me. When I came back from home ... after one month ... I was changed completely. ... I was just like normal.

*I found my sister being very good. She encouraged me and told me that I’m not going to die and I should not accept to die because if I die when – whatever happens whoever takes care of my kids he will not take care of my kids myself. She encouraged me so much. And that’s the thing – I thought maybe she could run away but the way, the first*

*step she showed me, it was so nice. Then he went. She came, we talked. She stayed with me for one week. And then she told me now because my rub is so sore, it's difficult because she's (tape indiscernible) at home, she's also married (tape indiscernible). She told me, 'Now I'm going to leave for you money, and the school is closed, you just come home with your children. We'll do anything and see whether you improve.' And I told her, 'O.K.' Then she called my husband and told how bad, she going back but when the school closed, let her – let him give me permission to go home, to go sand rest a bit. O.K when the school was closed I went home. I packed my clothes and my children's clothes, we went home, And we reach home, she was so good. She cared – she took care of me so much, so much. Every time I getting food, every time she was with me, she was encourage me, she encouraging me all the time. When I came back from home at after one month – I went there for one month and I came back from home, I had already – I was completely changed. I changed – I – I had my – I changed – I was just like normal.*

4. Loise: Actually, they (in-laws) thought I was just going to die the very week. Even they had decided, taking my properties. ... Even the blankets, they were carrying – they saw me as I was just useless.

*I was sick now and then before I went for testing. So I – yes – maybe this person and even when this man died, I was very weak. Actually, they thought I was just going to die the very week, Even they had decided, taking my properties, theyknew I was going to die, the relatives of the husband because with them, they knew I'm HIV. Yet myself, I had not – not yet gone for the test.*

5. Penninah: there was a time when I was crying on the bed saying that I will leave my children ... crying every now and then and saying, 'who is going to care for my children?'

*I can say that because I'm now living, there is time when I, I'm crying on the bed saying that I will leave my children, but now, I'm now still going on with my, my children, with my child. I'm glad so crying every now and then and saying. 'Who is going to care for my children?' – so happy now and they say that 'oh, am I going to leave me to my child, but I always pray for God, asking Him to help me and wake up. And now I can say God is with– with me. That is all I can say.*

6. Zuhura: I'm waiting to tell the eldest, just the elder. I'm waiting to tell her because she's the elder – the others are young. I want them to become a little older. One day they understand, now they're young. Because, if I tell them now ... every time they are in class, they will start thinking, 'My mother is HIV, my mother is HIV,' – a very hard fear. Now we will miss our mother, she will die. ... now I can't tell them ... because they are still young and I want them to concentrate on their education. They are doing well in school and I don't want to stress them with anything. Right now, I'm thinking how to ... tell her [her oldest daughter] but, – no I don't think she will take it badly because she's also in puberty.

*Yes, I want them to become a little older. One day they understand. Now they're young – because if I tell them now they will start to be every time they are in class they will start thinking, 'My mother is HIV, my mother is HIV,' you see, a very hard fear. 'Now we'll miss our mother, she will die like that'– because some people, they don't the message, they don't reach it, the message nicely to people. Now the children now, so*

*also they know is someone is HIV positive, they are going to die. Now I can't tell them now, because they are young and I want them to concentrate on their education the way I told you. They are doing well in school and I don't want to stress them with anything. Now even if they see I'm sick, they see I'm just taking my medicine, I just convince them to learn very well. Just like that. But I- I'm waiting to tell the eldest, just the elder. I'm waiting to tell her. Because she's the elder, the others are young. Right now I'm thinking how to – to – to tell her but I don't think she will take it badly because she's also in puberty.*

7. Amina Abdul: Me now ... I have another woman who is working at Kenyatta Hospital. I go there. I wash for her, her clothes, I clean her house. I go there Mondays, Wednesday and Friday. ... She give me some little money.

*Me now, I'm going – I – I have another woman who is working at Kenyatta Hospital. I go there. I wash for him, his clothes, I clean I his house. I go there Monday's, Wednesday and Friday, Yeah. He give me some little money.*

8. Sarah: You are not staying two hundred years, no. ... when I'm not here, when I am not, what about these children? [They're] staying ... with who? ... that give me the stress-up for these children.

*Sometimes you – you stress because when I see my children for my sister, there is nobody what the I see, these children, when I am not, when I not in, or when I am not, these children she's going where? You aren't – you are not staying for two hundred years, no. When – when that time, when I'm not here, when I am not, what about these children? She'e staying where – with who? This give me the stress-up for these children.*

9. Mama May: Maybe they talk ... behind ... You know, everybody cannot love you, everybody cannot hate you. ... Nowadays, I can see I have my friends and some other friends have disappeared.

*Mama May talk when I don't – behind– I didn't – behind hear any rumors (tape indiscernible). You know, everybody cannot love you, everybody cannot hate you. No – nowadays, I can see I have friends and some other friends have disappeared.*