ILLNESS EXPERIENCES OF PEOPLE LIVING WITH HIV IN KENYA: A CASE STUDY OF KISUMU COUNTY

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DECLARATION

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I, the undersigned, declare that this dissertation is the result of my independent and original investigation and that it has not been submitted in substance for any other degree, nor is it concurrently being submitted in candidature or achievement of any other degree at any other University.

Reference to, quotation from and discussion of the work of any other authors have been correctly acknowledged and cited within the dissertation. Any errors and omissions are however the responsibility of the author.

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George Evans Odero Owino

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DEDICATION

To the God and Father of our Lord Jesus Christ

who hath blessed us with all spiritual blessings in heavenly places in Christ.

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ABBREVIATIONS AND ACRONYMS

AIDS : Acquired Immune Deficiency Syndrome
ART/ARV : Anti-retroviral therapy / Antiretroviral
BD : Burden of disease
CCC : Comprehensive Care Clinics/Centers
CHW : Community health worker
DALY : Disability-adjusted life years
FBO : Faith-based organizations
FGD : Focus group discussions
HAART : Highly active anti-retroviral therapy
HIV : Human Immunodeficiency Virus
JOOTRH : Jaramogi Oginga Odinga Teaching and Referral Hospital
KAIS : Kenya AIDS indicator survey
KIIs : Key informant interviews
KU-ERC : Kenyatta University Ethical Review Committee
LVCT : Liverpool Voluntary Counseling and Testing
MMS : Ministry of Medical Services
MoH : Ministry of Health
NACC : National AIDS Control Council
NACOSTI : National Commission for Science and Technology
NASCOP : National AIDS and STI Control Programme
NCST : National Council for Science and Technology
NGO : Non-governmental Organizations
PI . Principal investigator
PLHIV : People living with HIV
PSC : Patient support center
PSG : Patient support groups
SSA : Sub-Saharan Africa
STI : Science technology and innovation
TB : Tuberculosis
UNAIDS : Joint United Nations Programme on HIV/AIDS
UNICEF : United Nations International Children's Fund
USAID : United States Agency for International Development
USD . United States (US) dollars
VCT : Voluntary counseling and testing.
WHO : World Health Organization

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ABSTRACT

Background to the Study: More than thirty years after the onset of the global HIV pandemic, HIV continues to be both a huge public health burden and a social concern. By the end of 2013, an estimated 35 million people lived with HIV globally. Nearly 70% of people living with HIV (PLHIV) resided in Sub-Saharan Africa with Kenya accounting for an estimated 1.6 million over the same period. Despite highly active antiretroviral therapy (HAART) enhancing the chances for longer life, PLHIV still encounter multiple challenges including stigma and discrimination and livelihood insecurity. These difficulties notwithstanding, literature suggests that PLHIV struggle to innovate within their social spheres to find means of leading meaningful lives. However, little research has been done in Kenya from a phenomenological perspective to describe the lived experiences of PLHIV in the context of improved quality of life and longevity.

Objective: The main objective of this study was to provide a detailed phenomenological description of the illness experiences of PLHIV in Kisumu County of Kenya. The study inquired into how PLHIV in Kisumu County made sense of their HIV status, how being diagnosed HIV positive affected their lives and which coping strategies they adopted in order to adapt to a life with HIV. The study also researched into the difficulties that PLHIV faced in adapting to their new status.

Theoretical Framework: The study was guided by the symbolic interactionist and the chronic illness trajectory theories. Both theories are embedded in the interpretative tradition. The interpretivist tradition views meanings as products of the process of social interaction through which agents mutually interpret events and phenomena, thereby creating commonly negotiated meanings. According to symbolic interactionism, this interaction process is mediated by symbols, chiefly, a commonly shared language.

Methodology: The study adopted a qualitative research methodology. The hermeneutic phenomenological design was used to guide data collection, coding and analysis. Ethical approval was granted by the Kenyatta University Ethical Review Committee and the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH). Data was collected through 49 in-depth interviews, (30 females and 19 males), eight (8) focus group discussions (FGDs) and six (6) key informant interviews. Data was digitally recorded, personally transcribed, deductively and inductively coded and analysed with the help of the MAXQDA qualitative data analysis software. Data is presented in form of quotations and interpretations of the researcher.

Key Findings: The study findings are presented in three parts, in chapters 3, 4, and 5 respectively. Each of these chapters deals with a specific domain as follows: being diagnosed HIV positive; effects of HIV on the lives of PLHIV and the coping strategies PLHIV adopted as well as the difficulties they faced. PLHIV got to know their status within four main circumstances: personal illness, spouse’s death or illness, antenatal care, and public health campaigns. The majority reported initially accepting their status and adopting positive living, although nearly all expressed some degree of fear, shock, and pain or sadness. Reconciliation to the diagnosis was mediated by psychosocial support, quest for health and longevity, the perception of high HIV prevalence and the present and future well-being of their children.

The effects on social relationships involved stable, stigmatizing and discriminatory, improved and restructured interaction patterns. The effects on capacity to fulfill social obligations included retained, regained, and diminished capacity to work. The sense of self was perceived as either being stable, disrupted, or restored.

Coping strategies adopted included receiving psychosocial and emotional support, practicing faith and religious beliefs, social engagement, adherence to medication and clinical appointments, livelihood enhancement, adoption of safe sexual behaviours, and abstinence from or minimizing the use of alcohol and other drugs. Difficulties faced included insecure livelihoods, stigma and discrimination, and inability to provide for their children’s education.

Discussion: People in Kisumu County were diagnosed HIV positive under a variety of circumstances and reacted in diverse ways in making sense of their diagnosis. The emotional and psychological reactions are a normal process that help people make sense of traumatic experiences. A number of conditions helped the participants reconcile with a positive HIV diagnosis. These included psychosocial support and counseling from patient support centers (PSC), families and support groups and the availability and accessibility of ART. PLHIV are creative agents who devise pragmatic mechanisms to live successfully with HIV amidst stigma, discrimination and morally judgmental attitudes. The coping strategies adopted have helped PLHIV to adapt well, and enabled them to continue with their social obligations, maintain their social relationships and retain relatively stable perceptions of self. PLHIV in Kisumu County are however still confronted by a number of difficulties that hamper their coping efforts.

Conclusions and Recommendations: PLHIV are able to cope and adapt well to the disruptions, contradictions and difficulties of living with HIV. However, for their coping to be adaptable, they need the psychosocial, emotional and material support of their families, communities, health providers and the wider society. It is therefore recommended that the design and implementation of policy and programmatic interventions should involve all stakeholders, including PLHIV. Other recommendations include provision of HIV-related information and education to the communities, review of the health education curriculum, ensuring sustainability of ART and provision of adequate health care resources.

STRUCTURE OF THE DISSERTATION

This dissertation is divided into 7 (seven) chapters as outlined in Table 0-1. Chapter one (1) presents the background to the study, including, introduction, the statement of the problem, and the theoretical framework. The conceptual and empirical literature based on the objectives and research questions are then reviewed including the global, continental and national HIV statistics. Chapter two (2) provides a detailed description of the study methodology and incudes the research objectives and research questions, the epistemological considerations, research methodology and design, methods of data collection, preparation for field research, the research process and data analysis, interpretation and presentation.

In Chapters three (3), four (4), and five (5), the findings of the study are presented based on the research objectives and questions. These included how PLHIV were diagnosed HIV positive (Chapter 3), the effects of HIV in the lives of PLHIV (Chapter 4), the coping strategies adopted and the difficulties faced in coping with HIV (Chapter 5). Chapter six (6) provides a critical discussion of the findings, the methodological considerations, and the strength and the limitations of the study. Finally, Chapter seven (7) brings together the key conclusions from the study and makes policy, programmatic and research oriented recommendations for possible action by the key actors in HIV care and treatment.

Table 0-1: Structure of the dissertation

Structure	**Chapter**	**Contents**
Background and Literature Review	Chapter 1	Background, theoretical framework, literature review, problem statement & public health relevance
Materials & Methods	Chapter 2	Research objectives and questions, epistemological considerations, research methodology and design, ethical considerations, research process, and data analysis.
Results Part I, II & III	Chapter 3	Being diagnosed HIV Positive
	Chapter 4	Effects of HIV on PLHIV
	Chapter 5	Coping strategies adopted & difficulties encountered by PLHIV
Discussion	Chapter 6	Discussion and methodological considerations
Conclusions and Recommendations	Chapter 7	Conclusions and recommendations

1 BACKGROUND

1.1 Chapter Overview

In this chapter, the introduction to the study is presented. The two theoretical frameworks guiding the study, symbolic interactionism and chronic illness trajectory model, are also reviewed. The review of the theoretical frameworks brings out their key arguments and their applicability to the present study. The chapter also provides a review of both the conceptual and empirical literature relating to the objectives of the study. The literature review includes the basic epidemiological data and dynamics of HIV at the global, the regional (SSA) and the national (Kenya) levels, how PLHIV got to know their HIV status, how they initially reacted to the information and how they reconciled themselves to and accepted HIV status. The coping strategies adopted by PLHIV and the difficulties they experienced in coping with and adapting to a life with HIV are similarly examined. The chapter concludes with a description of the statement of the problem and the public health relevance of the study.

1.2 About Health and Illness

Health and illness are two conditions characterizing the human experience (Radley, 1994; Carel, 2008). According to the World Health Organization (WHO), "[h]ealth is a state of complete physical, mental and social well-being and not merely the absence of disease" (WHO, 2006). Illness on the other hand can be conceived of as "...the experience of disease, including the feelings relating to changes in bodily states and the consequences of having to bear the ailment; illness therefore relates to the way of being for the individual concerned..." (Radley, 1994). According to Freund and McGuire (1999), a person's sense of self and his/her significant social relationships are inextricably linked to the state of the body and to its normal functioning. They add that the body is what gives a person his or her identity. Freund and McGuire conclude that due to the intimate and indissoluble connection between the sense of self and the body, a person's identity and wellbeing depends to a large extent on their health status and ability to competently fulfil the social obligations of life in their entirety (Freund and McGuire, 1999).

Carel (2008), in commenting about the question of being or existence, refers to the work of the phenomenologist Merleau-Ponty and avers that the body and sensory experience are the basis of personal being. According to the phenomenological view of being, “to be is to have a body that constantly perceives the world through sight, touch, smell and so on” (Carel, 2008). She goes on to say that “human existence takes place within the horizons opened up by perception” (Carel, 2008). Through these words, she conceives of the possession of a body as a precondition for having a subjective existence. Other researchers and theoretical expositors—including Charmaz (1983), Bury (1982), Freund and McGuire (1999), Nettleton (2006) and Williams (2000)—share the view espoused by Carel that the body is foundational to human existence and self-awareness.

Several authors propound the view that a state of being healthy is often taken for granted and is hardly taken into account until a person is confronted by an illness (Williams, 2000; Freund and McGuire, 1999; Carel, 2008; Radley, 1994). When a person is feeling well, when everything is running smoothly, and when a person is able to fulfill the expected social obligations—for example, occupational obligations, home duties either as parents or spouses, or leadership and membership obligations of a social group—then it is rarely the case that individuals think about their bodies. Additionally, when an individual is able to fulfil the reciprocity expectations of social interactions—for instance, visiting with friends, and attending social gatherings and other social occasions—an individual rarely gives due consideration to the body. It is only when the seamless harmony and the normal bodily functioning is disrupted through a drastic event, such as in the case of an illness, that consciousness of the existence of the body becomes vivid. It is then that the body becomes the center of focus (Carel, 2008; Freund and McGuire, 1999; Nettleton, 2006; Radley, 1994).

The kind of impact an illness is likely to have on a person's taken-for-granted realities depends to a large extent on whether the illness is acute or chronic (Radley, 1994). An acute illness is usually of sudden onset, peaks very rapidly and similarly comes to an end quickly. Therefore, even though an acute illness may lead to some physical discomfort and disruption of daily life routines, it is a condition from which quick recovery is expected and as such is not considered problematic to the self (Carel, 2008; Conrad and Bury, 1997). In contrast, chronic illness is of longer duration; often lasting as long as the person with the condition lives. Consequently, chronic illnesses, by virtue of their trajectory, have more profound and life-long impact on the taken-for-granted realities and meanings of everyday life (Bury, 1982; Charmaz, 1983; Nettleton, 2006; Radley, 1994).

HIV has been transformed from a death sentence to a chronic condition due to the development of highly active antiretroviral therapy (HAART) (Campbell *et al.*, 2011; Gilbert and Walker, 2009; Li *et al.*, 2010; Slomka *et al.*, 2013). As opposed to the time before the large-scale availability of HAART, when HIV was considered a ticket to immediate or imminent death, HIV is now a manageable condition with which a person can live for a long time. With an increasing number of people presently living with HIV, more being infected and fewer dying from the condition due to access to life prolonging ARVs, the challenge facing public health and health promotion is how to ensure for this special group an acceptable atmosphere in which they can "reach a state of complete physical, mental and social wellbeing" (Skolnik, 2008). Even though it may not be possible to have full physical health compared to before getting infected or even being diagnosed HIV positive, efforts still need to be made so as to assure as comfortable a life as possible for PLHIV. As Kaplun-Le Meitour (1992:xiv) nicely put it: "The chronically ill person has a need, and indeed a right, to receive the kind of support that will enhance these other values. This involves a change in our perceptions of illness, in our attitudes, and requires the use of health promotion approaches."

Living with HIV—like with any other chronic disease—brings with it an array of emotional, social, economic and physical changes and difficulties which challenge the routine, taken-for-granted realities of everyday life (Anderson *et al.*, 2009; Charmaz, 1983; Liamputtong *et al.*, 2012; Russell and Seeley, 2010; Wekesa and Coast, 2013). Chronic illnesses give rise to problems of a social, interactional and existential nature. These difficulties may call for a review of one's life priorities, relationships, occupation, and identity. Some of the results of such a review may lead to PLHIV leading restricted lives, experiencing social isolation, being discredited, or being a burden to others . Additionally, living with a chronic illness may lead to a loss of identity; necessitate the need to create new concepts of identity after onset of illness; and force and individual to seek ways of coping with the newly arisen identity (Asbring, 2001; Charmaz, 2002; Crossley, 1999; Radley, 1994).

In summary, chronic illnesses trigger self-identity crises and an urgent need for renegotiation of new selves (Asbring, 2001; Charmaz, 2002; Crossley, 1999). More fundamentally, chronic illnesses challenge prior meanings individuals had about health and illness, the taken-for-granted routines of daily life and their conceptions of self (Crossley, 1999). Being diagnosed with an HIV infection therefore challenges the way one knows him or herself and makes the self vulnerable and unstable leading to a problematic situation for the PLHIV. The self becomes vulnerable due to the fact that prolonged illness carries with it a moral question with a great potential for disapproval and devaluation (Charmaz, 1983).

1.3 Theoretical Framework

Social reality that comprises of experiences, actions and events is a very complex phenomena and it is not possible for any single theoretical framework to provide an exhaustive and adequate explanation for all its dimensions. As such, this study will review two theories that are considered relevant in making sense of the experience of illness and providing a plausible account of how PLHIV make meanings of HIV and how they cope with and adapt to an HIV positive status. These theories are the Symbolic Interaction Theory and the Chronic Illness Trajectory Model proposed by Corbin and Strauss.

1.3.1 Symbolic Interaction Theory

The experience of illness is the social reaction to disease conditions and is culturally and socially constructed and is thus specific to a given cultural and social context (Freund and McGuire, 1999; Nettleton, 2006; Radley, 1994). As opposed to acute illnesses, chronic illnesses such as HIV/AIDS have a longer time dimension and are likely to comprise part of an individual's biography or life world as long as the individual lives. The prominence of a chronic illness in a person's daily life varies throughout the lifespan and depends to a large extent on how the illness affects the ability of the ill individual to fulfill his or her social roles and to participate in social interaction and social activities. Since illness is a social experience, it is part and parcel of social happenings and is necessarily impacted by the social interaction process (Carel, 2008; Freund and McGuire, 1999; Nettleton, 2006; Radley, 1994).

Symbolic interactionism is an attempt to explain how people collectively construct or create meanings of things, events, actions, experiences and conditions such as illness through the process of social interaction. It also looks at the process of how social actors attach meanings to their actions and experiences and those of others and how these meanings are learnt. The meanings are conveyed through symbols which have a tangible existence. These tangible phenomena include language, words, sounds, posture, feelings, attitudes, color, movement or taste which are imbued with meaning by a certain group of people or to which a name or value is given. Symbols that are commonly shared among a certain group of people are thus necessary for communication or social interaction. The absence of commonly shared meanings would make interaction confusing—if not utterly impossible (Ferrante-Wallace, 2013; Newman and O'Brien, 2010).

Symbolic interaction theory has three basic premises that were formulated by Herbert Blumer (Ritzer, 2003). The first premise argues that people relate to and react to situations, experiences, actions and objects according to the meanings that these have for them (Ferrante-

Wallace, 2013; Ritzer, 2003; Wallace and Wolf, 2005). HIV may therefore mean different things to different people based on the meanings different people attribute to HIV. For example, the literature shows that HIV may be viewed as a death sentence or as biographical disruption which alters the meanings of taken-for-granted assumptions about social reality and social relationships (Anderson *et al.*, 2009; Russell and Seeley, 2010; Wekesa and Coast, 2013).

The second premise postulates that “the meaning of things arises out of the social interaction one has with one's fellows” (Ritzer, 2003). Meanings of things or illnesses are socially constructed through the process of social interaction as one engages with members of one's community or group. The meanings people have concerning objects, experiences, actions and other social phenomena and physical objects are not ingrained in the things themselves. Instead, these meanings are outcomes of a common interaction process which people engage in through the medium of symbols such as language (Ferrante-Wallace, 2013; Ritzer, 2003).

As people engage interact with others, they actively attribute meanings to the words, the actions and gestures of their interaction partners and tune their responses based on these interpretations. In other words, an active engagement with the interaction partner ensues to the extent that all that is said, how it is said and the accompanying body language are all taken into account to interpret and make a meaning out of each other's communications. This process generates a sort of negotiated or constructed reality. In its attempts to understand social reality, symbolic interaction perspective concentrates on the interactions of the members of society at the micro-level; that is at the level of everyday social encounters between individuals either as simple pairs or as groups (Newman and O'Brien, 2010).

The third and final premise holds that individuals deal with the meanings and change them through engaging in an interpretive process. All the things that confront individuals like chronic illness are responded to through the meanings that they have for the concerned individuals. However, people do weigh their options and make decisions on how to react based on a delicate balancing act. In deciding on a course of action, individuals define the most suitable outcome and the goal to be achieved even though this may not necessarily be the most logical or best outcome (Ferrante-Wallace, 2013; Newman and O'Brien, 2010; Ritzer, 2003). So, if for example, HIV is seen as a condition that confers stigma and leads to isolation and discrimination, people diagnosed with HIV will adopt practices that tend to conceal this fact.

The meanings attributed to experiences, illness and events are however not static or permanent. They are dynamic and with changed circumstances, they can also be changed. And the meanings associated with HIV are not any different. PLHIV may also seek to negotiate these meanings because over time, concealing one's identity becomes difficult. Through campaigns aimed at behaviour change and stigma reduction, the meanings held by communities are challenged and often new meanings emerge. Similarly, because more knowledge and more interventions such as Highly Active Antiretroviral Therapy (HAART) are available, HIV is transformed from a condition associated with quick death to a chronic condition. As a chronic condition, one can live for a long time with HIV while enjoying a relatively good quality of life. As a result, the image of HIV has changed and is increasingly being viewed as other chronic conditions.

1.3.2 Applicability of Symbolic Interaction Theory

This theory was deemed applicable because the purpose of the study was to establish the meanings that PLHIV attribute to their HIV positive status. Due to the proposition by symbolic interactionism that meanings are socially shared and constructed, this study expected that the meanings of HIV held by PLHIV would reflect to a large extent, the socially shared meanings concerning HIV. Similarly, since meanings have a bearing on reactions to the illness, responses by PLHIV were expected to be largely informed by how they interpreted the socially held meanings of HIV. Given that symbolic interactionism views individuals as creative agents capable of negotiating their own meanings and constructing their own definitions of the situation, the different individuals were presumed to have different definitions that were likely to be reflected in differential responses to life with HIV.

Meanings and responses may also vary based on social and demographic characteristics such as gender, age, level of education, occupation and place of residence—whether urban or rural. Variations in meanings could also be based on various groupings. For example, health care professionals may have meanings that may be at variance with that of PLHIV due to the fact that they represent different world-views. However, it was expected that the differences would not vary greatly between individuals who shared the same social environment. It was therefore expected that commonality of social context would lead to similar socially-defined meanings of HIV. Additionally, the fact that PLHIV interact within the context of social support groups, their responses and strategies of coping were generally expected to reflect a common pattern without necessarily being exactly identical.

1.3.3 Illness Trajectory Model

The illness trajectory model was developed by sociologists Juliet M. Corbin and Anselm Strauss and was the result of over 30 years of scientific studies in medical and nursing practice settings (Kirkevold, 2002; Robles-Silva, 2008). It emerged as a product of research work on the dying process and was fine-tuned with varying sets of patients in a variety of contexts. Although it was initially based on a study of cancer patients, it has been applied to the study of other chronic diseases such as diabetes, heart disease, multiple sclerosis and the aging process, and also HIV (Kirkevold, 2002; Nokes, 1998; Robles-Silva, 2008).

An illness trajectory is a theoretical framework which advances the idea that chronic illness progresses through a course or path that varies with the passage of time. It includes the actions undertaken by the patient, the patient's family or caregivers and health care professionals in helping manage the chronic conditions through its course (Kirkevold, 2002; Corbin and Strauss, 1992). The Corbin and Strauss trajectory model encompasses both the bodily manifestations, also known as disease, and the social experiences of the conditions conceptualized as illness. Disease or bodily manifestation is the objective reality of the chronic condition and includes its effects on the body and the accompanying symptoms. The illness aspect of the condition refers to the subjective experiences, the social aspects and the responses to the disease (Corbin and Strauss, 1992; Kirkevold, 2002; Lindsay, 2009).

The nature of the illness trajectory changes based on the severity of symptoms and physical impact of the disease on the body. It is characterized by moments when symptoms become severe and physiological conditions deteriorate. There are also likely to be moments of trajectory stability when symptoms abate or are relatively absent (Corbin and Strauss, 1992; Lindsay, 2009). The trajectory can be influenced by various factors among them the health status of PLHIV, family or individual socio-economic conditions, the social environment, the political environment, and a person's conceptions of self and emotional status (Lindsay, 2009).

The illness trajectory model postulates that illness is marked by eight (8) different phases (Table 1-1). Each phase is characterized by specific changes and difficulties with which the patient, his caregivers and the medical care system need to contend or to cope (Corbin and Strauss, 1992; Kirkevold, 2002; McCorkle and Pasacreta, 2001). The illness trajectory mainly focuses on illness management and adjustment to and coping with the various changes and challenges that occur across the illness course. These activities require the combined effort of the patient, the patient's family and the medical care system. Each of these actors helps to determine the character of the illness trajectory depending on their respective trajectory projections. Worth noting is that most of the work associated with illness is carried out by the patient and his caregivers or family members in the context of the home (McCorkle and Pasacreta, 2001; Robles-Silva, 2008). As a consequence of the different circumstances and socio-economic conditions of PLHIV, it was expected that each individual PLHIV would certainly have a unique trajectory. However, there are certain general patterns that illness trajectories assume and according to Corbin and Strauss model (Corbin and Strauss, 1992; McCorkle and Pasacreta, 2001; Robles-Silva, 2008).

The first phase, the *pre-trajectory phase*, takes place before any signs or symptoms of the illness are experienced. It takes place way before the presence of disease or illness is diagnosed. This is followed by an *onset phase, a* period when signs and symptoms of an underlying condition begin to emerge and diagnosis takes place. Discomfort, uncertainty and considerable disruption of normal life may result, requiring hospitalization or medical care. This is the *crisis phase.* The *acute phase*, which follows the crisis phase, refers to the period when medical intervention is geared towards controlling the signs and symptoms. This phase seeks among other things to prevent the escalation of symptoms or forestall the complications that may arise due to the illness. The acute phase normally occurs within the context of a hospital admission (Corbin and Strauss, 1992; McCorkle and Pasacreta, 2001).

A *stable phase* refers to the period that sets in with a successful intervention during the acute phase. This phase may however require vigilance and constant monitoring to maintain a relatively good condition of health. This, as it is in the case of HIV, may require some changes in diet, in sexual practices, in work habits and depending on CD-4 counts may require being put on a medical regimen of antiretroviral drugs (ARVs). Being put on ARVs is intended to reduce the viral load and thereby boost the immune system to enable it defend the body against opportunistic infections. Prophylactic use of antibiotics may also be prescribed to avoid opportunistic infections. Proper medical care and a healthy lifestyle have the potential for making PLHIV enjoy a longer *stable phase* in the illness trajectory. There may be many cyclic movements back and forth between the stable and *unstable phases*. An *unstable phase* may set in and this may be occasioned by inability of drugs to work effectively anymore. It may also be as a result of lack of adherence to medical regimens or engagement in unhealthy practices such as alcoholism, use or abuse of drugs, and engaging in unprotected sexual intercourse with multiple partners (Corbin and Strauss, 1992; McCorkle and Pasacreta, 2001).

The condition of the ill person deteriorates after sometime as the person's physical and mental health worsens to a point that recovery is no more possible or realistic. This is the downward *phase* from which one may not recover. The downward phase gives way to the *dying phase* that could be as long as a few hours or longer, but theoretically refers to the last moments before death (McCorkle and Pasacreta, 2001). The model is presented in Table 1-1.

Table 1-1: Chronic illness trajectory model developed by Corbin and Strauss

	Trajectory Phase	**Definition/Meaning of Phase**
1	Initial (Pre-trajectory)	No signs or symptoms are present
2	Trajectory onset	First signs and symptoms appear (including the diagnosis)
3	Crisis	A potentially life-threatening situation occurs (e.g. conditions requiring emergency care)
4	Acute	Symptoms require control with a prescribed regimen
5	Stable	Symptoms are managed and controlled
6	Unstable	Symptoms become uncontrollable by previously adopted regimen
7	Downward	Mental and physical status deteriorates
8	Dying	Death is preceded by a period of days, weeks or hours

(**Source**: McCorkle and Pasacreta, 2001)

1.3.4 Applicability of the Illness Trajectory Model

The illness trajectory model is based on the premise that chronic illness is a life-long experience that progresses through a particular path or course throughout the ill person's life. It proposes 8 phases across the illness course and describes this as the likely experience of everyone who acquires an incurable chronic illness such as HIV/AIDS. HIV has a pre-trajectory phase when illness is present but is not yet known to the infected person due to lack of signs and symptoms or because one has not been exposed to a condition such as hospitalization for other causes that may require ascertaining ones HIV status. Then, depending on how one gets to know about their status, there will be an onset phase when signs and symptoms begin to emerge and diagnosis is sought. The principal investigator (PI) expected that diagnosis would likely lead to a crisis phase to which different people were expected to react differently. Due to the effect of opportunistic infections there will be an acute phases that can be overcome through provision of adequate medical care and other forms of care and support such as nutritional supplements leading to a stable phase (Corbin and Strauss, 1992; Kirkevold, 2002; McCorkle and Pasacreta, 2001; Robles-Silva, 2008).

Due to ARVs, patients may have stable phases that can last as longs as 15 years or more. Occasional episodes of relapse into illness leads to unstable phases. However a person may recover from an unstable to a stable phase. As postulated in the trajectory model, there is an oscillation between stable and unstable phases as one falls ill and recovers over and over again. HIV also has a downward stage when medication is no longer able to keep away opportunistic infections. Finally, depending on a number of variables, a PLHIV succumbs to opportunistic infections in the dying phase—which can last from a few weeks to a number of months. As is postulated in the trajectory model, there are implications for the trajectory from contributions and efforts of the patient, the family members and other caregivers and the medical services providers (McCorkle and Pasacreta, 2001; Nokes, 1992).

The contribution of PLHIV in attempting to determine how his/her illness progresses through the choice of coping strategy and other illness related work is fundamental as this acknowledges the critical role played by the ill person as postulated in the model. The acknowledgement by the model that the medical service providers and family members play a significant role in an illness trajectory emphasize the social nature of the experience of chronic illness. Through the objective on difficulties faced by PLHIV, the PI expected to identify events, occurrences or circumstances that could impact negatively on the illness trajectory. How long one stays in the stable phase and ability to recover from an unstable phase was expected to be critical in ensuring that one is able to effectively perform their social roles and thus remain with a relatively strong conception of self. Therefore, it was expected that as long as PLHIV were still in a stable phase, they would experience a positive conception of self. Difficulty to overcome an unstable phase or a slide into the downward phase was expected to account for a diminished sense of self.

Through the trajectory model, the PI hoped to describe the experiences of PLHIV through their illness trajectory. Since the study was interested in describing accounts of PLHIV mainly from the PLHIV themselves, it is limited to those the accounts of PLHIV who have not as yet drifted to the downward and dying phases due to ethical, logistical and time considerations. However, anecdotes of these experiences were gleaned from the interviews with key informants and from focus group discussions (FGDs) during data collection.

1.4 Epidemiology and Dynamics of HIV/AIDS

1.4.1 Global HIV Statistics

Since its emergence some 30 year ago, HIV has become one of the main causes of human morbidity and mortality worldwide (Mayer and Pizer, 2000; Schneider and Lilienfeld, 2011). It is estimated that since the beginning of the HIV/AIDS pandemic, an estimated 78 million (71 million – 87 million) people have become infected with HIV and that about 39 million people have so far died of AIDS-related causes (UNAIDS, 2014a). The number of people living with HIV (PLHIV) is however still increasing (World Health Organization, 2012a). According to global HIV statistics, it is estimated that 35 million (33.2 million – 37.2 million) people were living with HIV as at the end of 2013 representing an increase of about 21% over the figures released for 2001 (UNAIDS, 2013, 2014b). In 2001 approximately 28.9 million people were living with HIV (UNAIDS, 2012a). The observed overall increase in the number of PLHIV over the decade has been attributed to the life-prolonging benefits of anti-retroviral therapy (ART) as well as to new infections (UNAIDS, 2011, 2012a; World Health Organization, 2012a).

Whereas the number of PLHIV continues to rise, that of those being newly infected as well as those dying due to AIDS-related opportunistic infections has shown a constant declining trend over the last decade. For instance, people newly infected with HIV in 2013 stood at an approximated figure of 2.1 million (1.9 million – 2.4 million). This represents a 38% decrease compared to 3.4 million (3.3 million – 3.6 million) recorded for the year 2001 (UNAIDS, 2014a, 2014b). Similarly, the estimated number of people who died due to AIDS-related causes at the end of 2013 was 1.5 million (1.4 million – 1.7 million) compared to 2.3 million (2.1 million – 2.6 million) in 2005 at the peak of the epidemic, a decline of 35% (UNAIDS, 2014a). Additionally, 12.9 million PLHIV eligible for ART were accessing these vital therapies representing 37% (35% – 39%) of all PLHIV globally. Whereas 38% of adults living with HIV were on ART as at end of 2013, only 24% of children living with HIV were receiving the medications (UNAIDS, 2014a).

1.4.2 Sub-Saharan African HIV Statistics

Sub-Saharan Africa (SSA) has been the hardest hit region of the world and continues to be the epicenter of the HIV/AIDS pandemic since all the indicators continue to remain high compared to other regions (UNAIDS, 2013, 2012b). Nearly 71% (24.7 million (23.5 million – 26.1 million)) of all PLHIV worldwide reside in SSA, among them 2.9 million (2.6 million – 3.2million) children (UNAIDS, 2014a, 2014b). Children living with HIV in Africa constitute

91% of the global total of children living with HIV (UNAIDS, 2014b). As with the global pattern, there were more PLHIV in SSA at the end of 2013 compared to 2001 when the figure was 20.9 million. The increase in number of PLHIV in SSA is also partly attributable to the life-prolonging ARVs and to those being newly infected. The figures for new HIV infections in 2013 (1.5 million (1.3 million – 1.6 million)) represented a 33% decline over the 2005 (UNAIDS, 2012b).

Those who died from AIDS-related causes in 2013 were estimated at 1.1 million (1.0 million – 1.3 million) which is not significantly different from the 1.2 million who died in 2001. However, AIDS-related deaths peaked in 2005 when 1.8 million deaths were reported. Compared to 2005, the deaths recorded in 2013 (1.1 million) represented a 32% decline. Despite this decline in number of deaths it still represented 64% of all deaths worldwide. Approximately 1.6 million AIDS-related deaths were recorded worldwide in 2013 (UNAIDS, 2014b). Indeed, by the mid-1990s, AIDS had gained the reputation of being the leading cause of adult mortality in SSA (UNAIDS, 2012; WHO, 2011). The 210,000 (180,000 -250,000) children newly infected with HIV in 2013 in SSA represented 90% of the new infections among children globally (UNAIDS, 2014b).

However, SSA has also made remarkable improvements in enhanced access to ART. As at the end of 2013, 37% of all people who were eligible for enrolment to ART were accessing it. The figure of those receiving ART was 57% at the end of 2011 but due to revised WHO guidelines (World Health Organization, 2013) which raised the CD4 cell count to 500cells/mm^3, the number of PLHIV eligible for enrollment to ART increased. Due to the dramatic improvement in access to ART in SSA, a drastic reduction in the annual deaths occasioned by HIV has been registered as been seen in the previous paragraph.

1.4.3 Kenyan HIV Statistics

Kenya had an estimated 1.6 million PLHIV and a national HIV prevalence of 6% (5.6% for males and 7.6% for females) as at the end of 2013 (Kilonzo *et al.*, 2014). Kenya had an approximately similar number of people living with HIV in 2013 as in 2001 (1.6 million). In 2013, an estimated 101,560 people were newly infected with HIV and approximately 58,465 deaths were recorded (Kilonzo *et al.*, 2014). By the end of 2011 an estimated 1.7 million had died of AIDS-related conditions since HIV was first diagnosed in Kenya in 1984 (National AIDS Control Council and National AIDS and STI Control Programme (NASCOP), Kenya, 2012). There exists considerable regional variations in HIV prevalence across the country. Apart from Nairobi County, five counties forming what was formerly Nyanza Province in western Kenya (Homa Bay, Kisumu, Siaya, Migori, and Kisii) have the highest HIV prevalence as well the highest numbers of PLHIV in the country. Moreover, Homa Bay, Kisumu and Siaya have what is described as hyper-active HIV prevalence of over 15% each (Kilonzo *et al.*, 2014). This information is presented in Table 1-2.

Table 1-2: Top 10 leading counties by HIV prevalence in Kenya

County	Population	Prevalence Total (%)	Prevalence men (%)	Prevalence women (%)	Adults LHIV (#)	Children LHIV (#)	People LHIV (#)	Rank
Kenya	**41,792,563**	**6.04**	**5.6**	**7.6**	**1,407,615**	**191,836**	**1,599,451**	
Nairobi	3,781,394	6.8	5.3	8.4	164,658	12,894	177,552	1
Homabay	1,053,465	25.7	23.7	27.4	140,600	19,370	159,970	2
Kisumu	1,059,053	19.3	17.8	20.6	118,500	16,326	134,826	3
Siaya	920,671	23.7	21.8	25.3	113,000	15,568	128,568	4
Migori	1,002,499	14.7	13.6	15.7	77,700	10,705	88,405	5
Kisii	1,259,489	8.00	7.3	8.5	56,000	7,715	63,715	6
Nakuru	1,825,229	5.3	4.5	7.5	53,700	7,898	61,598	7
Kakamega	1,782,152	5.9	4.4	7.3	48,500	9,452	57,952	8
Mombasa	1,068,307	7.4	4.5	10.5	47,800	6,870	54,670	9
Kiambu	1,760,692	3.8	2.0	5.6	42,400	4,256	46,565	10

(**Source**: Kilonzo *et al.*, 2014)

As of the end of 2013, when the WHO recommended point of initiation to ART was a CD4 count of 350 cells/mm^3, 78% coverage among adults was realized. However, with the revised initiation point of CD4 count of 500 cells/mm^3, the figure dropped to 63% of all who were eligible for ARVs. The revised guidelines brings more people into the bracket of those who need to be initiated on ART and thus poses an added challenge to the health care system. The case for children is even more challenging as only about 42% of those eligible are on pediatric ARVs (Kilonzo *et al.*, 2014). Kisumu County, the third leading county in terms of HIV prevalence (19%), was selected purposively because it has high prevalence levels compared to the national prevalence of 6% (Kilonzo *et al.*, 2014). The PI is also conversant with the county, having done a lot of work there and also being a native speaker of the dominant language (Dholuo), in which also the study was conducted.

1.4.4 Health indicators and Health System in Kenya

Life expectancy at birth in Kenya was estimated at 60 years, with 62 years for women and 58 years for men respectively. This showed a slight decline from 1990 when the comparable figures were 63 years for women and 59 for men. However, these figures are above the average for the WHO African Region, which is estimated at 56 year for women and 52 years for men. Life expectancy at the age of 60 for Kenya was 18 years for females and 15 years for males based on data for the year 2009 (World Health Organization, 2012b).

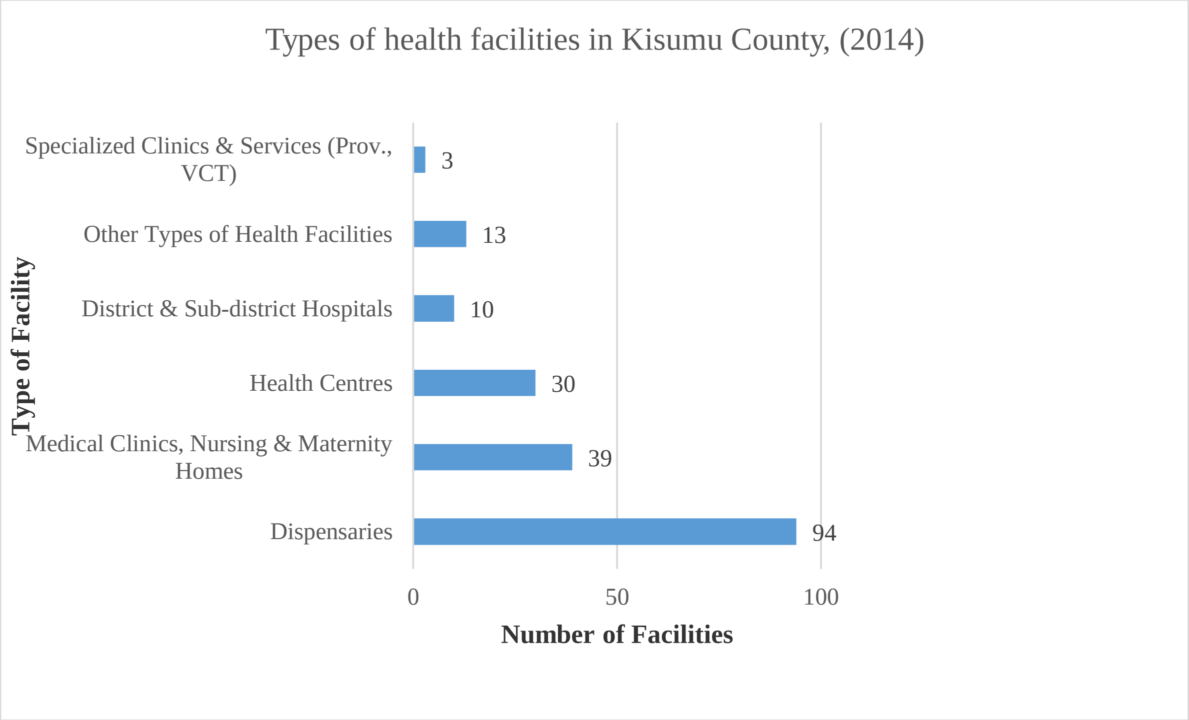
Kenya has a differentiated health system, comprising of public, non-governmental and private sector providers. At the apex of this system is the Ministry of Health (MoH), which is responsible for policy formulation, regulation and management of the national health sector. Nationwide, most health facilities are owned and operated by the Government of Kenya through the MoH, and the 47 county governments. The rest of the facilities are managed by private enterprises, Faith-Based Organizations (FBOs), Non-Governmental Organizations (NGOs) and private nursing and general practices (Ministry of Health, 2014). The national health system comprises of 3 national teaching and referral hospitals, 9 provincial general hospitals, several district and sub-district hospitals, health centers and dispensaries. A complete picture of this diversity is presented in Table 1-3.

Table 1-3: Health care facilities in Kenya and Kisumu County by type of facility

Facility Type	**National**		**Kisumu County**	
	n	**%**	**n**	**%**
Dispensaries	4477	49.6	94	49.7
Medical Clinics, nursing & maternity homes	2597	28.8	39	20.6
Health centres	957	10.6	30	15.9
District & sub-district hospitals	412	4.6	10	5.3
Other types of health facilities	282	3.1	13	6.9
VCT stand-alone	173	1.9	1	0.5
Specialized clinics & services	108	1.2	1	0.5
National referral & provincial hospitals	12	0.1	1	0.5
Total	**9018**	**100**	**189**	**100**

(**Source**: Ministry of Health, Kenya, 2014)

In Kisumu County there are a total of some 189 health care facilities. The main health care providers in Kisumu County are the County Government (87), NGOs (15), Private entrepreneurs (26), FBOs (15), Government parastatals (6), and communities (3). Besides the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) which is located at the Kisumu city, and also serves as a regional referral hospital, there are 3 district hospitals, 7 sub-district hospitals, 30 health centers, 94 dispensaries, 33 medical clinics, 6 nursing homes and 11 privately run hospitals respectively (Ministry of Health, 2014). Figure 1-1 details the multiplicity of health care providers in Kisumu.



(**Source:** Ministry of Health, Kenya, 2014)

Figure 1-1: Health care facilities in Kisumu by type and number, 2014

1.5 How PLHIV learn about and make Sense of HIV

How PLHIV cope is more than just a matter for the person to decide. It requires social support in both a material and emotional sense. Since life is lived not in isolation but in society with others, there is definitely going to be an element of social considerations in decisions that a person makes. Moreover, due to the overwhelming and disruptive nature of

HIV and AIDS, there are going to be several points in the lives of PLHIV where they will need to rely on social support.

Extremely distressing occurrences as exemplified by a chronic illness are potentially disruptive to the life of an individual. This is especially so with regards to the basic questions of being like concepts of morality, time and how people make sense of things. Consequently, a person trying to adapt to a chronic illness is confronted with basic difficulties of trying to construct an account that can make the experience not only meaningful to themselves but which can also be used to give a convincing description of the same to those with whom one interacts (Carel, 2008; Crossley, 1999; Williams, 2000). The fundamental difficulty people diagnosed with chronic illness face is to attribute an intelligible explanation and through this understanding of illness to regain one's sense of bearing and return to what can be considered a normal state of being (Crossley, 1999). In this section, literature is reviewed that deals with how a person learns about their HIV status, initially reacts to a positive HIV diagnosis and reconciles to the reality of being HIV positive.

1.5.1 How PLHIV learn about their Status

To be able to know about one's status as a HIV positive, contact with the medical professionals is necessary (Radley, 1994). In a WHO/UNAIDS supported international multi-site study that examined household and community reactions and responses to HIV and AIDS in developing countries, it was found that the greater number of people knew their status after visiting health facilities (Singhanetra-Renard *et al.*, 2001). The study was conducted in Tanzania, India, Thailand, Mexico and the Dominican Republic. In another study exploring the experiences of women living with HIV and AIDS who had participated in drug trials in Thailand, Liamputtong *et al.* (2012) found that most got to know about their HIV status as a result of coming into contact with health services.

As empirical findings show, getting to know about the existence of a chronic illness—in this case HIV—comes after episodes of illness and after one has been admitted to hospital or received medical attention (Radley, 1994). Research indicates that deliberate decisions to seek medical attention or to go for a check-up could be made after a person experiences disturbing symptoms, after recurring ill-health or after death or illness of a partner. In such cases, one gets to know their HIV status after experiencing severe attacks that necessitates a hospital admission. Due to these recurrent illnesses, doctors will often recommend routine tests to be done. On the basis of the test results, doctors then make a diagnosis as a way of establishing the facts about the attacks. These recurrent and unexplainable illness can thus be strong triggers to the desire to know one's HIV status (Morin *et al.*, 2006; Jürgensen *et al.*, 2012; Nyamathi *et al.*, 2011; Tarakeshwar *et al.*, 2006). These WHO/UNAIDS study showed that the main complaints were recurring headaches, diarrhoea or fever that could not be accounted for. Due to failure of the medical interventions thus far undertaken, a blood test was recommended. Subject to a positive diagnosis, the people were informed that they had acquired HIV and were referred to other hospitals for care (Singhanetra-Renard *et al.*, 2001).

Research seems to suggest some gender differentials in HIV testing behaviour. A good number of women got tested while in search of prenatal care or pregnancy-related services where they were subsequently diagnosed (Anand *et al.*, 2009; Liamputtong *et al.*, 2012; Maman *et al.*, 2014). A good number of women also chose to go for testing after their husbands fell ill and through this initiative got to know of their status (Liamputtong *et al.*, 2012; Singhanetra-Renard *et al.*, 2001). Men, on the other hand, tend to be admitted while in need of emergency medical care resulting from motorcycle accidents. Similarly, men, especially those who worked far away from the matrimonial home, went to take the HIV test after being urged by their wives who suspected marital infidelity believing that their husbands had had contact with sex workers during their absence from home (Liamputtong *et al.*, 2012; Singhanetra-Renard *et al.*, 2001).

Literature further indicates that people also get to know their status as a result of check-ups and medical examinations not directly related to specific illness episodes. Typical examples are when mothers visit an ante-natal clinic as part of routine procedures and are subjected to an HIV test. In this case, the knowledge of HIV status results not from an illness episode requiring medical attention but a routine check-up as part of the delivery process (Liamputtong *et al.*, 2012; Maman *et al.*, 2014; Singhanetra-Renard *et al.*, 2001; Tarakeshwar *et al.*, 2006). In a qualitative study with 21 HIV-infected adults whose purpose was to understand Chinese people's experiences of living with HIV/AIDS, Zhou (2009) found that the respondents knew their status when they underwent testing related to either blood donation or prior to some medical procedures such as surgery. In a study carried out in Thailand, some women got to know their HIV status when they sought health care for other interventions like the case of one female participant who underwent surgery to remove a lump in her breast (Liamputtong *et al.*, 2012).

Health promotion campaigns aimed at encouraging people to be counseled and tested is another medium through which a person can get to know their HIV status (Butler-Kisber, 2010; McArthur *et al.*, 2013; Rapport, 2005; Tarakeshwar *et al.*, 2006). Public health campaigns are mostly done in the context of mobile VCTs or through home-based counseling and testing (HBCT) where NGOs or CBOs involved in HIV activities with the support of community-based health workers visit homes to help scale-up testing and counseling. People tested in these forums are referred to integrated health facilities where they can be enrolled into ART and routine medical care.

Ignorance and other factors operating at the societal, institutional, and individual levels can delay diagnosis with regard to HIV. Some of the factors that act as barriers to HIV status knowledge include stigma and discrimination, lack of resources to access testing sites, distance to health facilities, and fear of knowing status or bliss of ignorance (Gardner, 2013; Goudge *et al.*, 2009; Ncama, 2007; Tarakeshwar *et al.*, 2006). According to the UNAIDS (2014b), more than half (52%) of people infected with HIV are not aware of their status. With the threat of new HIV infections annually, it is important that as many people as possible get to know their status. However, sometimes ignorance about once HIV status is due to misdiagnosis or reluctance to be tested on the part of the people. An interview-based study conducted in a metropolitan city in north China in 2004 by Zhou (2009) revealed that there were initial misdiagnoses due to physicians' lack of knowledge of HIV/AIDS. Due to these inappropriate diagnoses, it was not easy to initiate early medication and care. Instead, the PLHIV were initially treated for other conditions.

Therefore as we have seen above, people get to know they are HIV positive through a variety of ways. These can either be as a result of a deliberate and conscious choice triggered by unexplained and recurring episodes of illness, death or illness of a spouse or through health promotion campaigns advocating uptake of counseling and testing services for HIV. It can also result from provider initiated processes such as pregnant mothers visiting ante-natal clinics or someone requiring emergency surgery or blood transfusion. The knowledge of one's HIV status may trigger varied responses. The next sub-section presents literature on the various ways in which people reacted to a positive HIV diagnosis.

1.5.2 Initial Reactions to a HIV-Positive Diagnosis

The process of adapting to or incorporating an HIV positive identity into the self in a majority of cases begins with a diagnosis and different individuals react differently to an HIV positive diagnosis (Baumgartner and David, 2009; Baumgartner, 2007; Gardner, 2013; Russell and Seeley, 2010; Tsarenko and Polonsky, 2011). In a qualitative study on the experiences of Finnish older adults living with HIV involving 8 interviews, Nobre, et al. (2012) reported that individuals reacted with shock, contemplations of death, fear of their status being known by others, and resorting to alcohol while others expressed no shock at all. Almost similar findings were reported in other studies conducted in different settings (Baumgartner and David, 2009; Baumgartner, 2007; Liamputtong *et al.*, 2012).

As has been mentioned above, the most common reactions to a positive HIV diagnosis reported in most studies are feelings of shock, fear, amazement, denial and suicidal feelings (Anderson *et al.*, 2009; Baumgartner and David, 2009; Baumgartner, 2007; Liamputtong *et al.*, 2012; Ribeiro Nobre *et al.*, 2012). For instance, in a study by Baumgartner and David (2009), which involved interviews with a purposive sample of 14 adults ranging in years from 25-52 in the United States and who had been diagnosed with HIV for between 7 to 12 years prior to being interviewed, the main initial reactions were shock, fear, denials, sadness and fatalistic attitudes. Among these reactions, shock was the most typical being reported by 9 out of 14 interviews. In an earlier study by Baumgartner (2007), 10 out of 11 PLHIV responded with shock, denial, and fear. Only one respondent reacted with a sense of being relieved. In this study by Baumgartner (2007) as in the one already mentioned, shock was the most frequent reaction.

The reasons for expressions of shock could be due to the fact that the diagnosis was not expected and the participants could not come to terms with how this came to be. In one qualitative study exploring the experiences of women living with HIV in Thailand, Liamputtong *et al.* (2012) found that the reactions of shock, fear and thoughts of committing suicide were due to the fact that the women did not expect such a diagnosis. It was also due to the certainty that they did not engage in behaviours that could expose them to HIV infection. They were therefore angry that this could happen to them. Other reasons that the women mentioned is the perception of HIV as a death sentence in Thailand coupled with the fact that HIV has no cure (Liamputtong *et al.*, 2012).

Fear was another common reaction mentioned in some of the studies. In one study, seven women participants reported being afraid despite the fact that they did not consider a positive HIV diagnosis to be a death sentence (Baumgartner and David, 2009). Other participants reacted with fear because they thought they faced imminent death (Liamputtong *et al.*, 2012) while others linked their fears to expectations of being stigmatized (Baumgartner, 2007). Sadness was for others an initial reaction whereas two individuals reacted with an attitude expressive of fatalism (Baumgartner and David, 2009). Thoughts of committing suicide and actual attempts to do so were also reported in some studies. In a study among women living with HIV in Thailand, one female participant in attempting to take her life "jumped from the second floor of her house..," however, she survived the fall (Liamputtong *et al.*, 2012).

Another reaction that was reported in the literature is denial that often expressed itself in the form of an attempt by some participants just trying to push this knowledge into the back burner while others thought they had a bad dream from which they would wake up normal (Anderson *et al.*, 2009; Baumgartner and David, 2009; Gardner, 2013; Tsarenko and Polonsky, 2011). In another study, conducted by Baumgartner (2007), denial affected some of the study respondents and lasted for periods ranging from as short as six months to long periods of up to five years. Some participants using drugs or resorting to alcohol. Those who resorted to alcohol were trying to find a way of escaping the reality of their diagnosis. Others simply tried to continue with their lives as though nothing had happened (Anderson *et al.*, 2009; Baumgartner and David, 2009; Baumgartner, 2007).

Some studies reported apparently astounding findings in the sense that some respondents indicated having no feelings of shock or fear given their positive diagnosis with HIV. Contrary to expectations, they reacted with relief or with a relaxed attitude devoid of much emotion (Baumgartner, 2007; Ribeiro Nobre *et al.*, 2012). Among the 8 respondents in the study by Ribeiro Nobre *et al.* (2012), three did not express feelings of being shocked by the diagnosis. They had expected such an outcome since they narrated having lived sexually risky lives which might have exposed them to HIV infection and so they somehow expected a positive diagnosis. Hence when they got the results, the outcome did not come as a surprise to them.

It is normal for people diagnosed with a chronic illness not to immediately accept the outcomes of diagnosis especially where they feel they have not engaged in behaviours that can predispose them to such an illness. These reactions are not totally unexpected among people diagnosed with chronic illness since such a diagnosis heralds the onset of a life-changing event perceived as an undermining of the life-course (Newbould *et al.*, 2006). This experience is referred to by Bury (1982:169) as a "biographical disruption" for it interrupts the smooth flow of a person's life trajectory. A chronic illness such as HIV can be considered a "biographical disruption" since it causes a breach in a person's sense of reality and the taken-for-granted notions such as health functioning of the body (Bury, 1982; Freund and McGuire, 1999; Nettleton, 2006). The next sub-section contains a review of the how people diagnosed with HIV reconcile themselves to such a diagnosis and accept their status.

1.5.3 How PLHIV reconcile to and accept a Positive HIV Status

The theoretical and empirical literature reveals that a person diagnosed with a chronic condition such as HIV contends with a number of difficult questions. Such questions may have to do with why the tragedy has struck them, and the timing of the tragedy. As has been seen from the literature review on initial reactions, a person diagnosed as HIV positive is likely to doubt and subsequently deny the test results. They may also be concerned with how and from where they acquired the virus and what others may think about them. The impact of their positive status on their family members and how they would be able to manage in their new situation are also likely to be serious concerns All the concerns arise in an attempt to come to terms with the diagnosis and work out a way of rationalising this reality in order to continue with life as normally as possible. After reality sinks in, however, one gradually comes to accept this condition (Bury, 1982; Carel, 2008; Freund and McGuire, 1999).

When a person initially experiences strange feelings in the body that may signify underlying physical problems or ailments, the first reaction may include adoption of a wait-and-see attitude to observe whether the symptoms are serious. However, when the problems persist and cause sufficient physical discomfort or makes the fulfilment of social obligations difficult or impossible, the affected personally may either decide personally or be urged by significant others to seek medical attention. Depending on the severity of symptoms, the moments before seeking care may be characterized by varying emotional states such as anxiety, stress, worry, fear, and doubt. However, when a person gets a diagnosis, the fears or anxieties are either resolved or heightened depending on the outcomes. A diagnosis can either confirm a person's worst fears or bring a sense of relief (Carel, 2008; Freund and McGuire, 1999; Nettleton, 2006).

In a synthesis of the common features of chronic illnesses based on research findings, (Nettleton, 2006) argues that what stand out are the degree the illness has and the person’s life world are intertwined and its effects on the individual’s perception of self. According to Nettleton, chronic illnesses are “characterized by uncertainty, which begins prior to the initial diagnosis of the disease and continues throughout a person's illness career,” and “involves a considerable amount of work to develop strategies for coping with the emotional and practical consequences of the disease.” What appears to be a crucial point is that “it reminds us of the extent to which we rely on our body and of its significance in social interaction” (Nettleton, 2006).

Some studies on experiences of illness reveal that people recount or make sense of their illness within the context of their life stories or biographies (Bury, 2001; Williams, 2000). The chronic illness experience is represented as being incorporated in the life stories and mirrors the life experiences of individuals suffering from such illnesses. These stories of illness embedded in life accounts are referred to by Kleinman (1988) as illness narratives. According to Kleinman, an illness narrative is:

> A story the patient tells and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narratives are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating these meanings...The personal narrative does not merely reflect illness experience, but rather contributes to the experience of symptoms and suffering (Kleinman, 1988).

Other perspectives conceive of chronic illness as biographical disruption (Bury, 1982). This is because besides chronic illness interrupting ones physical body, it also “disturbs...the trajectory of one's whole life at a number of levels” (Nettleton, 2006). Levels of an individual's life that are disrupted according to (Bury, 1982) are “the taken-for granted assumptions and behaviours…” Chronic illness accordingly results in “profound disruptions in explanatory systems normally used by people such that a fundamental rethinking of a person's biography and self-concept is involved” and “there is a response to disruption involving the mobilization of resources in facing an altered situation” (Bury, 1982).

The process of reassessment of one's life according to (Nettleton, 2006), can involve one of two outcomes. The reassessment can either lead to a “loss of self” or “it also can serve as a turning point in life which can involve a changed identity” (Nettleton, 2006) Biological disruptions can also be associated with positive outcomes. This is because according to (Nettleton, 2006), “it can initiate a rethinking about the direction on a person's life, it can mean that the sufferer may become a more insightful person, and it may result in new opportunities never before imagined.”

Reconciling to a chronic illness should be conceived of as a complex and multifaceted process through which a person diagnosed with such an illness proceeds in order to come to terms with and incorporate the illness experience into his/her life. As such, it is probable that this process begins well before a positive diagnosis is given but takes a more noticeable form when a diagnosis is confirmed. Diagnosis provides a turning point in the sense making process. After the reality sinks in and one comes to terms with the fact that the diagnosis is true, the next stage is to work out ways of how to live with this condition.

As a way of transition from the initial reactions of being diagnosed HIV-positive, Baumgartner proposes a “post-diagnostic turning point” as a bridge to adaptive coping which she calls “integration.” This post-diagnostic turning point is proposed to be an invaluable link in the chain of incorporation of an HIV positive identity into the self. In the post-diagnosis phase, the PLHIV maps out the coping strategies that will make it possible for him/her to incorporate HIV into the self. This post-diagnosis turning point can be triggered off by meeting and sharing with other PLHIV, receiving support and acceptance from others, receiving medical attention or encountering a life-threatening disease, and receiving proper and accurate information about HIV such as that being HIV positive does not necessarily mean imminent death (Baumgartner and David, 2009; Gardner, 2013; Medley *et al.*, 2009; Wekesa and Coast, 2013). In their study with 14 PLHIV in the United states of America, Baumgartner and David (2009) reported that 9 of the respondents found sources of support to live with HIV identity from both the community of PLHIV as well as from outside this community.

1.6 Effects of HIV on the Lives of PLHIV

As has been discussed in the previous section, chronic illness such as HIV/AIDs can cause disruptions in a variety of ways to individuals. The disruptions, according to (Hyden, 1997), can be in the assumptions that people hold and in behaviours and people’s explanatory systems. The disruptions may require a rethinking of biography and self-concept in response to the disruption. According to Söderberg *et al.* (1999), problems common to chronic illness include their long duration and the altered life conditions, which may necessitate transitions or changes in all aspects of social life of the ill person. In a study on disruptions in the lives of women living with chronic fatigue syndrome and fibromyalgia, Asbring and Närvänen (2002) concluded that people with chronic illness suffer from loss of identity and are constrained to create new notions of identity after onset of illness. These notions relate to how they come to terms with their newly arisen identities.

Among the key findings in their study, Asbring and Närvänen (2002) reported that the illnesses involved a radical disruption in the women’s biography that had profound consequences for their identity particularly in relation to their work and social lives; that biographical disruptions are partial rather than total, calling for different degrees of transformation; and that many of the women also experienced illness gains in relation to the new identity. A study by Millen and Walker (2001), revealed that a positive HIV diagnosis necessitates an “involuntary, irreversible and undesirable status passage” among affected individuals leading to corresponding alterations in self-identity. In this section, both conceptual and empirical literature is presented relating to the effects of HIV on the social relationships, capacity to fulfil social obligations, and perception of self of people diagnosed and living with HIV.

1.6.1 Effects on Social Relationships

Man is a social being and as such, spends most of his life in the company of others. People belong to various social groups which can be of a primary or a secondary nature. *Primary groups* are those in which people maintain close face-to-face interactions with each other (Ferrante-Wallace, 2013; Wallace and Wolf, 2005). A number of studies have found links strong between social networks and social support with several benefits for people experiencing adverse circumstances such as life with a chronic illness (Dageid and Duckert, 2008; Dlamini *et al.*, 2007; Makoae *et al.*, 2008). In a literature review concerning the benefits of social support for PLHIV, Zhang *et al.* (2009) found that social support had the potential of boosting the immunity and delaying development of full-blown AIDS. Social support also made it possible for PLHIV to take up active coping strategies and improve adherence to medication. Moreover, social support was found to enhance psychological well-being and mental health besides improving the general quality of life of PLHIV and reducing the impact of stigma and rejection (Zhang *et al.*, 2009). However, when one is ill with a chronic and terminal illness such as HIV, the social support and strong social networks that are necessary for a good quality of life are not always forthcoming.

Among the effects of HIV on one's social self are exposure to discrimination, stigmatization and social exclusion (Dlamini *et al.*, 2007; Majumdar and Mazaleni, 2010). Some of the stigmatizing attitudes reported in the literature directed at PLHIV included apportioning of blame, insults, avoidance and accusations as well as hostility (Nattabi *et al.*, 2012). Being HIV positive may also result in one being subjected to discrediting definitions of the self, social ridicule, being laughed at and judgmental attitudes. For instance, in a study conducted among PLHIV in South Africa, PLHIV were referred to as prostitutes, and as “walking corpses” or “slow poison” (Dlamini *et al.*, 2007; Majumdar and Mazaleni, 2010). Social relationships may also be strained thus leading to denial of individual rights, being abandoned, separation or being socially excluded by family members or spouses (Nattabi *et al.*, 2012).

Other possible consequences of HIV on social relationships may include rejection, verbal abuse and dependence upon others (Dlamini *et al.*, 2007; Majumdar and Mazaleni, 2010). In a study conducted in Thailand among HIV positive women, Liamputtong *et al.* (2012), reported that one respondent received a rejecting treatment from the mother when she let her know of her HIV status. The mother stopped talking to her and tried as much as possible to avoid her. She was also made to use separate utensils from the rest of the family and to eat in a separate room. Additionally, she had to use separate facilities for washing her clothes.

In another study involving 9 PLHIV and 9 direct informal caregivers in rural areas of Eastern Cape Province of South Africa, Majumdar and Mazaleni (2010) found that PLHIV not only received minimal support from friends due stigmatization but also lost some of their friends. It was also reported that the PLHIV were not liked and people were not concerned about them for fear of contracting HIV. There was a general lack of acceptance and accommodation of PLHIV. Acts of physical violence, whereby people whose status became obvious through self or disclosure from other quarters were chased out of the family house, were also reported. In most cases, the victims were women. Sometimes the physical violence was only aimed at the possessions of the person living with HIV (Dlamini *et al.*, 2007).

Research indicates that HIV may also affect the relationships between school-going children and their peers. This could happen in cases where fellow students or pupils discover that either one or both of the parents of a fellow pupil are either ill or have died of HIV-related ailments. In a study by Xu and colleagues (Xu *et al.*, 2010), 11% of orphans reported that their relationship with their peers had worsened as a result of illness or death of their parents due to HIV/AIDS. About 25% of orphans reported significantly higher levels of teasing by fellow pupils compared to non-orphans. In extreme cases, children may experience violence by association whereby due to the status of one's parents, they do not receive good treatment in school (Dlamini *et al.*, 2007).

The need to provide care and support and help meet the basic needs of PLHIV—especially during times when they are critically ill—may stretch the material, emotional and physical capacity of caregivers, leading to a burnout or fatigue. The need to stick to treatment regimens, the physical incapacitation, and bodily appearance may make the ill person avoid social occasions leading to social isolation (Charmaz, 1983; Corbin, 2003; Nettleton, 2006). One can also be consigned to self-imposed isolation due to uncertainty of how one will be treated should one's HIV status be known. This can translate to PLHIV avoiding intimate relationships by either remaining celibate or alternatively by entering into an intimate relationship with a person of similar status (Nattabi *et al.*, 2012). Due to fear of commitment to help, friends may avoid the ill-person (Zhang *et al.*, 2009). Once a person is diagnosed with HIV, intimate relationships can be broken. According to a study by Anderson *et al.* (2009), a man reported that his previous relationship broke up because of his status.

As has been presented from the review of the literature, being HIV positive has an impact on interpersonal relationships. HIV has the potential of determining on how one can relate with family members, friends, relatives, faith group members and workmates. Being HIV positive also has an effect on how one is treated by health care professionals. Among the effects in relationships that HIV can lead to are experiences of stigmatization and rejection. HIV can also impede the way one relates and interacts with significant others such as family members friends and relatives. This is because infection with HIV disrupts common meanings and understandings concerning the attribution of meanings to the illness experience and issues concerning the way one contracted the illness.

1.6.2 Effects on Capacity to fulfill Social Obligations

Conceptions of self are an outcome of the capacity to fulfill or carry out tasks that are critical for each dimension of the totality of a person's being. This means that who a person perceive him/herself to be is inextricably linked to the ability to fulfill the various role expectations related to the respective social statuses. A mother, for instance, should be able to perform both the reproductive (bringing forth children) and productive (nurturing) functions. She should not only be able to bring forth children and raise them, she is also expected to maintain the household, prepare meals, do the household chores and so on. As a wife, she should also be able to fulfill the needs of her husband. To fulfill these roles, she should have the emotional, psychological as well as the physical capacity to do so. However, when one is diagnosed with HIV, the concept of self may be altered—since a breach is likely to be created either in the physical, emotional, social or psychological aspects of a person's being—thus undermining the capacity to fulfill the expected roles effectively (Corbin and Strauss, 1987).

According to Corbin and Strauss, there are several aspects to role performance. The roles can either be “routine or problematic, simple or complex, long or short, visible or invisible to others and so on...” They argue that “the term performance denotes both the capacity for action and appearance...” (Corbin and Strauss, 1987). Appearance, according to Corbin and Strauss, implies both how one appears to himself and to others and how any action performed appears. Appearance of action to others means what others who witness the performance think about the performance. Others can judge a performance either as a success or a failure based on whether or not the actor effectively carried it out. Any performance can have several target audiences or beneficiaries: These include actions performed (1) for the sake of other people, (2) in the presence of other people (3) with other persons and (4) through other persons (Corbin and Strauss, 1987).

Extensive research on chronic illness by (Corbin and Strauss, 1987), indicates that the ability to successfully perform social roles, irrespective of the nature of the performances or the respective audiences to these performances, can act as a major boost to a person's conception of self. They further argue that the reverse is true: that failure to effectively perform one's role-related duties and obligations for whatever reason is likely to lead to a diminished conception of self. Consequently, people are likely to gauge who they are in terms of what they can do (Corbin and Strauss, 1987). In this sense, it was anticipated in the study that ability to perform the routines of daily life including being able to engage in physical and productive activities such as farming would be an important aspect for PLHIV.

PLHIV are likely to claim a dignified self-esteem due to their ability to successfully engage in the affairs of everyday life. On the other hand, it was expected that those who would not be able to successfully carry out the social obligations would likely have a diminished sense of self. Among those who were hypothesized to have a diminished sense of self were to include those who would either be experiencing heath difficulties (due to weakened immune system and would either bedridden) or those who lack the social support networks and material resources to carry on with life (Charmaz, 1983; Corbin and Strauss, 1987).

In a majority of cases, unsuccessful performance is thought to be largely due to a body that is considered a “failed body” (Corbin and Strauss, 1987). A body can be considered to be a failed body if any or all of the following conditions prevail. These are reduced ability to do things and alterations in appearances; diminished or inability to receive sensations in given body organs; breakdown in the human communication process and changed awareness of things. Any or all of the above mentioned conditions can make it increasingly difficult for a PLHIV or with other chronic illness to carry out role-specific performances successfully. As such, circumstances that help restore capacity for action were hypothesized as being major boosters to the self-identity of PLHIV (Corbin and Strauss, 1987). Through reference to the illness trajectory model, the PI was expected that PLHIV who were as yet not experiencing the unstable and downward phases would have positive conceptions of self. This was likely to be explained by their continued capacity to engage in their daily routines and ability to successfully carry out these performances. Those who would have already experienced or would be currently in either of these phases was expected to manifest a greatly diminished conception of self.

1.6.3 Effects on Perceptions of Self

According to Mead (Corbin and Strauss, 1987), “the self is the continually active reconstruction of events and planning of actions in relation to objects, so different aspects of self are different processes in relation to different objects.” On the other hand,

> Conceptions of self refers to personal identity, a self-classification of who I am over the course of my biography. These conceptions are formed through integration of various aspects of self into a more inclusive whole. Every aspect of self corresponds to a given set of tasks that must be performed in order to fulfill the expectations of the particular social role. For this reason one can be a professor, mother, writer, piano-player and wife all at the same time. These tasks, like all those related to various aspects of the self, take place over biographical time, for they are part of one's past, present, and hopefully, the future. In turn, continual performance of self-related tasks requires a functional body (Corbin and Strauss, 1987).

An HIV-positive diagnosis can lead to a change in the flow of one's life in terms of one's priorities, life projects and dreams. PLHIV face the reality of resorting to shorter term plans, altering many aspects of their lives and organizing everything around their illness. This is particularly with regard to the treatment regimens, illness episodes and specific emerging symptoms. Additionally, a PLHIV is confronted with the burdensome task of coping or adapting to the various dimensions of the illness career with unlimited social, physical and psychosocial ramifications (Carel, 2008; Freund and McGuire, 1999; Nettleton, 2006). As Baumgartner (2007) has argued, the changes may involve identity centrality, whereby the HIV positive status becomes the center around which the lives of PLHIV revolve.

The self can be assaulted by chronic illness in very fundamental ways since the illness attacks the body—the physical being. The body is the medium through which people present themselves to and interact with the social world. Indeed the body is very basic to social interactions since humans are embodied beings (Carel, 2008; Freund and McGuire, 1999). Subsequently, any assault or attack on the body is likely to have implications for social interaction. A person’s sense of self or social identity is based on what he/she believes others think about them. If a person’s interpretation of what others think about him/her is positive, then this may lead to a positive self-image. On the other hand, if one thinks that others think negatively about him/her, this may lead to low self-esteem. People's reactions to the self can either be positive or negative depending on their evaluation of the body. Accordingly, it is important that an individual’s body is in its normal or near normal state as much as possible. This sense and experience of normality is however undermined by chronic illness (Bury, 1982; Carel, 2008; Charmaz, 1983; Freund and McGuire, 1999; Nettleton, 2006).

The conceptions of self can also be affected when the illness is unmanageable and undermines the person's ability to live a normal life. Literature indicates that when the person is so subdued and is unable to organize his life or perform daily tasks, they may be flooded with thoughts of suicide. When a person cannot effectively fulfill their social obligations (such as those of mother, father, spouse, worker, community member, Church member), then the person's self-image is likely to crumble and they are likely to suffer an identity crisis. The crumbling of a person's identity may result from episodes of illness or overwhelming sense of grief or loss associated with a HIV-positive diagnosis consequently rendering one physically, mentally and socially incapacitated (Carel, 2008; Charmaz, 1999; Freund and McGuire, 1999).

1.7 Coping Strategies adopted by PLHIV

The conditions that facilitate adaptive coping include high levels of social acceptance and low levels of stigma and discrimination (Anderson *et al.*, 2009; Medley *et al.*, 2009). Moreover, different social contexts and personal circumstances seem to call for the adoption of different strategies and actions in order to cope with HIV. Accordingly, PLHIV like any other human beings, manifest a great sense of creativity and innovation in studying their social environments and learning how to survive within them (Wallace and Wolf, 2005). PLHIV adapt strategies that they consider pragmatic to their situations. Some of the common coping strategies PLHIV adopt seem to transcend social contexts even though they are not uniformly practiced. These strategies include joining support groups of PLHIV, taking responsibility for their health, embracing faith and religious beliefs and disclosure of HIV status (Barroso and Powell-Cope, 2000; Baumgartner and David, 2009; Dageid and Duckert, 2008; Liamputtong *et al.*, 2012; Makoae *et al.*, 2008). In this section, empirical literature on the coping strategies adopted are presented.

1.7.1 Taking care of Oneself

According to literature (Barroso and Powell-Cope, 2000; Dageid and Duckert, 2008; Musheke *et al.*, 2013; Russell and Seeley, 2010), taking care of oneself incorporates themes such as engaging in positive behaviour change, by adopting new beneficial habits, and abandoning risky behaviours that can jeopardize tolerable standard of living. Taking care of oneself should be seen to encompass the activities generally referred to us “illness work” and “everyday life work” (Bury, 1982). Among the things mentioned by women in a study by Liamputtong *et al.* (2012) as comprising taking care oneself included adapting good nutritional practices such as eating balanced diets, engaging physical exercises, ensuring they had enough rest and not getting too mentally engrossed with their physical health and well-being. The women took care of themselves so that they could add more years to their lives. This coping strategy also involved doing everything within one's ability to stay healthy and if possible find a cure for the condition. In other studies, taking care of oneself also meant remaining optimistic and always having a positive outlook towards life in spite of the fact that one faced difficult circumstances. It meant not giving up to a defeatist mentality (Barroso and Powell-Cope, 2000; Liamputtong *et al.*, 2012).

1.7.2 Disclosure of HIV Status

Participants in a study by Medley *et al.* (2009) reported that an increasingly favourable social atmosphere had developed in the country over the years and since people were more understanding and more informed, it was easier to make one's status known to others as well as live positively with HIV. According to literature, disclosure was adopted as a coping mechanism for various reasons and decisions were also made concerning the extent of disclosure, whether to a close circle of family and friends or a more public disclosure. Among the reasons for disclosure to family and friends was the need to be understood and to be supported. Others disclosed in order to make public their status or to circumvent speculation and to be the ones to make the information about their status public instead of it being spread by others in form of rumours (Anderson, 1988; Anderson *et al.*, 2009; Baumgartner and David, 2009; Dageid and Duckert, 2008; Makoae *et al.*, 2008). Some disclosed because they felt moved to be a source of information for others and to help demystify the disease (Baumgartner and David, 2009).

In a study by Anderson *et al.* (2009), most of the respondents had disclosed their status to at least one person. These were mostly close family members and friends. Others opted for a closer relationship with the health care provider who knew their status as opposed to family members. Most participants in the study by Anderson *et al.* (2009) had decided against a more widespread disclosure instead restricting it to a few members of their social networks. In findings echoing those of other studies, reasons that influenced restricted disclosure included lack of assurance as to whether those to whom they disclosed would keep the information confidential (Liamputtong *et al.*, 2012; Makoae *et al.*, 2008; Baumgartner, 2007). Others had self-stigmatizing attitudes and did not want to associate with support groups of PLHIV. The need to keep one's status under wraps appeared to have deleterious effects for it often led to increased isolation as the PLHIV wanted to avoid contact with their friends and acquaintances. This is because of the fear that these significant others would notice changes in their physical appearance. In other words, it was difficult to face others in such a situation (Anderson *et al.*, 2009; Charmaz, 1983; Corbin, 2003; Williams, 1984).

Disclosure was also shown to have positive outcomes for most of the respondents in a number of studies. In a study by Liamputtong *et al.* (2012) women reported that they were able to deal better with their lives and other associated challenges since their family members knew of their HIV status. The fact that their family members received the news positively acted as a big source of relief and encouragement to the women. Family members appeared concerned and provided support and solace to the ill members so as to help them cope (Liamputtong *et al.*, 2012). In two studies among PLHIV in the United States, Baumgartner (2007) and Baumgartner and David (2009) noted that disclosure started with a close circle of significant others, then to a more open or public disclosure and finally to disclosure as the situation demanded. Public disclosure, even though in some cases involving more extensive and far reaching—as those done through electronic media such as television programmes, newspaper adverts and disclosure in social forums such as and AIDs conference and workshop—was mostly restricted to support groups or disclosure within the HIV community (Baumgartner, 2007; Baumgartner and David, 2009).

1.7.3 Faith and Religious Activities

Faith in God or a supreme being was a source of strength and solace for PLHIV. In some studies, it was noted that for faith led some participants to view life from a new and positive perspective. God was viewed as an ever present companion and friend who one could tell his/her problems and that he, God, was powerful enough to keep the PLHIV from harm and danger and help them realize positive outcomes (Anderson *et al.*, 2009; Makoae *et al.*, 2008; Russell and Seeley, 2010; Ribeiro Nobre *et al.*, 2012). Faith also enabled some participants to understand their HIV status as part of God's will or one's own destiny. For instance, in a study within a predominantly Buddhist context, *karma* was a strong theme in how faith played a prominent role in helping PLHIV not only to comprehend but adapt to a life with HIV

(Liamputtong *et al.*, 2012). Belief in *karma* assisted the women to accept their HIV status. Moreover, it helped them to change their actions making them resort to meritorious acts so as to accumulate benefits for either the present or next life. Consequently the women gave alms to the poor and provided support to Buddhist monks (Liamputtong *et al.*, 2012).

In a study by Anderson *et al.* (2009) the aspect of faith that was most beneficial to participants was a personal relationship with God as opposed to comfort and support from the Church, where sometimes preachers condemned a life of HIV and some members responded with glee. Relationship with God helped PLHIV to deal with isolation since they saw God as a companion and comforter. According to Russell and Seeley (2010), faith gave PLHIV a sense of hope that they could overcome the difficulties they faced if they became proactive and took steps to improve their situation. Moreover, some participants believed that God was a healer who could provide healing from HIV even if that was not fulfilled immediately. This kind of attitudinal disposition was a great source of hope and motivation for PLHIV to carry on with life (Anderson *et al.*, 2009; Russell and Seeley, 2010).

1.7.4 Support Groups

Since members of support groups are all people in similar circumstances or life situations, they help meet the emotional, social and psychological needs of their members. Research consistently shows that being part of a network or support group of PLHIV is one of the key ways or strategies used by people living with HIV to cope (Anderson *et al.*, 2009; Campbell *et al.*, 2011; Liamputtong *et al.*, 2012; Makoae *et al.*, 2008; Russell and Seeley, 2010). In the aforementioned studies, support groups give members a sense of identity, belonging and acceptance and help with overcoming negative outlooks such as being angry and sad. The group experience can give a sense of solidarity that one is not facing the condition alone but that there was a community of people with the same condition. Support groups also provide or restore a person's sense of self-worth through making one feel that whatever one shares is valued and will not be rejected. Therefore as has been documented in these studies, support group provides a good resource for overcoming stigmatization associated with a positive HIV status (Baumgartner and David, 2009; Dageid and Duckert, 2008; Liamputtong *et al.*, 2012; Nettleton, 2006; Russell and Seeley, 2010). In this sense, PLHIV can use support groups as effectives tool for positive resistance, advocacy and lobbying for services and sensitizing the wider community on the special circumstances they face. Being in a support group is a source of social power with which the narratives of the dominant prevailing and discriminatory social and cultural attitudes can be counteracted. Additionally, support groups provide a forum where members cannot only learn more about their condition but also how to confront the challenges associated with being HIV positive as well as challenges associated with life generally (Anderson *et al.*, 2009; Dageid and Duckert, 2008; Liamputtong *et al.*, 2012).

1.8 Difficulties faced in Coping with a Positive HIV Status

In this section, previous research findings on challenges to adaptive coping by PLHIV are reviewed. For a person diagnosed with HIV to adapt effectively and live positively with HIV, certain conditions need to be present within the society. However, society is not always ideally structured to cater for the needs of people diagnosed with HIV. Consequently, a life with HIV is an endless struggle to survive in an uncertain and threatening environment. Deliberate efforts can be made by key players in society—such as the government, civil society organizations, and PLHIV—to help ensure that the conditions that hinder adaptive coping are minimized. The main challenges reviewed in this section relate to health problems, disclosure of status to others, stigma and discrimination, negative feelings and worries about the future and livelihood and economic insecurity. These are presented below.

1.8.1 Health Difficulties

So far, the question was mostly about the health of the PLHIV themselves. However often some also have children with HIV/AIDS and in these cases, the health of both parents and children were important issues. According to literature, the key issues relating to health included occasional illness episodes ranging from not very serious—like fevers, headaches and stomach aches—to very serious conditions (for instance tuberculosis or meningitis) (Medley *et al.*, 2009). These illness episodes evoked fears and uncertainty about the future and undermined household livelihoods and economic well-being. Moreover due to the serious conditions, PLHIV may lose the capacity to engage in economically productive activities—such as agricultural production, regular employment or wage labour—with which to meet the needs of everyday life. Given that some of the illnesses may lead to dependence upon others in accessing basic needs (such as food, performing household tasks, or being taken to hospital) a person's sense of independence and control is likely to be undermined (Corbin, 2003; Freund and McGuire, 1999). Adherence to ARVs was also noted in the literature as a difficulty. Adherence posed a serious challenge especially in cases where a PLHIV did not have easy access to ARVs, where it hindered PLHIVs’ involvement in social activities or where it led to negative side-effects (Medley *et al.*, 2009; Remien and Mellins, 2007; Russell and Seeley, 2010).

1.8.2 Stigma and Discrimination

In the empirical literature, stigma and discrimination are recognized as persistent challenges of living positively with HIV. Several studies have shown that people who disclose their status or who are suspected to be HIV positive are treated as if they are no longer worthy of human dignity. They are perceived as being less than human and as if they no longer count in society. This stigmatization often translates into severe rejection, discrimination, being isolated and not being treated with dignity (Cloete *et al.*, 2010; Liamputtong *et al.*, 2012; Medley *et al.*, 2009; Remien and Mellins, 2007). This stigma often results in reluctance among people to get tested, unwillingness to go for treatment and care, and aversion to help-seeking simply because of fear of rejection and discrimination (Cloete *et al.*, 2010; Liamputtong *et al.*, 2012). A study done in Thailand revealed that some women who disclosed their status were discriminated against and faced rejection from those closest to them—the family (Liamputtong *et al.*, 2012). In South Africa, participants reported being chased out of the family house, being asked to use different utensils and being restricted in their own individual rooms (Cloete *et al.*, 2010). Stigma and discrimination therefore represents a significant challenge to an adaptive lifestyle for it makes it impossible for PLHIV to actively practice the actions necessary to make such a life possible and to continue with the normal activities of life.

Disclosure of one's HIV status to other people is promoted as one of the greatest steps to adapting to life with HIV (Chaudoir *et al.*, 2011; Liamputtong *et al.*, 2012). Disclosure not only frees one from the burden of a secret reality but also makes it possible for those to whom disclosure is made to offer help and support. Many PLHIV have reported a positive outcome from disclosing their status to their spouses, family members, relatives and the wider community. In some studies (Makoae *et al.*, 2008; Medley *et al.*, 2009) most of the women who had disclosed their status realized an accepting and accommodating response. Some of them reported that they had been responded to with an expression of love, emotional support and non-judgemental and non-discriminatory attitudes (Medley *et al.*, 2009).

However, not all people who disclosed their status receive positive treatment. Depending on the social context and the person to whom disclosure was made, some PLHIV have been abandoned, rejected, violated and stigmatized. Even though not many report this kind of treatment, a significant number still face negative responses (Medley *et al.*, 2009; Remien and Mellins, 2007). Rejection and abandonment was in some instances perpetrated by family members and close friends of PLHIV (Goudge *et al.*, 2009; Dlamini *et al.*, 2007; Makoae *et al.*, 2008). The rejection can be associated with lack of an understanding on the part of the perpetrators of stigma of the experiences of being HIV positive (Liamputtong et al., 2012). Additionally, the literature revealed that some PLHIV do not find disclosure easy for fear of the consequences that may accompany such disclosure. As Remien and Mellins (2007) found out, sometimes the decisions not to disclose may be due to a desire to avoid hurting significant others and breaking intimated social relationships—such as those with the family.

1.8.3 Negative Feelings and Worries about the Future

In literature related to the purpose of this study, PLHIV constantly face the irreversible fact of being HIV positive (Remien and Mellins, 2007; Russell and Seeley, 2010; Zhou, 2007; Ribeiro Nobre *et al.*, 2012). Being HIV positive is like an overarching status that overrides other realities and status of life. As these studies report, PLHIV constantly think about the radical changes that have occurred and continue to occur in their lives as a result of being diagnosed HIV positive. Some of the reasons that make PLHIV have negative feelings are problems with their own health, thoughts about their responsibility towards their children and whether they were in a position to help realize their plans for their children's future, and uncertainty about how long they (PLHIV) would live (Medley *et al.*, 2009; Russell and Seeley, 2010; Zhou, 2007). The constant thought of imminent and certain death cloud their lives with some PLHIV having constant negative feelings of worthlessness and of not being worthy of living. Some think that they are not good people since they are HIV positive and these thoughts make them view themselves negatively (Medley *et al.*, 2009).

1.8.4 Livelihood and Economic Insecurity

Previous studies have reported that to successfully adapt to a life with HIV, PLHIV need to have secure livelihoods both in terms of material resources such as food and finances to realize some other needs. As the literature shows, (Baumgartner and David, 2009; Ji *et al.*, 2007; Nyamathi *et al.*, 2011; Russell *et al.*, 2007; Selman *et al.*, 2013), PLHIV have needs like other normal people—including money for their children's school fees, money to purchase clothing, money to access medical care and money to purchase food. For PLHIV, there is the additional need for good nutrition if their quality of life is to be improved. As research shows, good nutrition is associated with a boosted immune system and a strong body to carry out the activities of everyday life (Dageid and Duckert, 2008; World Health Organization, 2013). However, PLHIV often do not have access to good nutrition either due to the fact that resources and assets have been depleted in paying for medication during previous illness periods, loss of employment, or due to other conditions—such as natural catastrophes exemplified by droughts—that destroy the means of livelihood that people rely on. These conditions translate to income and asset insecurity—a very difficult situation if one is to live positively with HIV. Moreover, availability of ARVs is of no consequence if there is no adequate nutrition for these medications require good nutrition to function well (Cloete *et al.*, 2010; Liamputtong *et al.*, 2012; Russell and Seeley, 2010).

1.9 Statement of the Problem

HIV is an example of a stigmatized and morally loaded chronic condition that challenges the taken-for-granted realities and routines of everyday life and the knowledge of the self (Bravo *et al.*, 2010; Hosseinzadeh and Hossain, 2011; Machine *et al.*, 2011). HIV potentially disrupts the way a person organizes and orders his/her life and contributes to the disruption of the social fabric of families, communities and entire nations. As has been demonstrated in the literature review, HIV leads to a host of difficulties for the infected individuals and their families. At a household level, it has deep-seated emotional consequences such as stigma, discrimination and rejection. HIV may lead to loss of household income due to the ailment and eventual death of breadwinners leaving in its wake high expenses for medical care. Due to ailment of those of productive age, it may affect household food security, with families having little or nothing to eat. Literature also shows that due to disability or death of parents, HIV contributes to an increase in the number of dependent children who become a burden to society. HIV similarly tends to have a unequal negative impact on women and young girls who tend to bear the brunt of the pandemic (Quinlan and Whiteside, 2007; UNAIDS, 2010).

Admittedly, great efforts have been undertaken at the international and local levels to address the HIV/AIDS pandemic and a lot of success is being achieved at all these levels (UNAIDS, 2013, 2014b). According to UNAIDS, for instance, the number of people dying from AIDS-related illnesses is declining; more and more people are living longer due to HAART and the rates of mother-to-child transmission (MTCT) of HIV have also gone down (UNAIDS, 2013). However, a number of gaps and challenges still remain that need to be addressed. For example, the levels of stigma and discrimination remain high and not all people eligible for ART services have access to them (Machine *et al.*, 2011; Mbonu *et al.*, 2009; Hosseinzadeh and Hossain, 2011). Globally, it was estimated that as at end 2013, about 42% of PLHIV had access to ARVs. In Kenya, it was estimated that in 2013, 78% of adults and 42% of children eligible were accessing ARVs (Kilonzo *et al.*, 2014). This means in general that quite a significant proportion of adults and children are still not being reached by the life-saving medications.

Improved access to treatment and care implies that PLHIV can live longer and be able to achieve more in terms of carrying on with their normal 'projects' of life (Baumgartner and David, 2009; Campbell *et al.*, 2011; Li *et al.*, 2010). Findings show that where PLHIV had access to ARVs, there were reductions in AIDS-related mortality of over 80% (Mukherjee, 2007). Additionally, PLHIV have been able to regain the capacity to fulfil their social obligations, dignity and place within society (Baumgartner and David, 2009; Campbell *et al.*, 2011; Liamputtong *et al.*, 2012).

Due to the increased possibility of living longer and of pursuing their mundane activities, PLHIV are likely to face key fundamental questions regarding their altered state of being (Baumgartner, 2007). They are also likely to face certain difficulties in coping with and adapting to HIV. On a more positive note, PLHIV are equally likely to innovate within their social spheres to find ways and means of leading a meaningful life given their circumstances. However, little research has been done in Kenya from a phenomenological perspective to describe the lived experiences of PLHIV in the context of improved quality of life and longevity. Therefore, the researcher felt it necessary to provide a phenomenological account on how being HIV positive affects the normal, routine ways of life of PLHIV in Kisumu County and how PLHIV cope with and adapt to these effects.

The purpose of this study, therefore, was to provide an elaborate account from a first-person perspective on: the effects of HIV on the lives of PLHIV; the way PLHIV make meanings of their HIV positive status; the coping strategies PLHIV have adopted; and the challenges PLHIV encountered in adapting to a life with HIV. In general terms, this study sought to provide a phenomenological description of the meanings PLHIV in Kisumu County of Kenya ascribe to their illness experiences and how they manage to cope with and adapt to an HIV positive status. In this study, adapting to HIV positive status means how a person manages to carry on with the normal and routine activities of life in spite of the life changing diagnosis of being HIV positive.

1.10 Public Health Relevance of the Study

In this dissertation, public health relevance is defined as a state whereby a condition or a situation, be it of social, political, economic or a cultural nature has either a positive or a negative implication for the health of a population or segment thereof. Health is significant as it is not only a goal to which all institutions of society should strive and a logical outcome of social and economic development but also a necessary condition for the realization of that development (World Health Organization, 2009b).

The public health relevance of this study stems from the fact that it aims to identify the meanings that PLHIV attach to their conditions in terms of the circumstances within which they are diagnosed as HIV positive, the effects of HIV in their lives, and the coping strategies they adopt. This information is important as it can inform a review of intervention strategies targeting PLHIV and the general community. The results may also provide a basis for wider community mobilization and contribute to the creation of a conducive environment for adaptive coping. Improved quality of life arising from a supportive social environment can only be realized when opportunity is availed for PLHIV to articulate issues of concern to them and in ways that makes sense to them. In this sense, the method adopted for this study, a phenomenological approach, provided a chance for the people most affected, PLHIV, to tell their story as they experienced it.

The process of how people make sense of, live with and respond to HIV, including how they cope and adapt, and the challenges they face are matters of socio-medical or public health concern. This is because the meanings of illness are shared by a culture or group and are derived from the beliefs, values, and world views of that particular group. As such, meanings have a much wider reach and coverage and transcend the individuals experiencing the illness. Moreover, being ill impacts not only the individual affected but his/her family, friends, network of relatives and the community at large in one way or another. Additionally, HIV may have far-reaching implications for other aspects of social life. Given that illness is experienced in the body, is something real, and is also closely related to the social life, it is consequently a social phenomenon and hence public health relevance of living with HIV (Roth and Conrad, 1987).

HIV/AIDS has a profound impact that has consequences for the entire social system. At the individual level, HIV is progressive and in conditions where medication and other forms of care and support are missing, it may lead to loss of physical strength and capacity to perform basic mundane functions thus hampering their engagement in productive activities—such as employment or in agricultural production. Infection with HIV may consequently lead to loss of household income and livelihood—in the sense of one losing a job or not being able to engage in income generating activities. Due to this loss, HIV increases the likelihood of dependency, poverty and loss of livelihood assets as these are sold to help pay for medical costs and other family needs such as school fees and other household expenses. When these assets are exhausted, relatives and community members are often forced to come in to assist hence intensifying levels of dependency (McCracken and Phillips, 2012; Skolnik, 2008).

HIV also negatively affects families and communities. For instance, HIV/AIDS has led to a rise in the number of orphans at levels never before contemplated. As children lose one or both parents to AIDS, they are exposed to an uncertain present and future and are often at the mercy of a sometimes very cruel society. Moreover, due to the high numbers of these orphaned children, many are unable to find foster homes where they can be taken care of and consequently often end up as street children or engage in risky sexual behaviours—either due to sexual exploitation and abuse by others or out of a need to survive when no other options are available (McCracken and Phillips, 2012; Merson *et al.*, 2012; Skolnik, 2008).

At the societal level, HIV has an adverse impact on the economic system, the workforce, the health care system, the public sector as well as the security sector. Similarly, HIV has damaging impacts on the education, political and the agricultural sectors. In some African countries, for instance, it is reported that HIV/AIDS-related diseases are decimating the workforce—especially the teaching fraternity and medical cadres—at faster rates than can be trained. The burden of HIV is further argued to be leading to socio-economic decay of several countries—especially those in SSA. Due to the impact of HIV on rural labour force, there are areas where agricultural production has been heavily impacted for there is no human power for preparing farms, planting and tending crops and collecting the harvest (Baylies, 2002; Hosegood, 2009; Pennap *et al.*, 2011; Skolnik, 2008; Zhao *et al.*, 2011).

HIV/AIDS represents not only a public health challenge for individual nations but also to all of mankind as it does not discriminate based on any category including international boundaries. Due to the possibilities provided by international travel, migration and other events that bring people from several nations together—including sports and games—diseases including HIV have increasingly taken on a global dimension. The epidemiology of HIV/AIDS is such an epidemic whose reach is truly global. HIV is therefore an issue of international or global health concern. In this sense, in so far as health is concerned, the global community is bound by a common destiny and responses similarly have to take a global orientation (Skolnik, 2008).

HIV disease as well as its social sequelae is also a human rights concern as it is mostly associated with the poorest regions of the world—especially SSA—and with the powerless and defenseless, mostly the young in age and the female in gender. Examples are children infected vertically by their mothers during birth or breastfeeding, and those adults infected horizontally by their partners or spouses. All these are largely unintentional occurrences. In terms of gender, more women than men are infected and among these women, younger women are at a greater risk. HIV and AIDS also disproportionately affect groups such as commercial sex workers, injecting drug users, long-distance truck drivers and other population segments who are exposed to infection due to their working conditions or lifestyle. It can be argued that issues of power are at play as these groups do not have adequate access to powerful social statuses and adequate resources to influence the course of their lives (UNAIDS, 2006).

Since the onset of the epidemic to the present time, stigma and discrimination have been consistently identified as key barriers to an effective response to the devastating effects of HIV/AIDS. Additionally, stigma is reckoned as a universal phenomenon operating both at the global and local levels. Stigma and discrimination are manifested at all levels of society and permeates through all its institutions. Since stigma is a key barrier to HIV related interventions it is an important focus for public health (Groh *et al.*, 2011; Makoae *et al.*, 2008; Melchior *et al.*, 2007; Nyamathi *et al.*, 2011; UNAIDS, 2007).

Additionally, HIV/AIDS contributes to the global burden of disease and is one of the leading causes of death. It is estimated that communicable diseases are responsible for about 44% of all deaths and for approximately 40% of the *burden of disease* [1](BD) as measured by disability-adjusted life years (DALYs)[2] in countries classified as low- and middle-income (Skolnik, 2008). HIV/AIDS, malaria and tuberculosis rank among the communicable diseases with the most remarkable impact in developing countries (McCracken and Phillips, 2012; Skolnik, 2008). Whereas data for 2002 showed that HIV/AIDS was the third leading cause of disease burden among women and men globally, it was listed as the leading cause of disease burden in WHO Africa Region (Pomerleau and McKee, 2005; World Health Organization, 2009a).

HIV was ranked as the sixth (6th) most significant cause of death in 2012 by the World Health Organization (WHO) (World Health Organization, 2014). HIV/AIDS accounted for about 1.5 million deaths in 2012 worldwide which represented 3% of all deaths. The other

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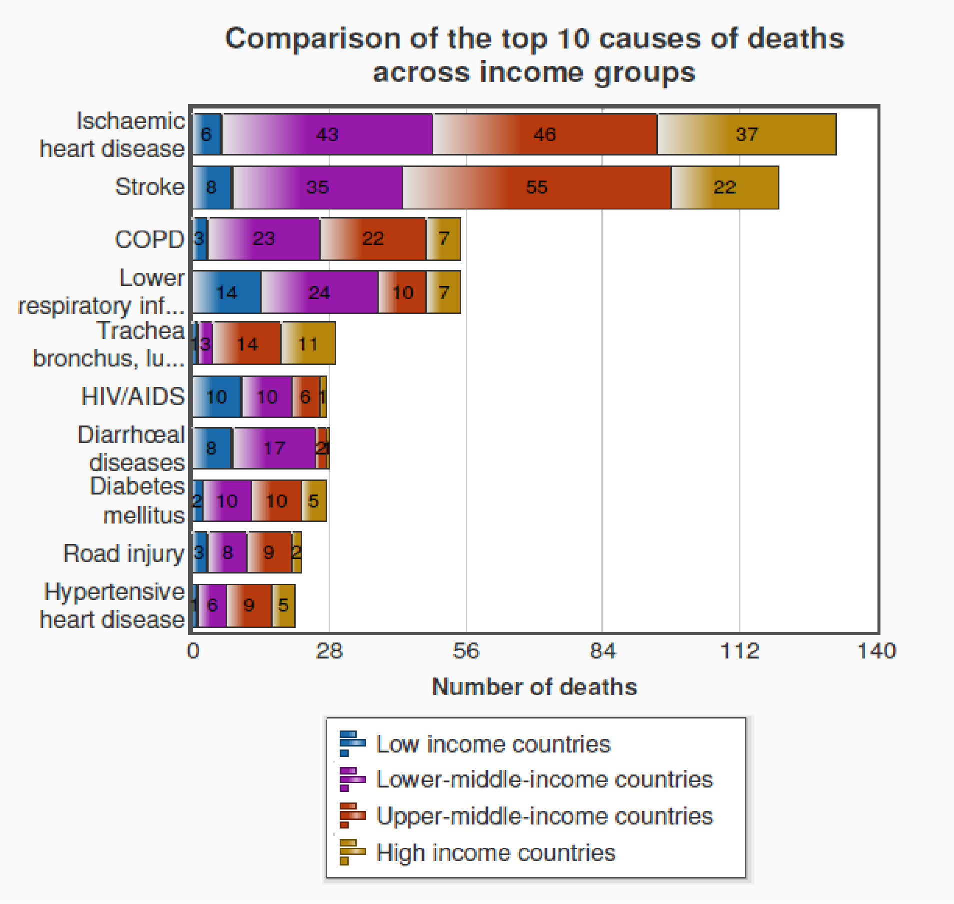
[1] "A measure of disease combining years of life lost due to premature mortality and years of life lost due to time lived in states of less than full health.(McCracken, Phillips 2012)

[2] Disability-adjusted life years: “The years of life lost to premature mortality and years lived within a disability, adjusted for the severity of the disability. One DALY is one lost year of healthy life. The DALY thus gives a wider picture of health problems (disease burden) than by just mortality statistics, through incorporating the non-fatal consequences of ill-health and injuries" (McCracken, Phillips 2012)

important causes were Ischaemic heart disease (7.4 million), stroke and other cardiovascular diseases (6.7 million) and lower respiratory infections (3.1 million) (World Health Organization, 2014). The greatest contribution of HIV/AIDS as a cause of mortality was evidenced in low-income countries where according to WHO, it featured at the third position among the top ten causes of mortality. It accounted for 0.72 million of deaths or 8% of the total. The only other diseases that outranked HIV/AIDS were lower respiratory infections ranked first and responsible for 1.05 million deaths or 11% of all deaths. At the second position was diarrhoeal diseases accounting for 0.76 million (equivalent to 8%) of the total deaths. (World Health Organization, 2014). Figure 1-2 provides a comparison of causes of death across income categories globally.



(**Source**: World Health Organization, 2014)

Figure 1-2. Leading causes of death globally (2012)

1.11 Chapter Summary

In this chapter, the theoretical, conceptual and empirical background to the study has been presented. The key sections of this chapter, including the introduction, structure of the dissertation, the theoretical framework, HIV statistics at the global, regional (SSA) and national levels (Kenya) have been considered. The chapter has described the two theoretical frameworks guiding the study—symbolic interactionism and the chronic illness trajectory model—highlighting their key arguments and their applicability to the study. Conceptual and empirical literature have been presented describing how the participants of the study learnt about their HIV status, and their initial reactions to and reconciliation with a positive HIV diagnosis. The chapter has also reviewed literature on the effects of HIV on the lives of PLHIV, the coping strategies PLHIV adopt and the main difficulties they face in coping with and adapting to a life with HIV. The statement of the problem is then presented and finally, a description of the public health relevance of the study has been given.

In the next chapter, the materials and methods including the research design, data collection methods and approaches to data analysis have been presented.

2 MATERIALS AND METHODS

2.1 Chapter Overview

In this chapter, the research objectives and research questions as well as the epistemological considerations including the research design and research methodology have been described. The chapter then explains the data collection methods, the study site and population and preparation for field research. The chapter also looks at the field research process, data recording, data transcription and data coding procedures. The analytic strategy, and how the findings have been presented, interpreted and explained are then laid out. Finally, an outline of the research process from the beginning to the end is presented.

2.2 Objectives and Research Questions of the Study

2.2.1 Objectives

The main objective of this study was to provide a phenomenological description of the experiences of PLHIV in Kisumu County, Kenya. The study focussed mainly on what being HIV positive meant for PLHIV and what coping strategies they adopted. In fulfilling this key objective, five sub-objectives, as outlined below, were formulated:

1. To establish the circumstances and contexts within which PLHIV in Kisumu County knew their HIV status;
2. To determine how PLHIV in Kisumu County make sense of their HIV status;
3. To identify the effects of a positive HIV diagnosis on the social relationships, the capacity to fulfill social obligations and the perceptions of self of PLHIV in Kisumu County;
4. To describe the main coping strategies PLHIV in Kisumu County adopted in order to adapt to a life with HIV;
5. To determine the key difficulties faced by PLHIV in adapting to their new status.

2.2.2 Research Questions

The key research question answered in this dissertation states thus: What meanings do PLHIV in Kisumu County of Kenya attach to their status as being HIV positive and what do they do, in cooperation with others or alone, in order to cope with and adapt to an HIV positive status? In order to operationalize the study objectives, specific research questions and sub-questions were formulated as follows:

1) **Under what circumstances and in which contexts did PLHIV in Kisumu County know their HIV status?**
    a) How did PLHIV get to know about their HIV diagnosis?
    b) Who makes the decision for HIV testing?
    c) In which facilities did PLHIV get to know their status?
2) **What meanings did PLHIV make of their HIV positive status?**
    a) How did PLHIV initially react to their HIV status?
    b) How did PLHIV reconcile to and possibly accept their HIV status?
3) **How does being HIV positive affect the social relationships, the capacity to fulfill social obligations and the perceptions of self of PLHIV?**
    a) How has being diagnosed HIV positive affected the social relationships of PLHIV?
    b) How has being diagnosed HIV positive affected PLHIVs' capacity to fulfil social obligations?
    c) How has being diagnosed HIV positive affected the perceptions of self of PLHIV?
4) **Through which ways did PLHIV cope with and adapt to their HIV positive status?**
    a) What strategies do PLHIV adopt in order to cope with and adapt to their status?
    b) What changes did PLHIV make in order to cope with and adapt to their status?
5) **What difficulties did PLHIV face in coping with and adapting to an HIV positive status?**

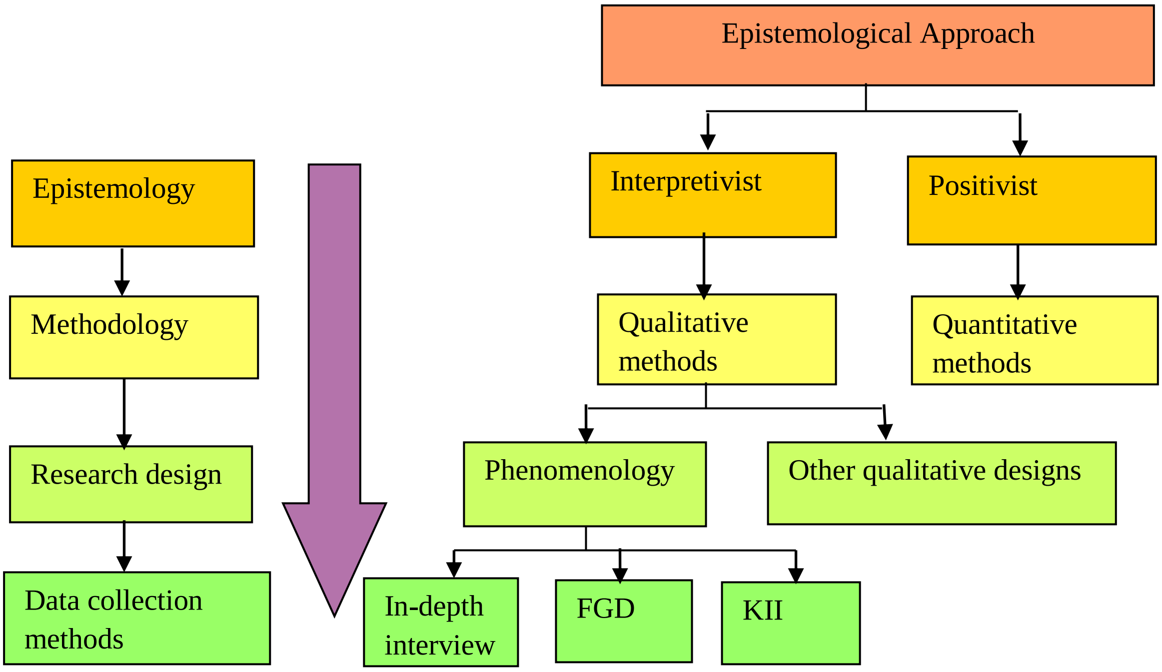
2.3 Epistemological Considerations

In this section the research methodology of the study is discussed, its appropriateness for the research question addressed and a justification for its selection given. The section begins by addressing the epistemological approach and then elaborates on the research methodology. Finally, the research design—hermeneutical phenomenology—is then presented.

2.3.1 Epistemological Approach of the Study

For successful execution and completion of a research project, a researcher needs to clearly spell out the *epistemological positions*, *research methodology* and *research design* adopted. Research Methodology has to do with how various methods and instruments of social research are applied to a particular research project (Della Porta and Keating, 2008). Design is taken to mean the way the entire study is organized from the initial stages of problem definition to the final stages including data collection and analysis (Cresswell, 2007).

The choice of research methodology and research design at the research level are necessarily guided by their appropriateness and relevance to the objectives to be achieved and research questions to be answered. Ultimately, however, the choice of research methodology and design is guided by overarching ontological, epistemological and theoretical considerations which are foundational to each particular discipline or subject of inquiry. In social science and most interdisciplinary areas such as sociology, political science, psychology and public health, the broad theoretical and epistemological approaches are either positivistic or interpretative approaches (Della Porta and Keating, 2008). The epistemological approach outline of this study is summarized in Figure 2-1.



(**Source**: Synthesized from the literature)

Figure 2-1: Epistemological approach of the study

Positivistic approaches have a number of key points. Among the points given prominence in positivistic approaches are (1) the existence of observable phenomena independent of the actors or perceivers, (2) experimentation, (3) value freedom, and (4) unity of method (Green and Thorogood, 2009). Positivists assert that reality exists independently of the observer and that only what can be empirically observed using the methods of science can be admitted as knowledge. According to this perspective, objective existence of phenomena—whether they be natural or social—warrant the formulation of appropriate methods to measure such phenomena.

The key focus in the positivistic approach is the development of precise and accurate ways of empirically measuring such phenomena. The methods mostly applied by positivists are the methods of science that were so successful in gaining an understanding of the natural world. Contrary to the positivistic view—that phenomena have an existence independent of the perceiver,—*interpretative approaches* argue that phenomena are products of subjective experiences. As such, to gain understanding of what counts as knowledge from an interpretative approach, it is essential to gain understanding of the subjective accounts of the study participants (Della Porta and Keating, 2008; Green and Thorogood, 2009; Kalof *et al.*, 2008).

Whereas *positivists* argue for a unity of method based on the methods of natural sciences, a counterargument propagated by *interpretive perspective* is that the methods applicable to the natural sciences are not necessarily appropriate for human subjects. The *interpretivist approach* asserts that the subjective and objective aspects of social reality are inextricably linked to each other. Although they acknowledge the existence of objective reality, this reality is however seen as being perceived and given meaning by the social actors since they are meaning-making beings. Social actors attach meanings to their actions and try to make sense of their experiences and place in the world (Della Porta and Keating, 2008; Green and Thorogood, 2009; Kalof *et al.*, 2008; Wallace and Wolf, 2005).

In contrast to natural phenomena, human beings are argued to be unpredictable as they can adjust their actions in response to a given situation. Within an interpretive perspective, the role of the researcher is neither geared towards discovering underlying causal laws of social action nor aimed at seeking generalized accounts of social phenomena. Instead, the role of the researcher according to the interpretivist approach should be to seek to uncover the meanings that social actors attach to their actions, their experiences and the social happenings around them. In general, interpretative perspectives seek to give prominence to the interpretations that social agents attach to their actions, to social phenomena, and to their experiences (Della Porta and Keating, 2008; Green and Thorogood, 2009; Kalof *et al.*, 2008).

In conclusion, it is thus reasonable to aver that the process of generating social scientific knowledge is not the exclusive domain of any particular approach, whether that be positivistic or interpretive. No particular approach can be considered to be superior to the other as each is based on different epistemological foundations. Moreover, based on these different epistemological foundations, neither of them is capable of providing a complete understanding of social reality. Emphasis should therefore be laid on a more inclusive attitude that accommodates the contributions that each perspective can make. In this sense, a good approach should, as far as is possible, aspire to a mixed-methods approach -in a process aimed at maximizing on the strengths of both perspectives (Kalof *et al.*, 2008). This study is guided by an interpretivist epistemological outlook.

2.3.2 Research Methodology

Arising from the epistemological considerations examined above, it is evident that the *research methodology* and *design* are determined by the nature of the questions to be addressed. With regard to research methodology, there is a distinction between two broad methodologies: *quantitative* or *qualitative*. These methodologies or ways of using research methods correspond to a large extent with the positivistic vs. interpretivist debate.

A *quantitative* methodology corresponds to the positivistic approach whereas the *qualitative* methodology corresponds more to an interpretative approach (Della Porta and Keating, 2008; Kalof *et al.*, 2008). However, according to Kalof *et al.* (2008), quantitative and qualitative methodologies are equally valid ways whose main purpose is to help gain an understanding of the nature of social or health reality and how things operate in the world. The two methodologies achieve this purpose in somewhat different ways. This difference is reflected throughout the entire research process including how the research problem is defined, how samples are arrived at, how data is actually collected and even how the data is analyzed and interpreted (Green and Thorogood, 2009; Kalof *et al.*, 2008).

In contrast to quantitative methodologies, *qualitative* methodologies seek neither to uncover general laws governing social phenomena nor to use general laws as a means of explaining such social phenomena. On the contrary, their main concern is to provide probable interpretations of reasons people give for their actions and how they make sense of their social milieu and experience. They also aim towards providing deeper insights into social or health-related phenomena as opposed to attempting to collect representative data (Bowling, 2009). In other words, qualitative methods seek to identify the meanings and motivations that underlie cultural symbols, social definitions of health and illness, and the subjective experiences of individuals. Based on the findings from study participants, qualitative methodologies ultimately seek to give an elaborate account of social processes, experiences and events. These methodologies do not seek to uncover universally applicable laws to explain reality because the subjective meanings that actors attach to their experiences and actions are context specific (Della Porta and Keating, 2008; Green and Thorogood, 2009; Kalof *et al.*, 2008).

Due to the epistemological differences behind these two methodologies, a choice of methodology should essentially be guided by the research question. As has been noted above, from an epistemological and philosophical standpoint, qualitative methodology seeks to uncover the understanding of social phenomena from the actors' or participants' point of view. It thus provides a viable means of understanding the feelings, the actions and the meanings of people living with or experiencing a particular illness (Bryman, 2008; Holloway, 2005a; Taylor, 2005).

In qualitative research, a distinction can be made between inductive approaches and deductive approaches to qualitative health research. Inductive approaches are those whereby coding and analysis are done primarily from the data without imposing any apriori notions and concepts or theoretical constructs. A good example of an inductive approach is grounded theory. Deductive approaches are those in which the analytic categories are derived from a theoretical framework, research questions, literature review or from all of these sources. In the deductive approach, a researcher has some prior expectations of data and will approach data collection and analysis in a structured manner informed by either or all of the above mentioned sources. In a purely deductive approach, one does not begin with an open mind as it were (Barbour, 2008; Gibbs, 2007; Holloway, 2005b).

The purpose of this study was to discover the meanings and interpretations that PLHIV give to their social and health experiences and how these meanings are significant to their understanding of their place in society. This study inquired into how PLHIV rationalize or make sense of what it means to be HIV positive and how they explained their place in the social and medical milieu that encompass them. This kind of knowledge cannot be legitimately obtained by a quantitatively informed approach to social research. Accordingly, the study adopted a qualitative approach to data collection and analysis. Qualitative approaches enable the collection of data that answer a different set of questions from those of a quantitative approach (Babbie, 1995; Barbour, 2008).

2.3.3 Research Design—Hermeneutic Phenomenology

The research design and data collection methods adopted in qualitative methodology are those predominantly geared towards generating textual as opposed to numerical data. These methods allow study participants to express themselves freely and to articulate the issues that are of primary importance to their lives, in their own words, and in a way that makes sense to them (Barbour, 2008). Additionally, due to its flexible nature, the qualitative approach facilitates the generation of data on issues that were neither expected nor anticipated prior to the research (Barbour, 2008; Holloway, 2005a). Among the common qualitative designs are phenomenology, narrative research, grounded theory, ethnography and case study (Cresswell, 2007).

This study used the *interpretive* or *hermeneutic phenomenology* as the research design. A phenomenological design views the world as socially constructed and subjectively experienced and that science is driven by human interests as opposed to being value-free (Gray, 2009). Consequently, hermeneutic phenomenology contends that social reality can thus only be understood by paying attention to the meanings and interpretations that individuals attach to their actions (Della Porta and Keating, 2008; Green and Thorogood, 2009; Holroyd, 2007). As such, a hermeneutic phenomenological design aims to collect accounts from several individuals on the meaning of a particular phenomenon for their lived experiences. The need for hermeneutic understanding becomes even more relevant whenever a study focusses on individuals faced by life-threatening conditions.

Life threatening conditions challenge taken-for-granted conceptions of reality and force people to seek meanings of such experiences. Being diagnosed as HIV positive, which has been transformed from a death sentence to a chronic condition by the development of life prolonging ARVs (Campbell *et al.*, 2011), is an example of a life-threatening condition. A positive HIV diagnosis has the potential of shattering a person's prior constructions of reality and necessitating the creation of new assumptions. In this sense, a positive HIV status potentially alters the regular pattern of a person's life necessitating the formulation of new meanings and ways of life (Cresswell, 2007; Holroyd, 2007).

Hermeneutic phenomenology begins by defining an issue whose meaning is to be described and interpreted, which for this study is life with HIV/AIDS. A group of individuals who have an experience with the phenomenon are then identified and a sample selected through appropriate sampling methods. Data is subsequently collected by use of appropriate qualitative data collection methods, which may include in-depth (semi-structured) interviews and FGDs. After data is collected, the investigator then generates information to develop a descriptive account of the meanings that individuals make of the phenomenon. The researcher goes further to provide a description of the fundamental nature or the core of the experience by comparing the accounts of the various individuals and synthesizing these accounts to generate their essential features. Finally, the researcher needs to go beyond a mere description of the core nature to an interpretation of these experiences, drawing out what the experiences really mean in context of literature and theoretical positions (Cresswell, 2007; Holroyd, 2007). From the foregoing, this study adopted a hermeneutic phenomenological design to yield the data that has been used to describe and interpret the perceptions, meanings and interpretations that PLHIV in Kisumu County had with regard to their experiences and to explain how they managed to cope and to adapt to a positive HIV status.

2.4 Data Collection Methods

The main methods used for this study were: (a) semi-structured, in-depth interviews, (b) focus group discussions (FGDs) and (c) key informant interviews (KIIs). The in-depth interviews were conducted through face-to-face interactions with the participants (PLHIV) so as to generate accounts on the experiences of living with HIV. Through FGDs, people can willingly discuss sensitive topics in a way not possible in the context of a one-to-one interview (Kitzinger, 2005). The FGDs were conducted with the principal investigator (PI) as the moderator and one research assistant as a note-taker and a recorder. The KIIs were used to collect expert information from individuals who were deemed knowledgeable on issues concerning care and support for PLHIV and who understood the various government policies governing such operations. The KIIs were conducted with nurses, community health workers (CHWs) and patient support group (PSG) leaders. Whereas nurses manage the PSCs, the CHWs are volunteers who have received basic health training and serve their communities on various health issues.

2.4.1 In-depth Interviews

In-depth interviews make it possible for study participants to narrate their stories in a way that makes sense to them and in their own words. Moreover, they make it possible for complex issues to be probed and clarified thereby resulting in deeper insights about how individuals experience a particular phenomenon. They also provide a relaxed and comfortable atmosphere in which individuals can tell their stories. Interviews provide the perfect atmosphere that compared to other methods is best suited for capturing individual biographies (Bowling, 2009; Taylor, 2005; Kitzinger, 2005).

In-depth interviews were conducted with the aid of a semi-structured interview guide fitted with appropriate probes to facilitate collection of sufficient data to answer the questions of the study (Taylor, 2005). The interview guides were developed from a synthesis of existing research and theoretical literature that were adapted to the objectives of this study. The key domains that formed the guide were the circumstances of learning about one’s HIV status, the initial reactions and thoughts that PLHIV had at diagnosis, and the process of reconciling with their status. The other main themes comprised the effects of HIV in the lives of PLHIV, the coping strategies they adopted and the key challenges that affected their coping strategies. An open-ended conversational style was preferred and the interview was started off with an open-ended question and allowed the interviews and discussions to flow. This was to enable the interviewees' voices to be heard (Crabtree and Miller, 1999).

2.4.2 Focus Group Discussions

For this study, FGDs were deemed appropriate since the topic is sensitive as it deals with HIV/AIDS, which is a stigmatized condition (Makoae *et al.*, 2008). The FGD method also makes it possible for participants to bring out feelings and issues that may no longer be clear to their memory. This is because the group process can act as a catalyst to memory. Moreover, it is possible for participants to build on each other's perceptions (Holloway, 2005a). Each of the sessions was audio-recorded to facilitate development of an accurate transcript of responses to provide a credible basis for data analysis (Bowling, 2009).

This study relied on already existing groups corresponding to the PSGs. Generally, there is the option of conducting FGDs with either pre-existing or newly created groups (Holloway, 1997). However, the essential consideration about these groups—whether they are pre-existing or newly created—is their level of homogeneity. Qualitative researchers are agreed on the need for homogenous groups for various reasons (Juma, 2001). Kitzinger (2005), for instance, asserts that homogenous groups have a higher potential for shared experiences and the members are already familiar with each other. This familiarity, which results from sharing in similar circumstances, facilitates the realization of the social network effect, a key element in the FGDs methodology.

Familiarity within homogenous groups helps to avoid the possibility of disruptive conflict, allows for in-depth exploration of the issues being discussed (Juma, 2001) and creates a conducive atmosphere for the participation of all members (Bowling, 2009). Bloor *et al.* (2001) argue that there is a high potential for conflict in cases where heterogeneous groups come together. Homogeneity can be based on gender, age, and education or sharing of certain common characteristics or circumstances such as having a similar chronic illness (e.g. diabetes, cancer or HIV). The FGDs comprised of between six (6) members for the smallest and thirteen (13) members for the largest group. In total, there were 59 participants for the 8 (eight) FGDs coming to an average of 7 participants per group overall. The largest groups were witnessed in St. Joseph's Nyabondo Mission Hospital where one group had 13 members.

The FGDs were conducted with the aid of a semi-structured and flexible FGD guide and they lasted between one and one-and-a-half hours each (Holloway, 1997).The FGD guides were also based on a review of the empirical and theoretical literature as well as the research objectives. The FGD guides were adapted for a group situation, ensuring that the questions did not inquire about the experiences of the participants themselves but inquired about hypothetical cases of people diagnosed with HIV. The key themes, as in the cases of both the in-depth interviews and KIIs, were the main circumstances under which PLHIV learnt about their status, how people normally reacted to diagnosis and the reconciliation process. They were also asked about the effects of HIV on the lives of PLHIV, how PLHIV cope with their status and the difficulties they faced.

2.4.3 Key Informant Interviews

Key informants are people from whom data is collected due to their connection to a particular population or community of interest and due to their wealth of knowledge, expertise and experience regarding the research questions being addressed (Bickman and Rog, 2009; Patton, 2002; Rubin and Rubin, 1995). In the context of care and support services for PLHIV in Kenya, the people mostly considered as key informants include community health workers, leaders of PLHIV support groups, community liaison personnel and HIV coordinators in the respective jurisdictions. For the purposes of this study, the key informants were the PSC coordinators in the two facilities, leaders of support groups of PLHIV and community health workers who provide care and support to the PLHIV.

The KIIs were conducted using interview guides containing ten different items fitted with appropriate probes. The items encompassed the basic themes as those in the in-depth interview and FGD guides adapted for use for the key informants. The main themes comprised the circumstances under which PLHIV learn about their status, the initial reactions to diagnosis, the reconciliation process and the effects of HIV on the lives of PLHIV. Other themes were the coping strategies adopted and the difficulties faced in coping. The items were modified to suit collection of information based on the experiences of others (PLHIV), even though some of the KIIs participants were themselves PLHIV. It was beneficial for this study to utilize the three methods mentioned above in data collection since each method has strengths and limitations that call for a triangulated approach.

2.5 *Study Site and Population*

In this section, the basic information about the study site, the study population and the sampling procedures and sample size are elaborated.

2.5.1 Study Site

The study was conducted in Kisumu County, in the western part of Kenya. Kenya is a country that lies in East Africa and is crossed by the Equator, bordered to the East by the Indian Ocean, to the West by Lake Victoria and surrounded in a clockwise manner by Tanzania, Uganda, South Sudan, Ethiopia and Somalia respectively. It has a total surface area of 582,646 square kilometers of which about 11,230 square kilometers are covered by water (Lake Victoria and the Indian Ocean) (Kenya National Bureau of Statistics, 2014).

Kisumu County was selected for four basic reasons. First, it has the highest level of HIV prevalence among adults in Kenya aged 15-64 years, 15%, which is more than twice the national prevalence of 5.6% (Maina *et al.*, 2014; National AIDS and STI Control Programme (NASCOP), Kenya, 2014). Secondly, there are several risk factors that increase vulnerability to HIV infection in this area. These include the practice of widow inheritance[3] and the fish-for sex phenomenon[4]. Thirdly, the author (George Owino) is familiar with the culture and is a native speaker of the local mother-tongue. Therefore, he understands the research context and the interpretations of illness meanings of PLHIV in Kisumu County. Last but not least, the author has worked in the Nyanza region including Kisumu County in an HIV prevention programme and has been involved in a number of research studies evaluating HIV treatment programmes in this region. An example of these evaluation studies include that by Gerberg and Stansbury (2010), in which the author participated as a senior assistant researcher.

2.5.2 Study Population

This study targeted people diagnosed or tested HIV positive and who were receiving care, treatment and support at Patient Support Centers (PSCs) in Kisumu County. This population included those enrolled in the care and support programmes who had both asymptomatic and symptomatic conditions and who were both eligible (according to clearly outlined criteria) and willing to participate in the study. The study was conducted among selected PLHIV in

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[3] Widow inheritance is the practice among the Luo of Kenya whereby when a husband dies, a brother, cousin or other male relative takes his place to provide for his family and also help maintain the wife in the clan/community.

[4] A practice whereby women fish traders, in addition to paying for fish from fishermen, also need to have sexual liaisons with them in order to be guaranteed access to fish.

two health facilities, namely: Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH)[5] and St. Joseph's Nyabondo Mission Hospital. The facilities were purposively selected to represent both an urban (JOOTRH) and a rural (St. Josephs) catchment area. They were also selected because of the well-established PSCs and different types of ownership structures. Whereas JOOTRH is a public health facility managed by the Ministry of Health of the Republic of Kenya, St. Josephs Nyabondo is a mission hospital.

2.5.3 Sampling Procedures and Sample Size

The logic of sampling in qualitative research is not aimed at obtaining a sample on the basis of whose characteristics generalizations to the general population are to be made. The main consideration guiding sampling in qualitative research is getting respondents who can provide both relevant and quality information to help answer the research questions. As such, the information to be gained takes precedence over the numbers of respondents to be included. For this reason, samples in qualitative research tend to be rather smaller compared to those in quantitative research and are often arrived at purposively (Hansen, 2006). Consequently, sampling for the study was by purposive sampling procedures.

Purposive sampling is recommended for qualitative research by most researchers and is based on the relevance or correspondence between research participants and the research questions (Bryman, 2008; Hansen, 2006). Bowling and Ebrahim (2005:226) define a purposive sample as one “in which respondents, subjects, or settings are deliberately chosen to reflect some features or characteristics of interest.” According to Vogt *et al.* (2012), purposive sampling, also known as judgmental sampling, is the key method in interview research and involves two key steps. The first step is the definition of the target population from which the participants are to be selected. This population is defined based on the aims of the study and required population characteristics. The second step is the selection of a section of this population (sample) that is to be involved in the study. The primary aim of this selection is to locate individuals who possess the characteristics defined in the first step and who have the capacity to provide rich information that can answer the research questions. It is only after these two steps are completed that appointments for the interviews are scheduled.

There are neither fast and hard rules nor absolute guidelines on sample size determination in qualitative research (Bowling, 2009). As has been seen earlier, precedence is given to the quality of information that can be gained rather than to the sample size per se. According to a

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[5] Formerly known as New Nyanza Provincial Hospital but has been renamed to Jaramogi Oginga Odinga Teaching and Referral Hospital.

review by Vogt *et al.* (2012), most published articles on qualitative studies tend to have sample sizes ranging between 20 and 40 interviewees. Besides basing the sample size on the general practice, theoretical sampling is another option that can be adopted. Theoretical sampling refers to the point when the themes, stories and issues are recurring in subsequent interviews and no new information or insight is being gained. At this point, also known as saturation, the interviewing can be stopped (Bowling, 2009). Based on the aims of the research, the different characteristics in the respondents and the logical considerations discussed above (Bryman, 2008; Hansen, 2006), this study had planned to recruit 48 PLHIV for in-depth interviews, between 48-64 PLHIV for 8 focus group discussions (FGDs) and 6 people with expert knowledge for key informant interviews (KIIs) from the two health facilities. This information is presented in Table 2-1.

Table 2-1: Proposed sample size by facility, sex and methods of data collection

	Facility				
Methods	**JOOTRH**		**Nyabondo**		**Total**
	Male	Female	Male	Female	
In-depth Interviews	12	12	12	12	**48**
Focus Group Discussions	12-16	12-16	12-16	12-16	**48-64**
Key Informant Interviews	2	1	1	2	**6**
Total	**26-30**	**25-29**	**25-29**	**26-30**	**102-118**

The sample for the 48 in-depth interviews and 8 FGDs was to comprise of the primary study participants—PLHIV enrolled in and receiving treatment and care services at the two facilities mentioned above. The sample was to be composed of both men and women who had been enrolled at the PSCs for at least six months. In the selection of participants for the FGDs, preference was to be given to members of pre-existing patient support groups (PSGs). Those who were to be interviewed as key informants were to include one (1) PSC coordinator, one (1) PSC nurse, two (2) Community Health Workers (CHWs) and two (2) support group leaders. It was intended that in constituting the FGDs, homogeneity was to be arrived at by having two (2) FGDs for men and two (2) for women.

2.6 Field Research Preparation

The key issues that were considered in preparation for data collection included an exploratory field trip to Kenya, seeking research authorization and ethical clearance, and defining the mode of achieving informed consent requirements. These issues are presented below.

2.6.1 Exploratory Field Trip to Kenya

In preparation for conducting the proposed research, an exploratory field visit to Kenya was done between July and August 2012 and through this visit, the PI accomplished a number of objectives. First, the trip enabled him to familiarize himself with the study area and to establish formal contacts and a working rapport with the key personnel in the facilities in which the study was to be conducted. He visited both facilities and met with the Director of Research at JOOTRH and with the PSC Coordinator and her key personnel at St. Joseph's Nyabondo. Second, he acquainted himself with the mechanisms of recruitment of research participants and the conditions under which the research process would take place. The PI also figured out the potential difficulties that he would meet and thus prepared adequately and in a timely manner to overcome them.

Third, he gathered information concerning the procedures for carrying out research as well as the ethical requirements within the two health facilities. The process of research authorization and ethical review is outlined in the *Research Authorization and Ethical Clearance* sub-section. The ethical approval application was done after the PI had returned to Germany and after he had redrafted the research proposal to take into account the ethical and other administrative requirements identified during the exploratory field trip. Finally, the trip was useful in helping the PI appreciate the kind of bureaucratic, social and scientific preconditions necessary for carrying out a successful qualitative research with PLHIV in the two facilities in Kisumu County. This kind of background information proved useful in the subsequent application for ethical approval at Kenyatta University and for application for research authorization from the Kenya National Council for Science and Technology (NCST).

2.6.2 Research Authorization and Ethical Clearance

Authorization to conduct research in the form of a research permit was granted by the NCST. The NCST is the body mandated to coordinate and authorize all research activities in the country in line with the Science, Technology and Innovation (STI) Act of 2013 (Kenya National Assembly, 2013). The study complied with all the relevant guidelines described in the ethically approved research protocol as well as those contained in the documents of ethical approval from both Kenyatta University and JOOTRH. The research also strictly adhered to the terms of the research authorization granted by the NCST.

As this study was conducted under the rules of the School of Public Health, University of Bielefeld, first, the Ethical Committee responsible for the University of Bielefeld was consulted.[6] Given that the study was to be conducted in Kenya, the ethical responsibility was delegated to Kenyan institutions. Thus, the study received ethical approval from the Kenyatta University's Ethical Review Committee (KU-ERC). Additional ethical review was done and approval granted by the Institutional Ethical Review Committee of the JOOTRH. Ethical approval by the Institutional Ethical Review Committee is mandatory for any research conducted at JOOTRH.

2.6.3 Informed Consent and Confidentiality

The participants were involved in the study based on their informed consent. They were briefed on the purpose, objectives as well as the potential benefits of the study before the discussions and interviews began and consent obtained. This was accomplished by reading out loud to them the content of the informed consent forms. For the in-depth interviews and KIIs, written consent was requested prior to commencement of the research whereby the participant (s) upon granting consent signed a prescribed consent form attached to the ethically-approved research protocol (Bowling, 2009). For the FGDs, a representative nominated by the group signed a consent form after the group had orally consented to participate in the study. The PI informed the participants that their confidentiality and privacy would be preserved and further that no identifying features of the respondents would be attached to the data. They were informed that instead, codes and other identifiers—such as socio-demographic characteristics—would be used to distinguish the data sources. The participants were further assured that the codes would not be used to reveal their identities but to help categorize the information.

Additionally, the PI and the research assistants treated the participants with courtesy and respect and viewed them not only as subjects for the study but as active partners in the process of data generation. The participants' time was used effectively by endeavouring to gather the information within the least amount of time possible. The research assistants committed themselves to keeping the information collected confidential. Since it was important for the discussions and interviews to be audio-recorded, permission to audio-record

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[6] At the time of seeking clearance for the study, the ethical committee of the neighboring University of Muenster was responsible; however, the University of Bielefeld founded its own ethical committee in 2013.

was sought before the sessions began. The audio-recordings are determined to be deleted after the research process is successfully completed and the dissertation procedures are finalized.

The study participants were additionally informed of their right to self-determination, whereby they had the liberty to decide to terminate their participation at any time and the freedom not to respond to any question or item they felt uncomfortable about (Bloor *et al.*, 2001; Bowling, 2009; Gibbs, 2007). The participants voluntarily engaged in the study and all sessions were completed without any incidents of either termination or declination to answer any item. There were also no extreme emotional situations that required any intervention.

2.7 Field Research Process

The main activities performed while in the field for data collection included the recruitment and training of qualified and experienced research assistants, gaining access to and recruiting study participants according to specified inclusion and exclusion criteria, finding suitable settings for data collection and creating rapport with the participants and administering the research instruments and carrying out the actual work of data collection.

2.7.1 Recruitment and Training of Research Assistants

The collection of data was carried out by the PI with the help of three research assistants. These assistants were recruited based on their language competency, research experience and academic qualifications. Prior experience in conducting research with specific emphasis on qualitative methods was required. Each of the research assistants had obtained training in the social sciences whereas two had bachelor's degrees with majors in sociology and anthropology and one had double majors in sociology and economics. Additionally, each of them had been involved in various research studies and had experience with both qualitative and quantitative data collection methods. They had also attended a number of workshops, seminars and trainings on community mobilization, HIV/AIDS behaviour change communication, counseling and gender sensitization. The research assistants were therefore considered to be well qualified for the work.

After the recruitment, the assistants were taken through the problem definition, the purpose and objectives, the research questions, the methodology, the sampling procedure and sample size, the methods of data collection and the ethical guidelines of the study. A practical session on how to conduct interviews was also held. During this session, the PI took the assistants through all the data collection instruments. This was to ensure that the meaning of every major concept in the instruments was clearly understood by all. The instruments were translated into the local language as most of the study participants were not fluent in the English language. Methodologically, translation was to ensure that a standard way of phrasing the questions and clarifying the concepts was developed. This standardization was necessary in order to guarantee consistency, reliability and validity of the data collection process. The translated instruments did not deviate in any way from the ethically approved English version except for being translated into the local language. The research team pretested the instruments among themselves to ensure that the items were clear and free from ambiguities. The research assistants were finally trained on how to operate the digital audio-recording devices to be used to record the patients' interviews, FGDs and KIIs.

2.7.2 Recruitment of Research Participants

The process of gaining access to the health facilities and the study participants and of getting to collect data for this study was a multistage process that involved getting through a bureaucratic chain of gate keepers from the national to the health facility level (Green and Thorogood, 2009). Lessons learned in this study revealed that gaining access is at best a continuous process that can be drawn out as it involves relationships and interactions with people in totally different institutional and cultural contexts (Butler-Kisber, 2010). For this study, the process began by applying for and obtaining ethical clearance from Kenyatta University Ethical Review Committee (KU-ERC) and research authorization from National Council for Science and Technology (NCST) as has been discussed in sub-section on *Research Authorization and Ethical Clearance*.

After all official and ethical procedures from the national and district levels were fulfilled, appointments were booked with the PSC Coordinators of both facilities in order to discuss the modalities and details of the research. The PSC Coordinators represented the lowest level of gatekeepers who interact directly with the PLHIV and whose support and advice is key in assuring success in this kind of research (Green and Thorogood, 2009). The PSC coordinators are responsible for all aspects of the treatment and care programmes for PLHIV in these two facilities. In the discussions, the PI first introduced himself, his institutional affiliation and the purpose for visiting the facility.

The PI then proceeded to describe the purpose and objectives of the study and the kind of assistance he expected from the PSC coordinators. Further issues that were discussed in details were: the characteristics of the eligible research participants; the inclusion criteria; the process of informed consent; how confidentiality of data would be assured; how the data would be collected; and how the results of the study would be shared with the facilities and participants. Logistical matters including the locations and timings for the interview and FGD sessions and other issues that required clarification and prior planning before the start of data collection were also addressed.

The PI shared with the PSC Coordinators the proposed plan for conducting the study including the number and characteristics of participants for the different methods of data collection (PLHIV in-depth interviews, FGDs and KIIs). After deliberations and some adjustments to the proposed plans, final and concrete appointments for the data collection were made. In many cases, appointments for FGDs were fixed to coincide with the regular PSGs meeting days that already existed as part of their normal activities. This was to ensure as little interruption to the participants' everyday pattern of life as possible. In the case of St. Joseph's Nyabondo, a member of staff of the PSC actually accompanied the PI and his assistant to two venues of PSG meetings where two FGDs were to be held. These FGDs were held some distance away from the hospital. Otherwise all the other sessions for PLHIV in-depth interviews, FGDs, and KIIs were held within the health facilities. The two PSC coordinators and their personnel helped in the recruitment of the study participants, in fixing of meeting appointments with the participants and in mobilizing them for these appointments. The process of gaining access to the research participants is outlined in Table 2-2.

Table 2-2: Stages in accessing research site, research participants and data collection

Stage	**Activities**	**Key Results**
Stage I	Application for ethical approval	Ethical approval document (s)
Stage II	Application for research authorization	Research authorization letter and permit
Stage III	Reporting to relevant district officials • District Commissioner • District Education Officer • District Medical Officer of Health	Endorsements from relevant government ministries
Stage IV	Holding formal discussions with PSC coordinators	Negotiated concrete data collection plan
Stage V	• Negotiating access to participants • Conducting interviews, FGDs and KIIs	• Informed consent forms; • Audio-records of interviews, FGDs and KIIs

2.7.3 Inclusion and Exclusion Criteria

PLHIV recruited were those above 18 years old; who were participating in the care, treatment and support programmes in one of the two facilities; who had received a positive HIV diagnosis of at least six months; who belonged to and were active members of a patients' support group (PSC) and who were able to communicate fluently in either English, Kiswahili or Dholuo language. Since participation was voluntary and based on informed consent, only those who were willing participated.

PLHIV were excluded from the study if they were under 18 years of age. Those who were not willing to freely discuss their illness experience due to issues with disclosure were also not selected to take part in the study. Since living with HIV is an emotive issue, those who were undergoing emotional or psychological and even social and physical distress at the time of the study were excluded from participating in the study. Those who were not able to communicate effectively in either Dholuo, English or Kiswahili were similarly not eligible to participate. The decisions concerning those who participated in the study were arrived at in consultations with the PSC Coordinators.

2.7.4 Setting for Data Collection

As it is desirable to get a quiet and private place for conducting interviews, FGDs and KIIs (Green and Thorogood, 2009), the interviews were mostly done in the context of the health facilities except in the case of two focus group discussions in St. Joseph's Nyabondo that were held away from the health facility. Due to lack of free rooms, the sessions were mostly conducted on verandas of buildings or under trees separated from the out-patient area. This was to ensure privacy and also to avoid distraction.

At both health facilities, however, the team had to contend with a noisy environment, which sometimes necessitated pausing both the interview and the recording for short periods of time. The PI and his assistants had to equally put up with other continuous interruptions like noise from animals, the blowing of the wind, and noise from traffic or other activities. However, the interruptions due to the noises were not very disruptive. Some of the interview sessions were slightly affected and in some cases, there were some inaudible portions but these were not serious such as to distort the flow of the participants’ illness accounts. Nonetheless, such portions necessitated more concentrated attention during transcription so as to ensure accuracy.

2.7.5 Rapport and Administration of the Tools

Rapport with the research participants was initially ensured through methods of access and was mainly by way of their trusted service providers. Being within the context of the health care provision gave the study an aura of legitimacy. The PI and his assistants introduced themselves before the start of every encounter and briefly introduced the purpose of the study and generally informed the participants of the intended goals and benefits as outlined in the consent form document. Thereafter, consent was sought from the participants. Once consent was granted, the participants were invited to feel free and to audibly discuss the issues at hand. They were assured of confidentiality and anonymity.

The team adopted a non-judgmental attitude since the issue handled—living with HIV—is a highly emotive and sensitive topic. The team was careful not to appear to be unsympathetic and insensitive to the status of the participants. The team showed genuine interest in the participants' responses and encouraged them to talk freely about their experiences. The researchers were also sensitive with regard to the use of time and endeavored to take the shortest time possible.

Attention had been paid to devising alternative ways of phrasing questions to ensure clarity. In asking questions, it was evident that some items were still not very clear and the concepts were somehow not easy for some respondents to grasp. To surmount these problems, the PI and his assistants interpreted the questions in a way that made sense to the interviewers. After the initial interviews, the general responses were emerging and these led the team on what to expect for various questions, thereby helping clarify difficult questions to the respondents. The PI and the research assistants quickly adapted to these interpretations and would foresee the trouble spots and prepared for them in advance (Green and Thorogood, 2009).

The research team had to however remain vigilant and attentive to emerging meanings and interpretations. Some of the methods of phrasing questions, such as those mentioned by Green and Thorogood (2009), were adopted. These include: use of open-ended items; being non-judgmental and espousing an open-minded attitude; use of non-leading questions and reducing specialized terms to a minimum. Appropriate probes and prompts were included to encourage the participants to tell their stories. This was achieved through interrupting the respondents as least as possible, using prompts and “non-verbal cues such as head nodding”, and through using probes like “anything else?”, “what happened”... (Green and Thorogood, 2009). In a few cases, some of the research assistants occasionally used leading questions especially where they expected a particular answer. However, these occurred mostly as follow-up questions and not as main questions.

2.8 Data Recording, Transcription and Coding

In this section, the recording, storage and processing of the raw data is presented. The key issues described include how the data were recorded, how they were labelled for uniqueness and anonymity and how the data were transformed into text. The coding approaches including the levels of codes are also described. The section also addresses how the data were managed to facilitate the next stage of analysis.

2.8.1 Data Recording

The biographic data of the respondents were gathered through a bio-data sheet and the data from the interviews and discussions were recorded using digital audio recording devices that made the process of transferring the information to the computer easier. The research team had four such devices. The research assistants were trained on the use of the gadgets during the training session. The audio capture of the discussions and interviews were only done after informed consent and permission to do so had been granted by the participants. The audio recordings were transferred to the computer at the end of every week. In addition to the audio records, each research assistant had a note-book to note some of the striking issues and key emerging themes as well as their thoughts on the process. The PI also kept a field notebook-cum-diary where the events of the day were summarized and thoughts on the research process, insights on the research findings, and new hunches and ideas were recorded.

De-briefing meetings were held at the end of every day to review the progress, to share thoughts on the overall process, to highlight any challenges and difficulties and to recommend any necessary adjustments. After leaving the field of data collection, the team would gather at some location in Kisumu town and review the activities of the day. Each of the research assistants would share their experience as well as their impressions of the entire process for each single day. The implications of these experiences and impressions were discussed and used to inform the activities of the following day.

2.8.2 Data Transcription

The transcription of the digital audio-recordings of in-depth interviews, KIIs and FGDs into text was done so as to avail a record of the research and provide a basis for coding and analysis. Every discussion or interview required about 3-6 hours of transcription time depending on the length of the recording. The interviews were predominantly conducted in the local language (Dholuo). As a native speaker of the local Dholuo language, the principal investigator (PI) personally transcribed the audio-records of the data and concurrently translated them into English. The audio recordings were imported for transcription using Express Scribe Transcription Software Pro version 5.51 (NCH Software, 2013). This software was used to make the process of managing the audio files and the transcription more efficient. Each interview audio recording was uniquely labeled with codes indicating the site and method of data collection, the identity of the research assistant, and the details of the respondent—which were so devised to ensure anonymity of the participants. Care was taken to ensure that no unauthorized persons got access to the audio recordings in keeping with the ethical guidelines.

Transcribing the audio recordings personally by the PI provided valuable insights that assured the quality of the transcripts and their fidelity to the original interviews. Personal transcription also helped save on time since outsourcing the transcription would have still required that the transcripts be proof-checked against the audio-recordings for accuracy. Another crucial benefit of self-transcription is that it allowed the PI to develop an intimate connection and familiarity with the data. This familiarity provided insights into themes and categories that functioned as codes and suggested initial thoughts on the analytical process. Self-transcription continuously triggered novel thoughts about the data that were not evident during the design of the study and development of research instruments thus providing alternative interpretative perspectives (Gibbs, 2007).

As the transcription proceeded, completed transcripts were imported into MAXQDA Plus Student License Version 11, a qualitative data analysis software. The data were stored as PI assigned codes on the basis of which the data were subsequently retrieved for analysis. The qualitative data analysis software MAXQDA makes the process of data storage and retrieval efficient and easy and does so in a short period of time compared to manual methods (Gibbs, 2007).

2.8.3 Data Coding

The process of analysis involved a series of actions. After being collected, qualitative data was transformed from audio to textual form to provide a reliable basis for data coding and analysis. As has been mentioned, transcription was personally undertaken by the PI. The PI is a native speaker of the language of the research respondents and in which the data was collected. The next step was coding. Coding is the process of identifying research themes from interview and focus group discussions (FGDs) transcripts. According to Gibbs (2007: 38) coding

> "…involves identifying and recording one or more passages of text or other data items such as the parts of pictures that, in some sense, exemplify the same theoretical or descriptive idea. Usually, several passages are identified and they are then linked with a name for that idea – the code."

Coding involved identifying the basic themes from the responses of the interviewees that corresponded to the various research questions. This was followed by the identification of the intermediate and major themes, which were deduced from the basic themes. Intermediate and major themes represent a higher level of coding and allow for patterns to be identified within the data. The patterns identified provided the basis for making generalizations about the data. The generalizations provided answers to research questions and generated explanations and understandings of the experiences of living with HIV (Gibbs, 2007).

Transcription and coding proceeded simultaneously. After the completion of transcription, the coding system was reviewed and refined. Even as transcription and coding were underway, analytical and interpretative insights that emerged from this close interaction with the data were promptly noted down in the research diary. These insights provided initial hunches and hypotheses for analysis and interpretation.

This study used both concept-driven and data-driven coding strategies. According to Gibbs (2007), concept-driven coding is where a PI builds codes based on "…research literature, previous studies, topics in the interview schedule, hunches…about what is going on, and so on" (Gibbs, 2007:44). This coding strategy corresponds to the deductive approach to qualitative analysis and was the one adopted in this study. The code book was however treated as tentative and considered amenable to amendments as the process of coding and analysis progressed because new ideas kept emerging from the text (Barbour, 2008; Gibbs, 2007). The second approach, data-driven coding, corresponds to the inductive approach and begins from the data themselves and does not depend on prior notions or concepts gleaned from literature or theory. The researcher starts "…by reading the texts and trying to tease out what is happening" (Gibbs, 2007:45). These two methods are however not necessarily mutually exclusive.

This study entailed a mix of both strategies (concept-driven and data-driven coding) whereby concepts or themes identified prior to data collection were used while sufficient flexibility was allowed to incorporate new ideas or concepts that emerged from the data as transcription and analysis continued (Barbour, 2008; Gibbs, 2007). The PI identified and interrogated his preconceived notions and ideas that could be a source of bias in the identification of codes, definition of analytical categories and analysis and interpretation data (Barbour, 2008; Gibbs, 2007).

In the concept-driven approach, three different coding levels can be identified. Coding levels mainly refer to the function a code is performing as well as the level of abstraction at which it is operating. The levels of abstraction denote the distance between the analytical codes and the responses and words/concepts used by interviewees. The three levels, beginning with the most basic are descriptive codes, analytic codes and pattern codes (Lewins and Silver, 2007).

Descriptive Codes

A descriptive code represents the lowest level of coding and relates to concepts, ideas, actions or themes as they appear in the data. They are the initial themes that are derived directly from the responses of the research participants and are used to facilitate the grouping of segments of text in terms of the ideas they are basically about. These codes are closely related to the aims of the study and could be based on the guiding theoretical framework, literature review, research questions or on the interview items (Gibbs, 2007). At this level of coding, the researcher defined grouping labels that served to bring together responses from various respondents that corresponded to the ideas represented by that label. More analytical work was done to these text segments at the next stage of coding. Descriptive codes are to be seen as tentative and are identified by reading though the transcripts to identify the chunks of text that fit to these pre-defined codes and applying the code to them (Lewins and Silver, 2007).

Interpretive or Analytical Codes

Once the data have been descriptively coded, the next stage involves closely reading and re-reading the coded segments and grouping those that have common characteristics or that are related with regard to a certain domain of interest. This process often entails breaking down the existing codes and developing a more analytical and detailed coding system. This process may also involve merging and/or splitting of codes based no how best they capture the emerging patterns in the data. At this level, categorization and classification occurs whereby similarities and differences between coded segments form the basis for developing higher level of codes and for grouping the chunks of text from the respondents. Analytic coding involves a constant process of comparing and contrasting the coded texts segments and those found to be similar are then lumped together (Barbour, 2008; Gibbs, 2007; Lewins and Silver, 2007).

Pattern Codes

Pattern codes are the next level of abstraction as the distance between researcher generated categories and the raw data increases. At the pattern code level, inferences are drawn and plausible interpretations made based on patterns or regularities observed from the data. This stage involves the exploration of the patterns with which codes defined at both the descriptive and analytical stages appear in the data, both within and across cases. It also involves deciphering the patterns that emerge from various sub-sets of data. In this study, the patterns were assessed based on how they were differentiated among other considerations: the health facility from which the PLHIV received care; their socio-demographic characteristics such as gender, age, marital status, education levels; the length of time a PLHIV had known their status; and the specific circumstances that surrounded their diagnosis. Cases or instances that appeared exceptional or non-typical were identified and the extent of their difference examined and possible explanations for these differences given (Barbour, 2008; Lewins and Silver, 2007).

2.9 Data Analysis, Interpretation and Presentation

In this section, the method of data analysis has been described. A clarification is also provided detailing how the main themes of the study were identified, explained and how data was presented.

2.9.1 Data Analysis-The Hermeneutic Method

The goal of analysis in qualitative research is to provide plausible and empirically founded interpretations of the meanings that social actors give to their social behaviours, actions and experiences. This implies the transformation of the data contained in interview transcripts from mere descriptive accounts as provided by the respondents to more abstract and analytic themes and categories provided by the PI. These abstract and analytic themes and categories are the devices through which the researcher gives structure and coherence to interviewees' accounts (Hansen, 2006; Holloway, 2005b; Pope *et al.*, 2006b). Analytic approaches for qualitative data are informed by the methodological and theoretical approaches underpinning the study, the research questions and research objectives (Pope *et al.*, 2006a), as well as by the preferences and competencies of individual qualitative researchers (Hansen, 2006).

The hermeneutic phenomenological method is the research design for this study that also influenced the analysis, interpretation and presentation of data. Hermeneutics is basically the science of interpretation of texts. According to Rapport (2005:131), hermeneutics is the description of experience as narrated by the respondent and as mediated by the PI's interpretation. In the hermeneutic phenomenological approach, data collection "has been described as a vehicle for gathering rich, in-depth data that are dependent on the interviewees' description of events as an example of the original" (Rapport, 2005:134). In this sense, the researcher adds value to the information gained from the interviewees by interpreting them in the context of a theoretical, methodological and empirical framework. The main thrust of the interpretive argument is that "meaning is unique and cannot be described" (Rapport, 2005:130). In order to arrive at meaning, Rapport argues that "interpretation is vital if we are to move beyond the data" (Rapport (2005:130). Therefore it is the researchers' responsibility to create meaning from what the respondents are saying.

Views on how to make sense of the phenomena under investigation such as those expressed by Rapport, (2005), are shared by Holloway (2005). Holloway (2005), emphasizes the necessity of fusing the understandings and concepts provided by the respondents with the interpretations that the researcher deduces from these respondents' accounts. The viewpoints of the respondents are referred to as emic accounts (an insider's perspective) and represent the inner understandings the research participants have concerning the phenomena under investigation. The explanations the researcher deduces from these emic accounts are known as etic accounts and represent an outsider's perspective. In providing effective and adequate interpretations of the experiences of living with HIV, the descriptive and everyday language accounts of the respondents have been transcended. This involved developing more abstract levels of theoretical and analytical concepts that went beyond the everyday accounts of the participants. This has been achieved through the coding, analysis and writing process (Holloway, 2005).

Van Manen has proposed a six-step process for executing the hermeneutic phenomenological method. This six-step process spans the entire research spectrum from problem identification and definition through to data collection, analysis and reporting of research findings (Rapport, 2005:133). This process epitomizes for van Manen the ideal of a hermeneutic methodological process. These steps are presented in Figure 2-2:

Van Manen’s hermeneutical six-step process

a) Turning to a phenomenon which seriously interests us and commits us to the world;
b) Investigating experience as we live it rather than as we conceptualize it;
c) Reflecting on the essential themes which characterize the phenomenon;
d) Describing the phenomenon through the art of writing and rewriting;
e) Maintaining a strong and oriented…relation to the phenomenon;
f) Balancing the research context by considering parts and whole.

(**Source**: Rapport, 2005:13)

Figure 2-2: Van Manen’s six-step hermeneutical method

The goal of data analysis in hermeneutic method is to make meaning out of the stories presented by respondents with the goal of having a better understanding of their experiences and their circumstances (Holloway, 2005; Pope et al., 2006a). This process of interpretation is heavily dependent upon the “personal historical background, concentrating on ones’ response to the language used by the participant, which carries along with it history and tradition” (Rapport 2005:134). The sequence then is to develop an understanding of what the respondents are saying, develop a plausible explanation of their accounts and come up with plausible interpretations of these accounts. In order to give a credible interpretation of the phenomena, the researcher’s explanations must be based on an understanding of the interviewees’ accounts (Pope et al., 2006a; Rapport, 2005).

The qualitative research literature document a variety of strategies that can be adapted to analyze qualitative data and create a generalized account of the phenomena under study. It is advised by qualitative researchers that these strategies should be used with a relative degree of flexibility given that there are no hard and fast rules for using them. Instead of being seen as straitjacket procedures, these approaches should be viewed as tools for guiding, reflecting on and aiding the discovery of interconnections within qualitative data (Hansen, 2006; Pope *et al.*, 2006b). The main analytic strategies identified in the literature include content analysis, narrative analysis, discourse analysis, grounded theory, framework approach, thematic/iterative analysis among other approaches.

2.9.2 Explaining Themes and Patterns

For this research, a thematic/iterative analytic approach embedded within a hermeneutic phenomenology was adopted. This analytic approach blends both deductive and inductive approaches. This approach relied on the predefined themes to identify major thoughts, concepts and categories emerging from the texts. Some of these themes were not foreseen during the research design stages The (Barbour, 2008; Hansen, 2006; Pope *et al.*, 2006a). Iterative analysis also known as the *constant comparison method* involves a systematic exploration of what the different interviewees are saying and the contexts in which they make their statements. During this iterative and constant comparison process, forward and backward movements within and across cases or transcripts within the database occur, even as the process of interpretation proceeds. As a result, themes are identified, refined, merged and others discarded (Gibbs, 2007; Pope *et al.*, 2006a).

The development of a generalized, interpretive account that describes the fundamental nature of the experience of living with HIV requires familiarity with the literature and various relevant theoretical frameworks. Such generalized interpretive accounts should be cognizant of the perspectives of the respondents and the various social, economic and political contexts in which they live. Generating such a coherent explanatory model of what it means to live with HIV also needs to take account of any "…elements in the data that contradict, or appear to contradict, the emerging explanation of the phenomenon under study". This involves an iterative process –going back and forth through transcripts and coded sections- of constantly comparing and contrasting "a variety of ideas expressed in order to arrive at a definitive understanding of the text" (Rapport, 2005:135).

The PI acquired an intimate connection to the interviewee's accounts from a number of sources. First, the PI was personally involved in the formulation of the research problem, research design and in the data collection processes. Even though research assistants were involved, the PI also conducted a number of face-to-face interviews with the respondents and was also in-charge of the entire process. Second, the PI transcribed the audio recordings personally. Through this transcription, the PI was able to come to grips with the structure of the experiences of people living with HIV (PLHIV) based on the various domains being investigated. Third, the PI is a native speaker of the language spoken by the study population and which was the language used in the data collection process. Fourth, the PI has been previously involved in research and evaluation of projects with similar target groups in the same geographical setting. As such, the PI is intimately familiar with the issues under investigation.

Identifying the themes and patterns was done through reliance on the *selective* or *highlighting* approach proposed by van Manen (Rapport, 2005). This technique, comprises of the following four stages (Rapport, 2005:35):

a) Searching for structures of experience.
b) Describing how structures are thematic of the phenomenon.
c) Searching for essential and incidental themes.
d) Explaining and interpreting essential and incidental themes.

In the preparatory stages of qualitative data analysis, the PI began by reducing the data from in-depth interviews, FGDs, and key informant interviews into text. After transcription, the PI drew out meanings from the text transcripts through reading and re-reading of the various types of data collected through the *constant comparison method*. This stage involved identifying and picking out the “structures of experience” (Rapport, 2005: 135). Structures of experience are representative phrases that most closely provide answers to research questions and that were key to the study as they were distinctly representative of the phenomena under investigation. These structures of experience were identified based on research questions and the PI’s hypothetic hunches as to the probable nature of the phenomenon. These representative phrases clarified and provided an analytic structure to the consistently emerging and the non-typical themes in the data.

In the second stage, the PI explained how the structures of experience were illustrative of the phenomenon. This was done by looking at the linkages the structures of experience had to specific aspects of the experience under investigation. For example, in the case of the question that sought to know how the respondents knew about their HIV status, issues like temporal aspects (when they knew their status), spatial aspects (where or in which facility), and decisional aspects (who decided for testing) of knowing status were some of the links that explained how each particular theme is related to the experience of knowing one’s status (Rapport, 2005).

The third stage involved exploring the database and selecting statements or sentences that corresponded to or were contradictory to the structures of experience identified in the first stage. The representative phrases were typical of the experiences described by the respondents and therefore provided the basis for identifying such statements from the numerous transcripts. The structures of experience also helped in identifying the apparently contradictory or inconsistent texts and which seemed out of place with the majority of the cases. These contradictory statements were not overlooked but were picked out and explained. The representative phrases were additionally important in selecting the portions or segments of data that are presented in the report as evidence for interpretations and conclusions arrived at (Gibbs, 2007; Holloway, 2005).

The fourth and final stage according to van Manen, (in Rapport, 2005), is to provide an explanation or interpretation of the patterns that have been identified in both the representative and non-representative phrases. Interpretations have been offered for the patterns within the data in order to try to rationalize why the patterns are the way they are. Similarly, probable explanations have been given for any contradictory findings. The explanations and interpretations made have been based on different demographic and social characteristics of the respondents such as age, gender and marital status. The important contextual factors such as the facility where one receives their treatment and care and the circumstances under which one got to know their HIV status have similarly been used as a basis for providing these explanations (Barbour, 2008; Holloway, 2005; Rapport, 2005).

2.9.3 Presentation of Research Findings

The research findings have been presented on the basis of research objectives and research questions. In doing so, the major patterns and general trends identified are presented while paying attention to the diversities that could have resulted from different contextual factors such as gender, age, marital status and facility where services are sought. The conclusions reached or interpretations presented concerning the meanings that the respondents attribute to their experiences are based on the data as provided by respondents. These interpretations have been compared with and presented in the context of literature and the theoretical orientations of the study. As a way of ensuring credibility and confirmability, representative quotations from the data have been presented to exemplify the patterns and interpretations made. Various possible alternative explanations or interpretations have been explored and what has been presented are the best compromise interpretations supported by the data (Holloway, 2005a; Lincoln and Guba, 1999; Mays and Pope, 2006).

2.10 Outline of the Research Process

The entire research process as illustrated in Table 2-3, involved development of the research proposal in consultation with the supervisor, and a field trip to gather information about the study area and study participants. The other activities included the preparation for data collection—that included applying for ethical approval, and research authorization—actual data collection, data processing, including transcription and coding, data analysis, and drafting of the dissertation.

Table 2-3: Outline of the research process

Time Frame and Place	**Activities undertaken**	**Outcomes achieved**
I. Proposal Development *2012 April -2012 June (Germany)*	• Reviewed related literature; • Defined research problem, objectives, questions, and methodology; • Constructed data collection instruments; • Attended doctoral colloquia (DC) and submitted qualifying papers (QPs); • Planned for field visit.	• Comprehensive draft proposal; • Attendance certificates • Field visit plan.
II. Pre-Research Visit *2012 July -August (Kenya)*	• Applied for research authorization from NCST; • Applied for ethical review at JOOTRH; • Held discussions with PSC Coordinator, St. Joseph's Nyabondo Mission Hospital.	• Research permit; • Ethical approval.
III. Preparation for Data Collection (Fieldwork) *2012 October - 2013 June (Germany)*	• Refined proposal incorporating field experiences and JOOTRH comments; • Applied for ethical review (in Kenya); • Attended DCs and submitted QPs; • Applied for DAAD approval for visit.	• Revised proposal; • Ethical approval; • Attendance Certificate.
IV. Data Collection *2013 July-August (Kenya)*	• Collected research authorization; • Recruited & trained research assistants (RAs); • Held planning sessions with PSC coordinators; • Collected data.	• Research permit; • 3 Trained RAs; • 2 Data collection plans; • 65 Audio data recordings.
V. Data Processing - Transcription *2013 September - 2014 March (Germany)*	• Transcribed audio recordings of interviews, FGDs and KIIs; • Developed thematic-based coding system; • Attended DCs and submitted QPs.	• 65 Audio data Transcripts; • 1 Code-system; • Attendance certificates.
VI. Data Analysis & Dissertation Writing *2014 April - September (Germany)*	• Analyzed and interpreted data; • Drafted results chapters of dissertation; • Attended DCs and submitting QPs.	• Analysis print-outs; • Written chapters; • Attendance certificates.
VII. Finalization and Submission of Dissertation *2014 October - 2015 March (Germany)*	• Revision of Dissertation; • Attended DC (s) and submitted QP (s); • Submission of Dissertation; • Disputation of Dissertation.	• Final Dissertation; • Attendance certificates • PhD Diploma/Certificate.

2.11 Chapter Summary

In this chapter, the research objectives and questions and the epistemological considerations incorporating the research methodology and research design have been presented. The chapter has also described the data collection methods, the study site and population and the preparation for field research. The field research process, data recording, transcription and coding techniques are also clearly outlined. In addition, the analytic method, the interpretation of the main themes and the presentation of the findings have been described. Finally, an outline of the entire research process has been presented.

In the next three chapters, the findings of the study have been narratively presented incorporating graphical and tabular aids. The findings also include representative quotations, analytical categories and PI interpretations of the key patterns identified from the data.

3 RESULTS PART I: BEING DIAGNOSED HIV POSITIVE

3.1 *Chapter Overview*

In this chapter, the first part of the study findings dealing with how the participants were diagnosed HIV positive are presented. The chapter initially describes the socio-economic and demographic information of the participants. The chapter then examines the circumstances under which people living with HIV (PLHIV) got to know their status, the health facilities where they were diagnosed and the length of time they had known their status. Next, findings on the key persons who made or influenced the decision for testing are described. Also presented in this chapter are findings on how the participants initially reacted to the test results and how they reconciled themselves to and accepted a positive HIV diagnosis. Finally, the PI presents a proposed model synthesizing the issues connected with being diagnosed HIV positive.

3.2 *Participants Socio-economic and Demographic Characteristics*

In the study, 49 (20 male and 29 female) PLHIV were interviewed over a two-month period—between July and August, 2013—in two health facilities in Kisumu County, Kenya. Similarly, a total of 60 participants (33 male and 27 female) took part in 8 FGDs across the two facilities. Most participants were aged 26 years and above with those 46 years and older being the majority (33%). The distribution of participants between the two study sites was skewed in favour of St. Joseph's Nyabondo, which accounted for 56% (61 vs. 48) of the PLHIV. Table 3-1 provides a detailed account of the demographic characteristics of the participants. An additional 6 people (2 male and 4 female) were involved in KIIs, but since they were not part of the primary target group, their socio-demographic information was not collected and is thus not included in the Table 3-1.

Additional information from Table 3-1 indicate that the majority (67%) had monthly incomes of not more than Kenya shillings (Kshs.) 5,000, (exchange rate at the time of the field research August 2013: EUR 1 = Kshs. 110, thus approx. equivalent 45€). One-half (50%) had up to primary (standard eight) level of education with 13 participants or about 12% having post-secondary education. About one-half (49%) were married and slightly more than one-quarter (27%) were widowed. Those who were either divorced/separated or single accounted for about 6% of all participants—those who were the main study sample, PLHIV.

Table 3-1: Socio-demographic characteristics of study participants

Characteristic	**Categories**	**Frequency (n=109)**	**%**
Sex			
	Male	53	48.6
	Female	56	51.4
Age in Categories			
	18-25	13	11.9
	26-35	32	29.4
	36-45	28	25.7
	46+	36	33.0
Data Collection Method			
	In-depth Interviews	49	45.0
	Focus Groups	60	55.0
Health Facility			
	Nyabondo	61	56.0
	JOOTRH	48	44.0
Monthly Income (Kenya shillings)[7]			
	≥5,000*	73	67.0
	5,001-10,000	32	29.4
	10,000+	3	2.8
Education			
	Primary	54	49.5
	Up to Secondary	42	38.5
	College+	13	11.9
Marital Status			
	Single	20	18.3
	Married	53	48.6
	Divorced/Separated	7	6.4
	Widowed	29	26.6

A total of 25 PLHIV (11 male and 14 female) were interviewed at St. Joseph's Nyabondo whereas 24 (9 male and 15 female) were interviewed at JOOTRH. Even though equal gender representation was envisaged, this was not realized at both facilities. It was intended that twelve (12) males and twelve (12) females would be interviewed per facility. Attempts were made to include people with varying levels of education and disaggregated by age as well. It had been planned that one-half of each gender from either facility range in age from 18-35

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[7] 1 € = 110 Kenya shillings

years while the other half was to be of age 36 years and above. However, this was not realized as the older (36 and above) tended to dominate. The dynamics of participant recruitment made it difficult to get the intended age requirements. It was also planned that the FGDs be disaggregated by gender. This was successful in JOOTRH but not at St. Joseph's Nyabondo, where all of the focus groups were mixed with varying gender compositions. In all the four FGDs conducted at St. Joseph's Nyabondo, women tended to dominated.

3.3 Circumstances of Knowing HIV Status

According to FGDs, KIIs and in-depth interview, people got to know their HIV status in contexts of personal or illness of a spouse, medical emergencies (such as rape or accidents), blood donation, suspicious and abnormal signs and symptoms, ante- or post-natal care, death of a spouse or parent (in case of youth infected by their mothers), miscarriages or still-births, during early preparations for marriage, peer influence (especially for the youth) and as a response to VCT campaigns targeting the general public.

A majority of the FGDs, KIIs and in-depth interviews concurred, however, that the main circumstance under which people learnt of their HIV was illness; either personal illness or that of a spouse, child or close family member. Such illnesses often led to personal suspicion of HIV infection. In a majority of cases, these illnesses were serious and prolonged and in a number of cases led to death of a spouse. In Table 3-2, the circumstances under which in-depth interview participants were diagnosed as HIV positive are presented.

Table 3-2: Circumstances under which PLHIV knew about their HIV status

Circumstances	**Female (n=30)**	**Male (n=19)**	**Total**
Due to personal illness	16	14	**30**
Due to spouse’s illness	6	1	**7**
Due to ante-&post-natal care	5	0	**5**
As a response to public health campaigns	2	3	**5**
Others	1	1	**2**
Total Responses	**30**	**19**	**49**

Though each experience was unique, there are four main situations that prompted the respondents to know their status. These four main circumstances are the following: personal illness, illness or death of spouse, antenatal care and response to public health campaigns that encouraged people to know their HIV status. Detailed accounts of the main circumstances of knowing HIV status are presented sequentially in the next sub-sections.

3.3.1 Personal Illness

Personal illness was the main circumstance under which the majority of the respondents got to know their status. About three-fifths of the in-depth interview respondents (*n*=30; 16 female and 14 male) knew of their status due to a personal illness. A remarkable feature of these illnesses was their protracted nature. Most of the respondents had suffered from a recurring illness that could neither be reliably explained nor effectively treated. They would be sick on-and-off for extended periods of time. In most cases, diagnosis came at moments when the respondents were admitted to hospital and an HIV test was a recommended by a doctor as a way of helping determine the underlying cause of the recurring illnesses. According to a male respondent:

> I got to know it when I was very sick. In fact I was sick. I would be coming to the hospital, I would have headache and slight diarrhea, and I would constantly come to the hospital. When I would be given some little drugs, enough drugs, it would dissipate and disappear but after some months it would recur. So I became very ill to the point that I was bedridden (R29: married male, age-group 18-25; 5).

A female respondent had this to say:

> How I got to know that I had HIV, initially, it really gave me great problems when I used to fall sick on-and-off, but I would not go for medical care. So when it reached sometime, this *herpes zoster* attacked me on this side. So it is at this point that I went to another hospital - Chulaimbo. So that is where they did for me counseling and they also tested me. So after testing me, they told me the nature of the results. So when the results came, it revealed that I was HIV positive (R15: married woman, age-group 36-45; 3).

Within the FGDs, personal illness also emerged as the main circumstance leading to a diagnosis with HIV. The FGD participants mentioned that most people, including themselves, got to know their status when they had been ill and sometimes after several episodes of illness and admission to hospital. One female FGD participant had the following to say:

> In most circumstances you will find that someone is down, bedridden, is when they get tested. Especially when they visit the health facility for other reasons is when they get tested and know their HIV status (FGDFY-009, 6).

The key informants seemed to concur with the assumption that most cases of diagnosis occurred in the context of personal illness. One key informant commented that: "under circumstances is when people are sick, when someone is admitted or visited a health facility, or PITC and VCT" (KII-003, 3).

The suspicious and unexplained symptoms for which people sought treatment included fatigue, swellings on the body, slight headache, and feeling chilly in the evenings. Another notable finding at diagnosis was co-infection with multiple disease conditions. In some cases, the participants were suffering from more than one opportunistic infection. The main diseases mentioned included malaria, tuberculosis (TB), typhoid, diarrhoea and pneumonia. A person could be infected with TB and typhoid or with malaria and diarrhoea simultaneously. As the above quotations indicate, most of the sick persons had been bedridden or were incapacitated and had to be admitted to a hospital for some time.

3.3.2 Illness or Death of Spouse

Some of the in-depth interview respondents (*n*=7; 6 female and 1 male) got to know their HIV status either when a spouse fell ill and was admitted to hospital or when they had lost their spouses to death. It is noteworthy that the majority of those knowing their status due to the illness or death of a spouse were women (6 out of 7). In cases where a spouse was taken ill and an HIV test was recommended, the respondents were asked if they would also be interested to know their status. The following excerpt from a female participant is typical of the cases involving the illness of a spouse.

> What made me know that I had HIV, my husband was sickling, and he became so ill to the point that he became bed-ridden. So we came here to Russia and he was admitted to the ward (R48: widow, age-group 36-45; 3).

Mostly, these respondents had accompanied their ill and disabled spouses to the health facilities for medical care. As can be noticed in the next excerpt, in a number of the cases, the sick spouses were not in a position to even consent to an HIV test being conducted on them.

> After being admitted to the ward, he was asked if he had already known his status. But he could not be able to talk, so I am the one who took the risk and told him…we were asked that "would you like to know our status?" and I responded that "I would like to." That "both of

> you the two of you", [and I responded] yes. Then his [blood sample] and also my blood was taken. So after they had been taken, when the result came back, it came back that he was positive and I was also positive (R48: widow, age-group 36-45; 3).

The accompanying spouses had to give consent on behalf of their spouses in cases where the spouses were incapacitated. In such cases, they either consented to personally receiving the test at the same time or opted to come for testing at a later date.

Some participants got to know their status when they had lost their spouses or when they had lost their infants. These deaths were in circumstances that necessitated the seeking of some explanations. A young male FGD participant had this to say:

> I had lost my partner, that is when I decided that…and I also had rashes on my mouth. That is when I decided that "this one, let me try the VCT and first and then see what happens." When I went to try this [testing] is when I was found to be positive (FGDMY-004, 16-18).

3.3.3 Antenatal Care

Diagnosis with HIV also occurred in the context of ante-natal care. Some of the female participants, who in most cases neither suffered ill-health nor suspected themselves to be HIV positive, only got to know their HIV status when they attended a clinic for ante-natal care. It is a requirement in Kenya that women attending ante-natal care be routinely tested for HIV. This testing requirement is aimed at reducing incidences of mother-to-child transmission (MTCT) of HIV to the unborn babies. As the interview excerpt below indicates, the respondent got to know her HIV status when she went to the clinic for pregnancy related health-care.

> How I got to know my status, I was pregnant. Then I came to the clinic normally like any other women, then here at Russia [JOOTRH], women who are expecting must go through an HIV test. When the test results were released, I got to know that I was HIV positive (R47: married woman, age-group 36-45; 3).

Five (5) female in-depth interviewees, or one-tenth (10%) of all in-depth interview participants, were diagnosed HIV positive during antenatal care. FGDs corroborated the finding that ante-natal care was one of the circumstances under which a number of women discovered their HIV status. One female participant in an FGD reported that:

> I also came to know about it [her status] when I was pregnant. When I came when I was pregnant, I was informed that I had to be tested. I was found to be infected. I knew that it is at that point is where I will begin life. It is only my condition that has changed but life has not come to an end. I accepted and the baby is negative.

In three out of eight FGDs, participants mentioned that women who attend ante-natal clinics are tested as a measure to prevent or reduce vertical transmission. In one FGD with women of child-bearing age, 5 of the 6 participants were diagnosed HIV positive during pregnancy.

3.3.4 Public Health Campaigns

Some in-depth interview participants (*n*=5; 3 female and 2 male) were persuaded to get to know their status from public health campaigns aimed at promoting uptake of voluntary testing and counselling (VCT). Of the three female and two male participants, the women's decision to take up an offer to be tested in a public health campaign was purely voluntary. According to a 36-year-old widow:

> We went for testing in 2006—a testing campaign was brought here at Nyamaroka …So when we went—I had not become suspicious about my life, I was just okay. So when I went and we were tested then the test came out that I was HIV positive (R5: 36-year-old widow, 3).

Two male participants who got to know their status as a result of such campaigns, were triggered by some underlying cause. They had experienced or witnessed some symptoms in their bodies similar to those mentioned in a public health promotion as being possible signs of infection with HIV. This made them to decide to offer themselves for testing. The following statement from a 36-year old male is illustrative:

> There were sometimes when it reached evening hours, I would feel cold and I imagined that it was even malaria. So I would take medication. It would cool down but it would recur. So one day, there was an outreach near Arina so I said "let me just go and test today". So when I was tested, I turned out positive (R44:36-year-old, married man).

Among the young male FGD participants, a number opted to be tested and voluntarily walked into a VCT. Compared to those who are older, more young people were inclined to seek voluntary testing and counselling. One FGD participant had the following to say:

> The way I got to know my status, I was having, I was having friends. And the way I could hear my friends telling such stories, one day those, those, those people [mobile VCT] came there at Jua kali (open air workshops). There is a day they came there to Jua kali, and then they put a tent there….The way they put a tent there, we also just went like a joke. That is

> where I was tested and later I was found to be positive. Then the other day, I came here at Russia and I was tested again and later I was found to be positive (FGDMY-005, 22).

Generally speaking, the respondents in this study got to know their status within the framework of four key events in their lives. These ways included personal illness, illness or death of a spouse, antenatal care, and through response to a public health campaign. The most important reason was personal illness whereas the least common reason was response to public health campaigns. Testing took place in a variety of facilities and settings and this is considered next.

3.4 Facilities where Status was known

The respondents (PLHIV) to this study were all enrolled into care and treatment at St. Joseph's Nyabondo Hospital and Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH). Most of the respondents had known their HIV status at either St. Joseph's Nyabondo Hospital or JOOTRH. As shown in Table 3-3, of the 49 study participants, more than one-third (35%) learnt of their HIV status at St. Joseph's Nyabondo Hospital while a further one-quarter (12) got to know their status at the JOOTRH.

Table 3-3: Facilities in which PLHIV underwent HIV testing

Facility where testing was done	**Female (n=30)**	**Male (n=19)**	**Total**
St. Joseph's Nyabondo	10	7	**17**
JOOTRH	8	4	**12**
Liverpool VCT (Tivoli)	5	2	**7**
Others	6	7	**13**
Total Responses	**30**	**19**	**49**

St. Joseph's Nyabondo Hospital and JOOTRH are among the major treatment facilities in Kisumu County. St. Joseph's Nyabondo Hospital lies in a rural district in Nyakach sub-County whereas JOOTRH lies within the city of Kisumu. Another seven participants were tested at Liverpool VCT. The VCT is located within Kisumu City Centre and is not attached to any major health facility. It mainly offers VCT services and refers those tested to JOOTRH or other health facilities for enrolment into care and treatment.

Slightly more than one-quarter of respondents (12) had their HIV status tested in various other facilities apart from the two main facility where they were receiving care. Some of these facilities included Kisumu East District Hospital and Lumumba Health Centre within the city of Kisumu. Other facilities where testing was done were outside Kisumu county. Two participants got to know their status in Nairobi, the capital city of Kenya.

3.5 How Long Status has been known

According to the study findings, some of the participants could have been living with HIV for between a few to several years before being actually diagnosed as HIV positive. This seems to be the case because a good number of participants had been suffering from recurrent illnesses that defied treatment. Such symptomatic, recurrent illnesses, and the weakened immune system—as evidenced in being bedridden—strongly suggest high viral loads and advanced viral activity. This is the case with HIV since the virus compromises the immune system and makes the body susceptible to a myriad of opportunistic infections as reported by the participants. What can be reported in this study, however, are the self-reported time periods in which the PLHIV were diagnosed as HIV positive. This information is presented in Table 3-4.

Table 3-4: Time period PLHIV were diagnosed HIV positive

Period status known	**Female (n=30)**	**Male (n=19)**	**Total**
1999 and earlier	2	1	**3**
2000-2004	8	2	**10**
2005-2009	11	8	**19**
2010-2014	5	6	**11**
Missing	4	2	**6**
Total	**30**	**19**	**49**

The person who had known their status the longest among the study participants had known her status for about 24 years. This was a 51-year-old female participant. The person who knew their status most recently, in 2013, was a male respondent. The majority of the participants knew their status starting from the 2000 onward, as only two people knew their status earlier than this date. Nearly 30% of the participants (14) had known their status for at least nine years and about 70% for at least 5 years as at the time of the study. The year of testing and of knowing ones status could however not be established for two participants.

3.6 Decision-making for Testing

HIV testing ought to be voluntary and individuals ought to personally decide as to whether they would like to be tested or not (National AIDS and STI Control Programme / (NASCOP), Ministry of Health and Sanitation, Kenya, 2010). Additionally, testing requires that a person gets into contact with health care facilities where such services are offered. Alternatively, one could get such services from mobile testing platforms (e.g. mobile VCT). The mobile VCT services are offered as part of a public health effort to help reduce HIV infection. Early HIV diagnosis is important as it allows for early enrolment into care and treatment.

In this study, the decision to take an HIV test could however be made on behalf of the person needing it, especially if this person is incapable of making such a decision due to illness. This was mostly the case for people taken to the health facilities by family members. The decision to be tested could also be influenced by friends, relatives or prompted by the health care workers (PITC) when the symptoms or ailments one was suffering from gave reason for them to suspect infection with HIV. This was the case for recurring ailments that defy treatment. The main decision makers or influencers are indicated in Table 3-5.

Table 3-5: Main person making or influencing decision for HIV testing

Decision Maker for Testing	Female (n=30)	Male (n=19)	Total
Self	14	8	**22**
Health care provider/personnel	8	6	**14**
Family members/relatives	3	4	**7**
Friends & others	2	1	**3**
Total	**30**	**19**	**49**

As indicated in Table 3-5, there were four main categories of people who influenced a PLHIV's decision to be tested for HIV. The participants could either make the decision by themselves or were influenced by health providers, their families and relatives or by friends or other acquaintances and work colleagues.

3.6.1 Decision made by Self

Nearly one-half of decisions for testing made by in-depth interview participants (48%; *n*=46) were made by the participants themselves. Of the 22 in-depth interview participants who made the decision to be tested by themselves, 14 were female whereas eight (8) were male. The following statement from a female participant who knew her status in the context of an ill spouse was common:

> How I got to know, first of all my husband was ailing. So I carried him and brought him for testing. We really struggled over this with him. So later when he was overwhelmed with the illness, he accepted. So when he went, he was found to have HIV. This also gave me the courage [to do the same] and I said that "let me also go for testing, because sometimes if you have, perhaps I also may be having it." So when I went for testing, I found that I was having [HIV] (R9: widow, over 46 years old, 3).

Nearly one-half (6) of the 14 women were prompted to make the decision for testing due to husband's illness and admission to hospital or death. Three women made the decision in response to a public health outreach while two other women due to their own recurring illness. In all the three cases, public health information worked in combination with other factors such as concern for the well-being of their children and underlying symptoms of HIV. For three women, their decision was related to their children. One of these women had suffered a miscarriage. Public health education and concern for children's wellbeing prompted the other two to get to know their status.

For five of the eight male participants, their decision to get tested arose from their constant on-and-off sickness. Two male participants had been tested earlier and did not accept the results and lived in denial for some time. They did not also take steps to inform their wives about their test results. In one case, a male participants lived for four years after diagnosis with HIV and only opened up to the wife when the wife got tested positive in the context of ante-natal care. Mostly, the decisions to go for testing were as a result of a trigger such as a public health outreach coupled with symptoms of sickness or on-and-off illness.

3.6.2 Decision initiated by Health Workers

The next most important source of decisions for testing were influenced by the health care personnel. The health workers accounted for nearly one-third (30%) of all decisions to be tested for HIV. The following excerpt is illustrative.

> They requested me…if I could accept to know my status—because when I was coming [to the hospital] I did not know anything [was unconscious]. So after I got better, they came and asked me [If she would accept an HIV test] (R1: married woman, age-group 26-35, 13).

A total of eight women and six male participants were influenced in their decision to test for HIV by health care workers in the health facilities where they went to seek medical attention due to illness. Among the women, five out of eight decisions were based on recurrent illness, whereas three were based on ante-natal care. Of the six male participants, five were urged to consider taking an HIV test after recurring illness episodes. Only one male participant was tested after the death of a spouse coupled with the death of a child. In Kenya, PITC is one of the actions recommended for health service providers to help strengthen the national response to HIV as most people only know their status in the context of debilitating illness.

3.6.3 Decision influenced by Family/Relatives

Family members and relatives influenced decisions in 15% of the cases among whom three (3) were female and four (4) were male. All the seven respondents were those who knew their status in the context of personal illness. The decision for the four male participants was either made on their behalf or they were urged by their siblings to go for testing. Three of these male participants were influenced by a brother and one by a sister. For the three women, one was influenced by a step-mother, the other by the mother and in the last case, by a cousin. Following is a statement from a participant whose decision was influenced by a brother who is a medical doctor.

> Then my brother whom I follow,—he is a doctor—he told me that “you know, gentleman, as far as this sickness of yours is concerned, I would like you to go and be tested for HIV so that you can be enrolled on medication.” Then I came. The time when I was coming, they tested me, and I was found to be HIV positive (R29: married male, age-group 18-25, 5).

These family members and relatives were concerned about the constant on-and-off sickness of these relatives. They were therefore interested in helping them get a definitive diagnosis to help them explain or understand the reason for those recurring illness episodes.

3.6.4 Decision influenced by Friends and Others

Friends and other factors accounted for 7% (3) of all decisions. Of these three cases, two were female. Whereas one male participant and one female participant were advised by a friend to seek testing for cases of recurrent and protracted illness, one female participant was tested as an occupational requirement by her employer. A male participant who got influenced by a friend had this to say: “When I was sick and I was just sick on-and-off, then a friend of mine—he had known his status—told me that, ‘this sickness which is affecting you, try and go and know your status’” (R33: male, aged 46 years and above, 3).

Peer influence was also mentioned by some young male FGD participants. One male FGD participant had this to say: “The way I got to know my status, I was having, I was having friends. And the way I could hear my friends telling such stories, one day those, those, those people came here at Jua kali…we also just went like a joke. That is where I was tested and later I was found to be positive” (FGDMY-005, 22). After diagnosis, PLHIV reacted in a number of ways. The next section addresses the initial reactions of PLHIV to their diagnosis.

3.7 Initial Reactions to a Positive HIV Diagnosis

According to information gleaned from in-depth interviews, FGDs and KIIs, the study participants reacted differently to being diagnosed HIV positive. The majority reported accepting their status and adopting positive living. Other reactions included notions of immediate or imminent death, concerns about the source of infection, and shock. Worry, fear, shame, denial of results, painful feelings and suicidal thoughts were also expressed. In most cases, the participants reported having experienced two or more of these emotions. Some, however, mentioned being neither shocked nor fearful but indicated being satisfied to know their status and to be enrolled on medication. Figure 3-1 illustrates the reactions to the diagnosis by in-depth interview participants.

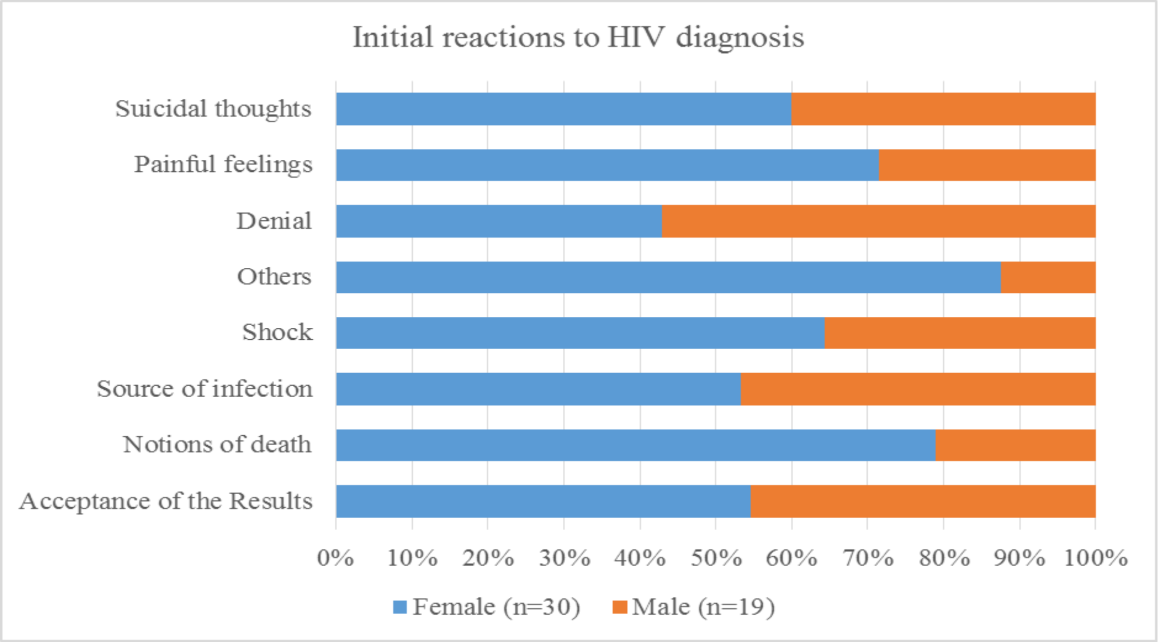

Figure 3-1: How PLHIV reacted when diagnosed HIV positive

3.7.1 Acceptance of HIV Test Results

According to information contained in Figure 3-1, 22 (45%) of the in-depth interview participants reported accepting their test results. One of the participants who accepted their status had this to say:

> I felt that it was good because there was nothing that I could do. I concluded that once I have got it [HIV], it is the way someone can be befallen by some tragedy because even if I did something extraordinary, it has befallen both of us. So I just decided that I should just stay with medication and prolong my life (31-year-old, married woman).

One key informant (KII participant) mentioned the importance of accepting the outcome of an HIV test for optimal health outcomes when he stated that:

> What they do initially? After someone has known their status, they must accept their status, then after accepting, then he seeks for care. Then also, after someone has known their status, they are advised to disclose (KII-003, 23).

The above statement underscores the importance of acceptance for those diagnosed HIV positive. In a statement reflecting the reactions of some of the FGD participants, a female FGD participant commented that:

> I also came to know about it when I was pregnant. When I came when I was pregnant, I was informed that I had to be tested. I accepted to be tested and I was found to be infected. I knew that it is at that point is where I will begin life. It is only my condition that has changed but life has not come to an end. I accepted and the baby is negative (FGDFY-003, 44).

One female FGD participant found this information so traumatizing that she reacted to the news by bursting out crying. But after counselling, she accepted to live positively.

> I cried, I really cried; because that is the time when I got married. Because I said, "now if I should not return to the house completely." But I was consoled and counselled nicely till I understood and went and called my husband. We were counselled together, and I accepted that life (FGDFY-008, 46).

The above quotation indicates that people diagnosed with HIV experience many emotions. In the case of this FGD participant, she cried due to what the diagnosis meant for her immediate and distant future. However, she was able to accept her status after counselling.

Among those in-depth interview participants who accepted their status, eight indicated experiencing neither shock nor fear when they were informed that their test results had turned out positive. The respondents who expressed not being shocked offered some plausible reasons that help explain such reaction. For two women, their husbands were the main reason as to why they did not get shocked after testing. One of them, a 29-year-old widow, had gone for testing expecting a positive test result because her husband, who had been ailing on-and-off before his death, had tested HIV positive.

Some FGD participants also mentioned not being shocked for the same reason as the previous two in-depth interview participants. A female FGD participant made it clear that she was not shocked because of the behaviour and occupation of her husband:

> Me when I learnt I was positive, I wasn't shocked. Because of the kind of husband that I had. The kind of work that he does. So I just concluded that he was the source. And then I just started to "be in the boat" (FGDFY-012, 48).

When asked about the occupation of the husband, the female participant responded that he was owning and running a bar. She concluded that the occupation of the husband could have been the reason for his infection and therefore for her own positive HIV status.

Some respondents expressed no shock because of suffering from on-and-off sicknesses for a long time that they longed for the relief that ARTs could provide. These respondents went for testing in order to know the cause of their recurring illnesses and to get proper medical attention. According to the quotation below, knowing their HIV status made it easy for them to make sense of the on-and-off illness they had experienced.

> No. I could not experience shock because you know sometimes when you go to look for life...you know the time you feel that "this thing that is happening to this person, it seems like I also have the same thing, because why am I just experiencing a weight reduction when I see some people in our hospital there, just moving like this." So after that person [health care personnel]—he first of all did for me that thing very well, counseling, very well—I just gave him my hand and after he had... and after telling me that one [the result], I did not get shocked (R8: widower, ≥46 years, 11).

The above data show that people who for some reason perceived themselves to be at risk of being infected with HIV were more ready and willing to accept their results.

3.7.2 Denial

A number of participants in FGDs and in-depth interviews mentioned denial as one of the main reactions to diagnosis. The following quotation from a male FGD participant epitomizes the attitude of denial:

> Okay, looking back, I did not feel like I was sick. Because I felt like there was nothing, no problem with me, health wise. Because I felt energetic and all that, and I could do my things normally because I knew PLHIV, I knew they were kind of emaciated. Something of the sort. That is how I knew PLHIV could be like. But me I was feeling okay. Such like things are the reasons that kind of made me to live under denial (FGDMY-006, 109).

Among in-depth interviewees, seven (13%) did not believe the diagnosis and as a result, did not immediately allow themselves to be initiated into care and treatment. One widowed in-depth interviewee in describing her initial reaction had the following to say:

> But me personally I had not got tested. So, later I went and got tested at Tivoli. I still did not accept. So I came back here to Russia [JOOTRH]. I got tested again and I found it to be so. I still did not accept it. I had to go further. I told my sister my problem. Then she told me that "because you are like you are doubting, then let me send you money you go to MP Shah and re-test". When I went there, it was found to be like that [HIV positive] (R39: widow, aged ≥46 years, 7).

Six out of the seven in-depth interview participants who had reacted with denial and disbelieved the test results later sought confirmation of these results in other testing centers. They did not trust the initial results and doubted the accuracy of the machines. A widower aged ≥46 years old had this to say: "Then some courage just came to me that 'those machines are not trustworthy, me I cannot be positive.’ Then it took a while, something like a month then I went again to another place” (R31: Widower, aged ≥46 years, 4).

Those participants who denied the initial test results visited an average of three testing facilities before finally accepting the results and deciding to be enrolled into treatment. One female participant, (R40:32-year-old-separated woman, 25), was first tested in JOOTRH while being treated for TB. She rejected the results and sought further tests at Kisumu District Hospital, Lumumba Health Center, Liverpool Voluntary Counseling and Testing (LVCT), and Pandpieri Community Center. She finally decided to join care at JOOTRH.

3.7.3 Shock and Painful Feelings

A total of 14 respondents reported either being shocked or greatly shocked by the results of the diagnosis. Among those who expressed this emotion, the majority (9) were women while five were male participants. A married male respondent in the age range of 26-35 had this to say:

> I was shocked. I was greatly shocked because how I contracted it was not clear to me. Because I am not the kind of person who liked going out with women. Even the ladies whom I would talk to were not there (R20: married male, age-group 26-35, 22).

Five of those who expressed being shocked indicated that they were greatly shocked with one reporting being seriously shocked. According to one female participant, “I was greatly shocked when I discovered that I was HIV positive. It became very overwhelming for me…I was deeply shocked that I nearly fainted” (R14: widow, age-group 26-35, 13 & 17).

The FGD participants also mentioned shock as being a typical initial reaction by PLHIV at the time of diagnosis. The following statement by one male FGD participant is characteristic:

> Okay, majority of the people including me I was shocked. I could not believe it. I said no, this is just rubbish. Something like this cannot happen. Because I knew my status. I knew who I am. So for example like in my case, I got to know my status around 2003. I was very young boy, in form one. Then I said no this can’t be true. I was shocked (FGDMY-003, 65).

The reasons they gave as to why they experienced shock included not expecting to be tested HIV positive, not knowing from where they got the infection and not being sure whether they would cope with the condition.

According to the results from in-depth interviews, the news that they were HIV positive was very devastating for some of the participants and they indicated experiencing a lot of pain in their hearts. One middle-aged widow confessed that:

> Personally, I felt very painful. I felt painful and knew that that life of mine has ended like that. Even though the doctor was endeavouring to counsel me, I did not see that I could live…I felt very painful in the heart but I did not cry before the doctor. I just gathered courage because I had told him that I would accept whatever results would come out (R17: widow, aged 26-35 years, 23-25).

As the above quote suggests, the pain they felt seemed linked to the notions of death associated with being HIV positive. One gentleman had the following to say suggestive of the pain he felt:

> It did not go down well with me. Along the way, I thought about many things and I said that "now, if personally I have been taking care using protection and you there is away in which you are here and there is a way in which you are doing things." And I concluded that "before you die, you may not know the means by which you may die" (R43: married man, aged 26-35 years, 36).

One male participant in an FGD just put it in very simple terms: "You get to have a lot of sorrow and become stressed in that situation" (FGDMY-001, 32). These accounts highlight painful and sorrowful feelings as some of the emotions experienced by the participants.

3.7.4 Notions of Death and Suicidal Thoughts

Notions of immediate or imminent death were expressed by 19 participants (15 females and 4 males). The participants mostly visualized themselves as either "going to die soon" (R15: 33-year-old married woman, 11-13), believed that their lives "would come to an end" (R14: widow, aged 36-35 years, 15) or considered themselves as already dead. As one lady reported, "[I thought] that my life had now come to an end" (R1: married woman, aged 26-35 years, 25). Others even said: "…I was already a dead person at that time" (R25: 37-year-old widow, 13) or: "I felt that I was someone who had already died…so I counted myself as someone who was already dead" (R41: divorced woman, aged ≥ 46 years, 25).

These notions of death as either immediate or imminent arising from being diagnosed as HIV positive were also evident among the four male participants who reported having entertained thoughts of death. According to one of them: "The way I knew that if someone contracted HIV then obviously, death, he was going to die. So I was thinking I have already acquired a ticket, I could die any time" (R28: 25-year-old married man, 25). Another male participant who viewed HIV as being equivalent to immediate death commented that: "You know, most people…when someone imagines that he has contracted HIV, someone reckons that he is now someone who has died. He is someone whose life is no longer there" (R29: single man, aged 18-25 years, 23). It can therefore be shown from the findings that these ideations of immediate or imminent death preoccupied both the male and female study participants.

Evidence from this study show that being diagnosed with HIV had the effect of evoking thoughts of suicide as the following excerpts from one male and one female in-depth interview participants show. The male participant indicated being troubled and disturbed by this news to the extent of actually attempting suicide. He had the following to say:

> Like I have told you, initially, it really troubled me. It disturbed me so much. I even committed suicide...attempted suicide...which did not work out because some people realized that I was not normal. So they came to save my life. Again there is a time I went into so much drinking and smoking. I wanted to just finish up myself like that. That also never worked. Then I got down to serious business and said, "No, this is not the right way, let me follow the right way" (R21: married man, aged 26-35 years, 16).

One female in-depth interview participant narrated a story similar to that of the previously quoted male participant. In her case, were it not for counselling from the PSC personnel, she had planned to take her life together with that of her unborn baby:

> A lot of thoughts crossed my mind. I said that …it is better I die together with the baby I am expecting. The sisters really gave me advice and told me that, "this is something that many people have… Nowadays it is like malaria. In the past is when it was bad because there was no medication. But now, there is medication it is therefore like mala…malaria." So I came to relax and resolved that there was no need of hanging myself [committing suicide] (R34: married woman, aged 18-25 years, 13).

These accounts were corroborated by some FGD participants. One female youth FGD participant in a talk with her guardian had the following to say:

> You know, I have been tested HIV positive, and I have not been counseled and I had not accepted. I am going to kill myself. So I was, that nurse told me, "No you do not have to do anything. This is not the end of the world." And I told her, "No, do not tell me anything. I know one who is HIV positive is dying the next day." That was the perception in my mind. And it was there that I had planned that I must kill myself from there, there. So I just decided, I waited and it reached at night. I told my nurse that, "may you please go and bring me some water.' Because I wanted her to go so that I can kill myself (FGDFY-009, 64).

As the above statements show, thoughts of suicide were very vivid in the minds of people diagnosed HIV in this study. If it were not for the pre- and post-test counseling that they underwent and the intervention of friends and relatives, a number would have actually committed suicide.

Given the nature of HIV as having no cure, and the impact it has on a person's life, especially its relation to death and stigma and discrimination, PLHIV expressed varied emotions in trying to come to terms with their diagnosis. This sub-section has presented the various initial emotions and thoughts that people diagnosed HIV positive experienced. The next sub-section addresses the factors facilitating acceptance and reconciliation to a positive HIV status.

3.7.5 Other Emotional Reactions

Among the other reactions were worry, fear, embarrassment, and concerns about the source of infection. The worries that some in-depth interview participants experienced were associated with the information they had received about HIV. For instance, one widow was worried because she imagined someone with HIV does not have good chances of survival and that such life is difficult. The statement below contain the sentiments of this widow:

> I initially developed worries that could it be...because it is being said that if you are HIV positive you may not survive well, you are required not to perform very physically demanding tasks. If food is not sufficient then you could die because if you are on medication...So such worries came to my life and I imagined that should I take poison and die (R5: widow, aged 26-35 years, 11).

The other emotional reaction was fear. One female participant indicated having developed fear in the following terms: "When I first heard that I had the virus, I first developed fear (mmm) and then I said that 'I want to live. Because there are ARVs, I will live' (mmmhh) mmm. That gave me encouragement" (R2- widow, aged ≥46 years, 39-41).

One 35-year-old married man experienced fear combined with shame because he thought he would be exposed to ridicule if people he knew saw him at the point of treatment:

> What was bringing about this shock, was the shame/embarrassment which I imagined that if I will now go there to start being on medication and sometimes meet people there I knew. So the fear that was arising was that if I happen to meet someone, so someone would know how, that I have been affected [infected] (R10: 35-year-old married man, 31).

Fear was also reported as an initial emotional reaction by FGD participants. One female youth admitted that, “On my side, when I was tested, admittedly I had fear. The first day. The way I went home, I informed my husband and he did not quarrel. I then came and asked for the next visit [appointment]” (FGDFY-006, 107). As the above quotes show, the emotions were often intertwined and triggered other emotions.

How someone came to acquire HIV was a core question that troubled both male and female participants who expressed thoughts related to the diagnosis outcome itself. A total of 15 participants (8 females and 7 males) were concerned about how they got infected. The following statement by one female participant was illustrative: “The way I…in fact it was a painful experience for me because I did not know how I acquired it. I did not know how I acquired it…” (R45: widow aged ≥46 years, 25). According to one of the male participant: “I had some thoughts because on the basis of my conduct, I did not see that I was having some affairs. This made me think that perhaps it was [my wife] who was responsible” (R16: 31-year-old married man, 25).

One other married man aged 26-35 years argued that he had not been involved in acts that could expose him to infection. He therefore concluded that it must have been his spouse responsible. Another said: “I was greatly shocked because how I contracted it was not clear to me. Because I am not the kind of person who liked going out with women” (R20: married man aged 26-35 years, 22). The societal perceptions of a person’s moral probity was a significant concern that if not well handled through proper counselling could inhibit a person diagnosed with HIV from accepting to be enrolled in HIV care and treatment.

These male participants manifested the commonly held belief, which actually represents the scientific reality in Kenya, that 77% of new HIV infections are transmitted through heterosexual intercourse (NASCOP & NACC, 2012). They did not give thought to other possible means of HIV transmission. They only thought heterosexual intercourse was the vehicle through which they got infected and that their wives were the main sources.

Upon further analysis, the findings revealed that none of the female participants sought to place the responsibility for their infection on anyone else. However, they were also concerned with how they could have acquired HIV. In contrast, five of the seven male participants, in addition to being concerned about how they could have acquired the infection, each of them went ahead to actually speculated on the possible “external” sources of their infection. Three of them concluded that their wives were the most probable sources of their infection. Two male participants, however, did not try to establish the source of their infection and the person to whom blame for their status could be attributed. The findings indicate that none of the participants expected to be tested HIV positive.

3.8 Reconciliation to and Acceptance of a Positive HIV Status

In this sub-section, data is presented to answer the question on how the PLHIV reconciled themselves to their diagnosis as HIV positive and how they came to accept their status. This sub-section concerns itself primarily with the considerations that made PLHIV resolve to accept their status, to enrol into medication and to start the journey of positive living.

The participants of this study put forth determined efforts to overcome the initial shock, fear and other emotional and physical reactions related to the results of their diagnosis. Not all participants readily accepted the test results when they initially received them. As presented in the sub-section on *Initial Reactions to HIV Positive Diagnosis, a* number of participants were sceptical about the results and went into denial. These participants visited other facilities to have confirmatory tests done. However, in all the cases, the test results were confirmed as positive and the participants ultimately resolved to accept the results and to get enrolled into care and medication.

The in-depth interview, FGD and KII transcripts revealed that different factors interacted in helping the participants to accept the fact that they were HIV positive and to eventually reconcile themselves to living positively. As is indicated in Table 3-6, the key points mentioned by in-depth interviewees that helped them in this transition were categorized under four thematic areas. These four themes are psychosocial support and the influence of role models, quest for health and longevity, normalization strategies and the present and future well-being of their children. These categories are not necessarily mutually exclusive but interacted with each other. Moreover, the participants expressed being influenced by a multiple of these factors. These factors are sequentially discussed below.

Table 3-6: How PLHIV accepted their HIV status

Reconciling to being HIV positive	**Female (n=30)**	**Male (n=19)**	**Total**
Psychosocial support and role modelling	11	12	**23**
Quest for health and longevity	15	9	**24**
Normalization strategies	10	6	**16**
Children’s present and future well-being	13	2	**15**
Total Responses (multiple responses)	**49**	**29**	**78**

3.8.1 Psychosocial Support and Role Modelling

Psychosocial support was a key influence in helping the participants to reconcile with the fact that they were HIV positive. Psychosocial support took the form of counselling provided by health facility personnel, mutual support and encouragement given by CHWs, support groups of PLHIV and family members, as well as testimonies and peer-counselling from other PLHIV who had lived with HIV for longer periods of time. These forms of psychosocial support were intended to encourage the participants that being HIV positive was not the end of life and that life-prolong medications (ARVs) were available and accessible.

Psychological counselling provided mainly by trained counsellors at the patient support centres (PSC) was an important component in the transition to acceptance. One key informant in underscoring the centrality of counselling said that: “normally, these people are counselled and you have to prepare them properly until he/her personally accepts to be tested.” One in-depth interview participant, a 31-year-old single female participant, said: “The counselling, the way we came here for counselling and then we were counselled on how we can be on medication, how we can live. So I just became strong and decided that I just get enrolled on medication” (R26: 31-year-old single woman, 41). Counselling also played an equally important role in the decision by a good number of the male participants in accepting to be on medication. According to a married man aged 36-45 years:

> When I was in…enrolled, in fact when I was, initiated I was taken to the counselling session and I found people there. And I found that people could live with this thing as long as God will give them life (R30: married man, aged 36-45 years, 59).

Apart from counselling provided at the health facility and by extension health workers such as community health workers (CHWs), social support was instrumental in helping people newly diagnosed with HIV to come to terms with the diagnosis and to decide to live as HIV positive. Social support took the form of membership and participation in support groups of PLHIV and the empathetic accommodation and help from family members, friends and relatives. A lady who was ≥ 46 years old and who was living in separation from her husband hailed the benefits of support groups when she remarked that: “What was of the greatest help to me is that when I came here to the clinic, I joined the support group” (R35, separated lady, aged ≥ 46 years, 4-5). The support of family, relatives and friends was also important. One lady commenting on the role of support of her father said that:

> When I knew my status, it somehow shocked me, but my father tried to talk to me and said “that is something that could happen to anyone” that I just take treatment seriously, maintain taking my medications, and I will just be well (R41: separated woman, aged 26-35, 17).

Another example of support from relatives was a man who got encouragement from his brother and his wife. This man stated that: “…we were counselled on adherence and then we were instructed and my wife also encouraged me, my brother also encouraged me and informed me that “do you know so and so”? [To which] I answered in the affirmative. “Yes, so and so is [has been] on medication for many years, so do not fear”’ (R29: single man aged 18-25 years, 19).

The knowledge and testimony of other people who had lived with HIV for longer periods of time also acted as motivation for PHIV to reconcile to their status and accept to live positively. Often, this kind of information was obtained in the context of support group meetings or was shared by members of support groups when they went out to conduct community outreach activities. According to one married man aged 36-45 years:

> Because I found somebody…that counseling group, we…we had some people who had lived with the HIV virus for eighteen years, and he was our counselor. So this thing…in fact he encouraged us, that if at all somebody is…and he is looking so healthy, you cannot even imagine (R30: married man aged 36-45 years, 59).

An FGD participant stressed the importance of support groups and role models in helping with acceptance and reconciliation in the following excerpt:

> If I can speak for myself… At MCH, we have some organization called mothers-to-mothers. There, there are mothers and they are also positive. And they were taken for trainings. So they come back, after you get tested and you turn positive, first of all, you will be handed to these mothers. They counsel you, they talk to you, and they tell their experiences. When you just see them, [you will remark] "so they are just like me". So from there, you will just be okay. Your shock goes away. They have support groups, we also go for support groups. We see mothers with their children. For example if you have not given birth, you are still pregnant, you see a mother carrying a baby, a negative baby. So those mothers-to-mothers are helping (FGDFY-011, 78).

Part of the procedures for support group meetings required members to introduce themselves. This introduction covered aspects such as their HIV status, the length of time they had lived with HIV, the challenges they were facing and some of the methods they used to overcome their challenges. In this way, the support group meetings provided a perfect opportunity for the participants to learn from and provide mutual encouragement and support to each other.

Often, the participants were influenced by more than one of the considerations presented above in deciding to enrol into medication and to live a positive life. All clients presenting themselves for HIV testing received counselling before and after testing and were encouraged to join support groups of PLHIV. In many cases, they received acceptance, support and accommodation within the family circle and among their circle of friends. These positive experiences all worked collectively and positively to help PLHIV reconcile to the fact that they were HIV positive and to begin a new life of positively living with HIV.

3.8.2 Quest for Health and Longevity

Thoughts related to individual health and well-being of the participant that influenced decisions to accept HIV status included an unquenchable desire to overcome the recurrent illnesses and to continue being alive. The knowledge of the existence of highly active anti-retroviral therapy (HAART) was important in inspiring this quest for longevity of life. The desire to continue living was expressed in various ways. The participants used different metaphors and figures of speech to express their thoughts. One widow aged ≥46 years expressed this when she said: "I want to live, still I want to, I desire to live (R2: widow aged ≥46 years, 31). This participant used the phrase, "I want to live", although with slight variations 4 times in one paragraph. Some of the terms included: eradicate infection, support life, "look for life", and "rescue my life".

In some cases, acceptance was related to PLHIV's need for a rationale for and solution to their constant on-and-off illness episodes. A man co-infected with TB had this to say:

> Yes I had to accept, because there in the past, I had really been ailing and even fell blind and did not even know what was happening. So after being blind, when I got well, then TB. So I said "okay, so if this has been what is happening inside me, and it has now become obvious, let me just pick it up so that I also just do my things because I want to do my things" (R49: 35-year-old married man, 21).

One lady who had initially denied the HIV test results when informed of her status, after being tested for the first time, decided to accept her status after the test result had been confirmed in more than one place. After the confirmation, she realized the grave danger that her life was in. Consequently, she decided to stop being in denial and to accept her status in order to get her life. She had this to say:

> "If all those three places tested me positive, —because they also did for me with the rapid one—and it was turning out positive. So I asked that "four places, I have been tested that I am positive, what should I do? I need to accept now, I need my life" (R40: 32-year-old divorced woman, 25-27).

As the above statements indicate, acceptance was a key element to joining care and taking responsibility for one's health and well-being. Additionally, there was a sense of fear of death and a strong motivation to live longer after they were informed in counseling of the possibility of one living longer and positively with HIV. One 51-year-old widow had this to say:

> But being that I had it—because I left there because I needed help. Like some accept easily and others take time to accept, me I was running so that I do not die because we were informed that if you go there and they start treating you, then you would not die. (R13: 51-year-old widow, 19).

According to the findings, the desire to live was based on the fact that medications that could prolong life were available. They had heard before, or had been informed during counselling that there were medications that could help them reduce the damage the virus could do to their immune system. The information from counselling sessions encouraged many of the PLHIV to accept their status. One man asked himself the question: "The thoughts that I had at first, I thought I would die, then I later came to think that "aren't there some medications that people nowadays take to support them? I have accepted and I will proceed with it (R44: 36-year-old married man, 23). According to a 36-year-old married man:

> I just took it light [ly], I did not have difficulties with it because we had been sensitized that now there are medications. So there is no need for someone to die yet there are medications that someone can use. So I accepted the status (R44: 36-year-old married man, 27).

Concerns about one's physical health and well-being coupled with the availability of the necessary medications and care and support options for positive living were very strong motivations in making one decide to be enrolled into HIV care and treatment. Physical and physiological health and well-being was therefore, among other considerations, a key point in reconciling to a positive HIV status.

3.8.3 Normalization Strategies

For those who were motivated to reconcile to and accept their HIV positive status and go on with life, one key consideration was the perception that there were already many people infected; some of whom they did not expect to be vulnerable. A lady who initially received the news with shock had this to say: "After knowing my status, frankly I initially was shocked, then after I regained courage. Because at the time when they were testing me, I saw that there were many people" (R15: 33-year-old married woman, 19). For this female participant, she found safety in numbers. Being diagnosed HIV positive was something that she could cope with as she realized she was not the only one affected. She perceived that it was a problem that had apparently affected many people. This rationalization was shared by a number of the participants.

Based on the fact that people of different professions such as doctors, nurses, and policemen were also among those receiving care at the PSC, the participants viewed it as a wider human tragedy and reality that affected not only them but others as well and that it could infect anyone irrespective of social status or position in society. In this regard, HIV was perceived as a problem confronting the entire humanity and as such, not an individual tragedy. One lady who immediately accepted her status after being informed of the test results was encouraged when she became aware that HIV could infect anyone. She commented that:

> After I had discovered that I had HIV, I now accepted to live with HIV because I discovered that I was not alone. That it is something that can happen to a doctor, it can happen to a policeman, it can happen to a pastor, a small child and even nurses have it. So I did not see any burdens after that (R14: widow, aged 36-45 years, 36).

This fact, that HIV did not discriminate and could infect anyone irrespective of social status, made HIV a condition that one could afford to live with as long as one was receiving medical care and was able to continue with their life as normal.

HIV was also perceived to be just like any other disease. The emphasis that the opportunistic infections are the ones that cause death rather than HIV per se, was an additional motivator for those diagnosed positive to get enrolled into care and adopt positive living. Even though they were aware of the long-term effects of HIV and that there was no cure for it, they believed they could control its progression to AIDS by strict adherence, good nutrition and positive living. A man espoused this perspective with his perception of HIV as being like any other disease:

> I did not see any problem on that. I just feel like that HIV is just like any other disease. But I was told that HIV does not kill. But people can live positively. I can live positive and not worry about this. I just see it as a way of may be living. I have confidence on it that HIV does not kill people who live positively. So I feel it is just okay with me (R22: 41-year-old married man, 19).

The information that HIV does not kill could have contributed to making it appear less dreadful compared to the case in the past. Moreover, the possible benefits of positive living helped the study participants to make a quick decision to accept their status and to get immediately initiated into HIV care and treatment.

3.8.4 Present and Future Well-being of Children

Ten participants—among whom eight (8) were women—mentioned the well-being and future of their children as one of the key points in accepting and reconciling to their HIV status and taking steps to be enrolled into care and treatment. They indicated that they still had young, dependent children who they needed to prepare for life. One married female participant aged 26-35 years captured this perspective when she mentioned that:

> The way I took the fact that I had HIV, I first considered the community and saw that I was not alone in the community. Secondly, I looked at my children, that “suppose, I took the virus and put it at the forefront, would I manage to support my children?” This is what made me to even develop courage itself (R7: married woman, aged 26-35 years, 11).

So, the need to be in a position to support their still very young children was an important element in deciding to accept one’s HIV status and to be enrolled immediately into care. Even some persons who had difficulty accepting that they had indeed tested positive, realized the futility of persisting in denial. In spite of the pain they felt about being found to be HIV positive, they had to pick up the pieces and start a new phase of life. They recognized that they could only be able to safeguard their children’s present and future well-being if they did something to realize the dreams they had for their children.

One widow aged 36-45 years concluded that the best decision given the circumstances was to accept her status and find out what she could do to continue being alive. She had the following to say:

> So after coming back to my normal senses, the only thing that I now desired is how I would now live with this illness because I saw that the man [husband] was going. I concluded that "now, I cannot now force anything, so it has found me. So the best thing, I should accept that it is there and consider how we were going to live on" because I was still having children (R48: widow, aged 36-45 years, 11).

Some male participants also expressed the need to be there for their children and to help see them properly prepared for life as a motivation for doing all they could to live positively with HIV. A 35-year-old married man narrated that:

> But if you just stay there because of considering what others will say, and this will not help you because someone will not help in your life and your family… This is because I was considering that I have children, and these children, if I stay for long and this thing takes long on me [without being enrolled on medication], then the children will not have a reliable source of dependence. So I decided to just begin (R10: 35-year-old married man, 31, and 9).

The previous quotation is from a man who initially had thoughts and concerns of shame and embarrassment at what others would think about him if they saw him also receiving treatment from the same facility. However, he came to realize that people's concerns were not very important reasons to stop him from enrolling into care. He appreciated that he had to take responsibility for the well-being of his own family and that of his children. This, he acknowledged, had to begin with a decision to live positively and accept to be enrolled into care.

Part of the considerations the PLHIV had for their children included how they would be able to get an education and thus be self-reliant in the future. So, the thought of dying while the children were still young, not having acquired adequate education to enable them stand on their own, and not having a good foundation for the future, was especially worrying for the women. As one female participant put it: "You worry about 'those children of mine how will I take care of them that I am the one who is sick and their father is also infected. How will I take care of them or how will they be educated"' (R11: 36-year-old widow, 31). Another female participant had the following to say:

> I was left with 4 children. And so when I was considering my life, I was thinking that perhaps if I also died then my children would not have a good life. Because when I look at the family background, then I realized that these children of mine cannot do well. So I sat down one time and decided that I had better know my status and if there is medication so that I can be there for the children before I get down with another disease. So this is why I came to know my status (R37: 41-year-old widow, 3).

As we have seen in this sub-section, the key factors and considerations that made PLHIV to accept their positive status and be enrolled into treatment, care and support were categorized into four main themes. First, they obtained different forms of psychosocial support from the PSC, support groups, family members and friends, and peer-counsellors and role models. Second, they were motivated by concerns about their constant on-and-off illness episodes and their deteriorating health condition and the possibility of longer life. The health concerns were coupled with the availability of effective medical treatment and care. Third, the PLHIV realized that HIV infection did not only affect a certain category of people but a broad spectrum of society. They also discovered that they were not the only ones infected but rather many people were already living positively with the virus. Finally, they were concerned about the present and future well-being of their children. They reckoned that if they would live a little longer, they could provide the care and education necessary for their children to grow into self-reliant adults.

3.9 HIV Test-seeking Behaviour Model in Kisumu County

In this section, a proposed HIV test-seeking behaviour model in Kisumu County is presented. This model is synthesized from the findings of the study. In the model depicted in Figure 3-2, the main circumstances under which testing is done are indicated to the far left. At the center of the model are the triggers, events that lead to a decision for testing. Also included in the model are the key persons who were responsible for deciding about the need for a test. At the far right is the outcome, the decision to be tested for HIV and the facilities where testing is done.

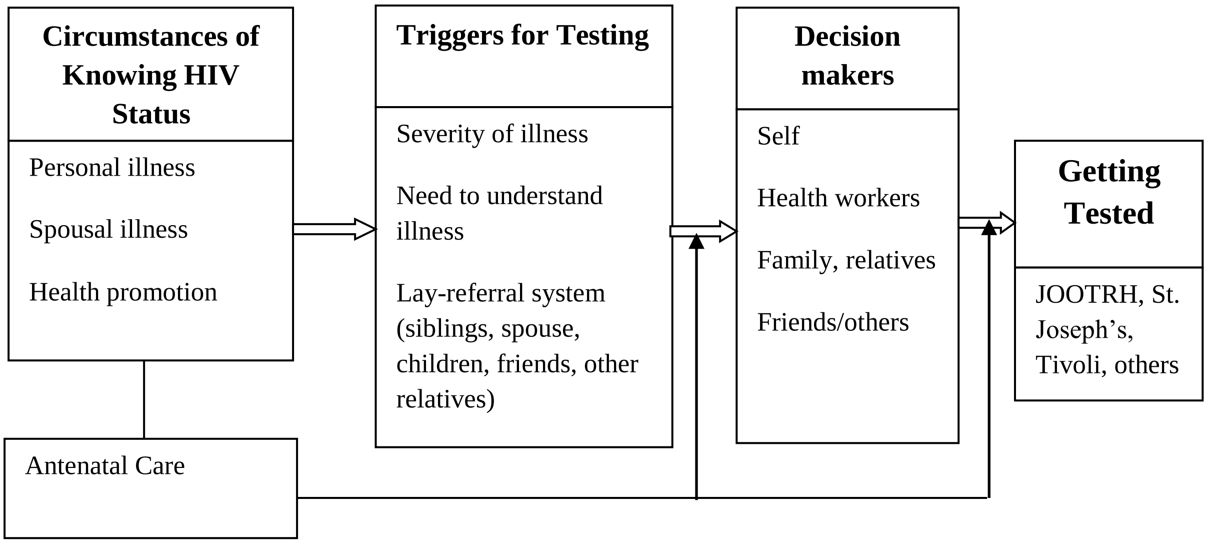

Figure 3-2: HIV Test-seeking behaviour model of PLHIV in Kisumu County, Kenya

According to Figure 3-2, there were four main reasons or circumstances leading to testing. These circumstances were personal illness of the study participant, the illness or death of the participants' spouse, antenatal care services and response to public health campaigns. In most cases, the circumstances leading to testing were in themselves often not always sufficient considerations for an HIV test to be sought or to be undertaken. Except in the cases of antenatal care, in all the other cases, these necessary conditions for testing had to be accompanied by certain triggers. These triggers included severity of illness as evidenced in the length of time one had experienced illnesses, whether the illness was recurrent and the intensity with which the illness had affected the ill person.

The other triggers were the need to understand and be able to make meaning of the underlying causes of the recurrent illness and the operation of a *lay-referral system*. The *lay-referral system* refers to the network of friends, family members, and relatives which often plays a key role in urging persons suffering from some unexplained illness or symptoms to seek medical attention and a diagnosis for such conditions. The main components of this *lay-referral system* were spouses, brothers, sisters, cousins, parents and friends.

3.10 Chapter Summary

Testing for HIV took place under four main conditions. These included personal illness, death and/or illness of a spouse, antenatal care and response to public health campaigns. Most participants had lived with HIV for at least five years with the earliest case being diagnosed in 1992 and the latest in 2013. The facilities where testing was done included St. Joseph’s Nyabondo Hospital, JOOTRH, Kisumu District Hospital, Liverpool VCT and Lumumba Health Centre. The decisions to get tested were mostly made by the participants themselves. However, for some participants, others (close family members—such as siblings, parents, and spouses— relatives, friends, and health care workers) were influential in their decision to get tested for HIV. Most common reactions to HIV test results included acceptance, shock, fear, painful feelings, feelings of relief or no shock and denial.

The factors that prompted PLHIV to reconcile with their HIV status and to accept to be enrolled into HIV care and treatment were grouped into four main categories. Firstly, they received psychosocial counselling from the health care personnel and CHWs. Secondly, they had an undying longing for good health and long life. Thirdly, the perceived high levels of HIV prevalence within the community helped them realize they were not the only ones infected with HIV. They were thus encouraged to live positively. Finally, they were concerned about the present and future well-being of their children and wanted to do whatever they could to remain alive so as to nurture their children into mature adults able to fend for themselves. In the next chapter, findings on the effects of HIV on the lives of PLHIV are examined.

4 RESULTS PART II: EFFECTS OF HIV ON LIVES OF PLHIV

4.1 Chapter Overview

The current chapter presents findings on the effects of being diagnosed HIV positive on the lives of PLHIV. First, the chapter deals with the effects of HIV on social relationships of PLHIV. The chapter then looks at how being HIV positive affected the capacity of PLHIV to fulfil their social obligations. Finally, findings on the effects of HIV on perceptions of self of PLHIV are examined. Information on the effects of HIV in the lives of PLHIV is important for two main reasons. First, the information helps ascertain the types of changes PLHIV have experienced in their lives since knowing their HIV status and secondly, it provides a framework for capturing the meanings PLHIV attach to the experience of being HIV positive and the probable rationale for such meanings.

4.2 Effects on Social Relationships

Social relationships refer to the sets of interactions that PLHIV have with other people such as with family members, relatives, friends, workmates, neighbours and other people within their social spheres. The study findings reveal four major patterns regarding the impact of being diagnosed HIV positive on the social relationships of the participants. The main patterns and the responses by both males and females are presented in Table 4-1.

Table 4-1: Effects of being HIV positive on social relationships by gender

Effects of HIV status on social relationships	**Female (N=30)**	**Male (N=19)**	**Total**
Stable social relationships	21	13	**34**
Stigma and discrimination	11	4	**15**
Restructured interaction patterns	5	5	**10**
Improved social relationships	4	3	**7**
Total Responses (multiple responses)	**41**	**25**	**66**

As Table 4-1 indicates, a majority of the participants reported not having observed any substantial change in their relationships different from what they had before diagnosis. A number reported experiencing problems whereas others noted an improvement in their social relationships. Others reported having restructured their interaction patterns based on the realities of their new condition. The effects of being HIV positive on relationships are closely linked to disclosure of HIV status to others, for it is only when other people get to know a person's HIV status, by whatever means, that any subsequent changes can be observed. These effects on social relationships are described in the subsequent sub-sections.

4.2.1 Stable Social Relationships

A majority of the study participants, 21 females and 13 males, reported that being diagnosed HIV positive and even disclosing their status to significant others, such as close family members and to other relatives and friends, did not have a notable impact on the way they interacted or related. Their social relationships have to a greater extent remained normal and they interacted with others as they had done in the past. In some cases, however, whatever initial disruptions they experienced occurred at the early stages subsequent to diagnosis when the other people did not have sufficient information on HIV or still harboured some prejudice. But after those disclosed to understood that someone could live positively with HIV, they dropped their pessimism and prejudicial notions.

The finding that the relationships remained normal or largely the same without any noticeable changes was a testimony expressed by both male and female study participants. One male participant stated that "In my house, I do not see any meaningful changes that have occurred since then…" (R16: 31-year-old married man, 55). Another male remarked that "What I have seen is that we are just relating normally and there is nothing…" (R20: married man, aged 26-35 years, 44).

One participant was very emphatic on the fact that there has been no observable change in his interaction with his family members and indicated that his children are actually involved in helping him in adherence to medication. He said that:

> No, no, no...There is no change because I have a daughter who used to always remind me of my drugs. Ehh "have you taken drugs today". So the problem is not there. The kids are just normal, because I told them it is just normal. My family took it as normal (R22: 41-year-old, married man, 39).

One lady remarked that: "There are no changes in my interactions between me and other people. I see that everything is just okay" (R45:51-year-old separated woman, 51-55). One female participant who noted some difficulties at the beginning had this to say: "[However] things have just resumed their normal state. Initially is when there were a few difficulties and conflicts. Things just became normal" (R34: married woman, aged 18-25 years, 25-29). This female participant had disclosed her status to her husband, her elder sister and her mother. Therefore the statement by one female participant, that "there are no changes" (R27: 27-year-old single woman, 75-84), was a common response by most of the participants although it may have been stated in slightly different terms.

In general, some participants reported seeing no much significant impact of being HIV positive on their social relationships and others perceived their interactions as just being normal or their status as okay and comfortable. These participants did not have extreme experiences to suggest that being HIV positive had altered their social relationships. The relationships remained more or less the way they had been before.

4.2.2 Stigma and Discrimination

A total of 15 participants, comprising of 11 female and four male, reported experiences of stigma and discrimination. Among the women, the most affected were widows. Of the 11 women, seven were widowed and they reported more difficulties in social relationships than the other categories of women. The stigma and discrimination expressed itself in several forms. Among the most prevalent forms were friends distancing themselves, and deserting or rejecting the participants. One of the widows remarked thus:

> There are some friends I used to have that when they knew that I had HIV, it appeared like now they were pulling out. Even female friends whom I had who were close to me, I could now see that they were keeping away from me. They were looking at me from far. For an example, there is a co-wife of mine, she is married to my in-law, and we used to love each other very much. But when she saw that I was beginning to be ailing/sickly…when I had rashes, she was now keeping off (R2: widow, aged ≥46 years, 83).

Besides cases of being deserted by friends, there were also cases of abandonment by family members. A 31-year-old female participant who was discovered to be positive while her husband tested negative was abandoned by the husband. Below is an excerpt of the discussion:

> Interviewer (I)**:** And you said that your husband was also tested together with you and he was found to be also infected…no he was found to be negative
>
> Respondent (R): Yes he was found to be negative.
>
> I: And he chased you away or…
>
> R: Yes he sent me away.

> I: So currently, you do not stay together with him?
>
> R: No, we stopped staying together some time ago (R26:31-year-old separated woman, 67-75).

Another female participant reported losing the trust of her husband in their marital relationship since her husband was negative while she was herself positive. She remarked that:

> I have lost trust because since the husband is negative and I am positive, I do not know where this disease came from and you know you cannot be able to read somebody's mind. Because mostly, people know that HIV is acquired through sexual intercourse. So perhaps he was imagining that I am having sexual intercourse with someone else who had HIV and that is where I got HIV. So the trust, I think it is lost (R42: married woman aged ≥46 years, 77).

The results show that it was more difficult for female participants who were diagnosed to be HIV positive while their husbands were diagnosed HIV negative. They were more often than not put away from the matrimonial home or the husband simply left and began a new relationship.

Some participants also reported being branded by those to whom they disclosed their status or who got to know their status from other sources. As the case of this widowed man aged ≥46 years indicates, the PLHIV often found it difficult yet they had to live within a context where they were the unwilling objects of gossip and backbiting.

> You know some of them have not known their status and you know that there in the village, if someone gets to know that "that person is HIV positive" you know that those are things that are there. Some people take it negatively. So instead of being close to you, they remark that "you know that person is HIV positive" (R31: single man aged ≥46 years, 35-44).

According to the statement of this widower, this was a reality they had to accept and live with. Even though they yearned for closeness from their fellow village mates, all they received were responses of being exposed to open shame.

Other forms of stigma and discrimination were insults and ridicule. As the case of one widow reveals, one's HIV status was in some cases used as a tool against him or her in instances of any disagreements that ended in verbal confrontations.

> Like in our home, we live in a home that is full with people. You may find that when you have a disagreement with someone, the person would hurl insults at you making references to your status. Another sister-in-law told my child not to be boastful because she is the one who would

> take care of him [when the mother finally dies] (R17: widow aged 26-35 years, 56).

The PLHIV viewed the perpetrators of the acts of insult and ridicule as being insensitive to their circumstances. As the participant further indicates:

> …Meaning they have already concluded that I would not be around for long. So that is something the child walks around knowing through other people because they have informed him that his mother could die at any moment (R17: widow aged 26-35 years, 56).

These statements, that were intended to injure or get back at the PLHIV, as the previous excerpt indicates, could also end up affecting the psychological and emotional well-being of the children of PLHIV. The stigmatizing and discriminatory treatment thereby not only affects the PLHIV but their dependants and relatives as well.

There are those who reported being considered as though they were already dead or were likely to die soon because they had been infected with HIV. As this aged ≥46 years male participant reported:

> I had some people giving summary comments such as "this guy is dying, he has been infected by that big disease. Him he is dying." There are people who gave me up to one week [to live] and there are people who gave me just three days. But I am still alive over this entire period but a majority of them, some of them have also died (R33: married man, aged ≥46 years, 65).

The statements from in-depth interview participants presented above are corroborated by FGD participants. One male youth who participated in one of the FGDs for instance had the following to say:

> There are a lot of challenges. I was discriminated, even sharing a cup, talking with the kids, playing with the kids, I was not allowed. Even my plate, I was not supposed to touch anything they were using to play. So that was discrimination to the highest order (FGDMY-001, 158).

A key informant also indicated that PLHIV face discriminatory treatment in the social relationships on account of their HIV status.

> Social relationships get changed. You may find that the way you were friends, some will abandon you, but there are some who will still remain with you. At least you will find that there are some who will stay with you and others who will abandon you. Others will also take like a blame game, they will say that you were proud or things like that (KII-002, 33).

The above statements show that some of the PLHIV did not find very welcoming treatment from their social circles. And as has been shown from these experiences, some PLHIV indicated experiencing problematic social relationships with the most affected being widows.

4.2.3 Restructured Interaction Patterns

One other important impact of being HIV positive on social relationships was evidenced in the restructuring of interaction patterns. The most prominent theme in changed interaction patterns is the creation of new social relationships with people of a similar HIV status. This included membership in a support group of PLHIV. This trend applied across gender. The following statement by a 31-year-old widow is illustrative:

> No, till now since I joined the 'HIV world', most of my friends, they are people who are HIV positive. The reason, this is the person, who even when I am not feeling well, I can share with them, because they know what I am. So I can share with such a person deeply…So when I joined the 'HIV world' it made all my friends to be people with whom we are in the support group. These are the people I can leave to go and visit, we can share stories concerning our life, and how we are faring on (R37: 31-year-old widow, 33).

The reasons they advanced for interacting only with PLHIV are diverse and include among other things that these are the only people with whom they share many things in common and who could understand their situation. A 48-year-old married man shared similar sentiments and had the following to say:

> Mostly, I make friends with people who know their status. I make friends with people who know their status. You know people who know their status, if you make friends you share advices. Mostly, at least sometimes they have something good that can help you and you also have something good that can help them (R36: 48-year-old married man, 51).

Other notable changes included diminishing the importance of certain types of relationships while enhancing others. Some of the participants indicated limiting their interactions with others, some sort of self-isolation. A 36-year-old widow demonstrates an instance of diminishing certain types of relationships when she says that: "No, friends you now abandon them" (R11: 36-year-old widow, 113-117) and a male participant indicated that "…those who were my friends whom I used to hang out with, I no longer hang out with them so much" (R28: 25-year-old married man, 71-79).

The theme of isolation also came up and was only mentioned by at least two male participants. One man said that "I spend much of my time at the hospital [PSC] or stay at home" (R28: 25-year-old married man). Another male participant, emphasizing the theme of dropping old friends or diminishing the importance of earlier associations had this to say: “Socially, there are things that are around me now. Before I knew my status, there are friends we could go together with to places such as to the bar. After knowing my status, I had to cut out some other friends and groups” (R44: 36-year-old married man, 59).

Findings from FGDs seemed to substantiate the idea that some PLHIV opted to restructure their relationships. In a representative statement, one FGD participant stated that:

> Yes. I was living with my brother, my elder brother, to whom I disclosed. We were many in that house. I had to isolate myself when I started taking these drugs. Later is when I came back to reunite with them. But I was to live alone. My brother sponsored that because he did not want any other person to know about it. So I lived alone for some time like two years (FGDMY-003, 179).

A key informant also made a statement that resonated well with the theme of changing interaction patterns with the following statement: “Well, when someone discovers that he is HIV positive, so he must change his relationships. He may still retain some friends of the past, but in most cases, he will change, because his lifestyle also must change” (KII-003, 53).

The changes in the way PLHIV interacted and with whom they interacted seemed to suggest that a restructuring of the nature, type and purpose of social relationships was an important change or effect of being diagnosed HIV positive. Most notable is the creation of new sets of social relationships while others are diminished.

4.2.4 Improved Social Relationships

Eight participants reported some improvements in the relationships they had with others. This improvement is seen in two main forms: more enhanced social relations and more love shown to them (PLHIV) by family members. A widow aged ≥46 years had noted an improvement in her relations with her siblings. According to her:

> What I observed when my siblings knew that I was HIV positive, they became more close to me that whatever gives me trouble they would not like. If they get to know that I have any problem, they act very fast. My parents likewise...I could have a burden with school fees they could even give out maize even five sacks to be sold to pay for the children’s school fees. They have been very, very close to me…So I have seen that they have been very close to me (R2: widow aged ≥46 years, 61-63).

A 31-year-old married man also reported similar closeness when he remarks that: “I can see that we are fonder than it was before because now we know our status different to how it was in the past” (R16: 31-year-old married man, 71).

FGD participants also gave testimony indicating that some of them experienced improvements in their social relationships. One FGD member, in expressing the positive impact experienced, narrated that:

> Okay, me, I’d always been on the negative side of it. I always thought of disclosure from the negative side of it more than the positive side. But as I had experienced, it has done me more of the positive than the negative. Because whoever I had disclosed to they are supportive and encouraging. It hasn’t been anything kind of negative on me (FGDMY-006, 173).

A gentleman realized changes and improvements in the way the Church treats issues concerning HIV and PLHIV. He reported positive changes on the part of the church leadership and membership.

> It was not very easy. Yes. To start and involve people and telling them that HIV is a reality, that “fellow Christians you must accept, if at all you are positive you must live positively.” They have accepted even condoms. The Church is in fact now proclaiming condoms. Consistent [consistent use of condoms]. The pastor is saying. So it is something which the Churches have adopted. It is there with us, it is the Christians who are getting sick, our children, so we must accept it (R30: married man aged 36-45 years, 70-75).

The changes observed in the Church above are not easily attained. As the participant indicates, they initially did not find it easy but things have so far began to change and positive outcomes are being observed where before opposition was the order of the day. In some cases, people have experienced improved social relations with other types of people while having problematic relations with others. It is possible for a single participant to be the subject of such contradictory experiences.

4.3 Effects on Capacity to fulfil Social Obligations

In reviewing the effects of being diagnosed HIV positive on the capacity to fulfil social obligations, three main patterns were observed. First, being HIV positive and the knowledge of one’s HIV status did not have any major impact on one’s ability to fulfil the roles for a substantial number of participants. Second, being diagnosed HIV positive had the effect of helping PLHIV regain the capacity to work and therefore ability to fulfil the socially expected roles. Finally, being HIV positive resulted in diminished capacity to work. This information is contained in Table 4-2.

Table 4-2: Effects of being HIV positive on capacity to fulfil social obligations by gender

Effects on capacity to fulfil social obligations	**Female (N=30)**	**Male (N=19)**	**Total**
Retained capacity to work	9	12	**21**
Regained capacity to work	16	5	**21**
Diminished capacity to work	9	4	**13**
Total Responses (multiple responses possible)	**34**	**21**	**55**

The findings from both in-depth interviews, FGDs and KIIs are presented in the following sub-sections beginning with retained capacity to work.

4.3.1 Retained Capacity to fulfil Social Obligations

Despite being diagnosed as being HIV positive, some PLHIV indicated that this did not in any way interfere with their capacity to perform daily activities and to fulfil their social obligations. For some, changes were only initially observed before they knew their status, when they often fell sick-and-off, but that was not very serious. In essence, they did not notice any remarkable changes and after being placed on treatment and care and attaining full recovery, they were able to carry on with their activities normally.

Compared to female, more male participants reported not experiencing notable changes to their ability to carry out their duties as usual. The following statement by one of the female participants was typical:

> No...I still perform my tasks...I have never noticed any problem with performance of tasks. I have not noted any problems with task performance, to be honest. I just do them till the point that I feel exhausted, because getting tired is normal. That is when I can take some rest. Sometimes, I can just work fulltime from morning till evening, without feeling tired. So when it is about 5pm or 6pm so I can decide that "now let me take a bath and rest. Perhaps my mind can now be clear." But any fatigue or that I am weak based on medication, that I have not noticed any setback (R5: widow, aged 26-35 years, 139).

The participants seemed to lay emphasis on the fact that they were able to perform the duties expected of them like any other person, just like the people who are not infected with HIV. This was to underscore the fact that they did not notice any meaningful differences. The following statement by a male participant is illustrative:

> Yes there are no major changes, I...I...I wake up every morning and do my duties as normal, as any other person, and there is no any change. There is nothing that distinguishes me from other people just because I am living positively. I am doing my things the normal way, I go to places where people go in the normal way. There is no clear...clear distinction between me and someone who is not living positively (R21: married man, aged 26-35 years, 30).

Discussions with FGD participants and key informants corroborated the above sentiments of in-depth interviewees. A male youth participant in an FGD narrated his experience as a student in both primary and secondary schools in the following terms:

> Mine when I was in class eight, I never knew I was going to perform. I performed and went to secondary school. When I was in secondary school I never knew I was going to perform. Now I am in Maseno [a university in western Kenya]. Now that I am in Maseno, I do not know if I am going to perform (FGDMY-001, 234).

A key informant in highlighting the role of ARVs as critical in sustaining capacity to fulfil social obligations averred that: "There I do not think there are any serious changes…When someone is well, provided that one enrolls into care and stays alive, I do not think there can be any change [in capacity to fulfil social obligations]" (KII-003, 59, 61).

The participants under this category did not experience any disruptions to their ability for normal functioning that could be attributed to their being HIV positive. In spite of having been diagnosed as HIV positive, they still perceived themselves as capable of effectively performing their daily activities and fulfilling their social obligations. They also did not notice any differences between themselves and other people who were HIV negative or who had not yet known their HIV status. As such, they considered themselves as normal.

4.3.2 Regained Capacity to fulfil Social Obligations

The other major pattern was regained capacity to work and to fulfil social obligations. Some of the participants indicated that before they knew the reason for their recurring illnesses and being put on ARVs, they were not able to perform many of the normal daily activities expected of them. Due to constant illness, they had lost strength and stamina to do their daily activities and were often fatigued. One 31-year-old, single female participant indicated that "I did not have strength. I was constantly fatigued" (R26: 31-year-old single woman, 81). The following narrative by a married female participant aged 26-35 years captures the sentiments of most of these participants, both male and female:

> Since I got to know about my HIV status, I can see that I am living well. I carry out my duties well, and I do not see any problem...because that you could find, before I got to know my status, I would fall sick on-and-off that I could not go on with my duties. So since knowing my status I have not lain on bed because I am sick [have known my status] since 2006. I have not been confined to bed on account of being sick. I have not been admitted, except when it is a small case of some slight flu, some light case of malaria. But I go on with my daily life (R1: married woman aged 26-35 years, 69).

As the statement indicates, this female participant's health status underwent a marked improvement compared to the past after she got to know her status. She was able to resume her normal activities as a result. Her experience is representative of many other participants who after knowing their HIV status and subsequently being enrolled into care, recovered physically, regained their strength and resumed their daily routines. According to a 31-year-old married man: "I find that now is when I am more effective because compared to the past, I did not have a lot of capacity. But nowadays there is a lot of strength because of the medications we are using" (R16: 31-year-old married man, 82-83).

Being on medication was crucial in helping these participants to recover a state of normalcy. According to 31-year-old married female participant:

> Personally, I also have a change because I can carry out my chores. In the morning after waking up, I take my medications, then I just do my duties and eat as usual like any other normal human being can do. I prepare my things, my children are fed, I clean my things, and I do my things because I am well. It is only that now, a child, someone who has a small child must have some bodily changes because now I must see to it that that child of mine has proper nutrition (R12: 31-year-old married woman, 51-53).

As this participant's account indicates, PLHIV are not any different from those not infected with HIV since both categories are preoccupied with the same social obligations such as 'doing ones things', ensuring that children are taken care of and fed and ensuring that the general cleanliness of the home is observed (R12: 31-year-old married woman, 51-53).

4.3.3 Diminished Capacity to fulfil Social Obligations

The third pattern of effects on capacity to fulfil social obligations involved those who recognized that they were still able to perform some of their activities however with certain limitations. Some participants reported only being able to perform certain of their duties but not others due to diminished strength. For instance, a 35-year-old man indicated that he could not now perform tasks "requiring a lot of energy" (R10: 35-year-old married man, 61).

Others noted that they could not work for long periods of time like in the past. What was clear is that they had lost their full strength and had to live in the present recognizing that they were delicate. They were therefore forced to accept the fact that they could not match their previous capacities. A 35-year-old married man reported that: "But I came to find that the strength I had in the past is now going down. Whatever I would do with a lot of energy, I now could not. I found that my strength is diminished" (R10: 35-year-old married man, 37). A 36-year-old widow had this to say:

> Yes you just perform them. So you just perform them because you do not have an alternative because you have been befallen by the misfortune of being both the driver and conductor [the sole-breadwinner]…But really, you cannot really work the way you used to work as in the days when you were still well...You realize that you have somehow lost your strength slightly (R11: 36-year-old widow, 74-83).

In a summary of the accounts of some FGD discussions prepared by one of the research assistants, it was found that "HIV affects the person's ability to carry out household roles in case of being down" because "at times one gets fatigued to carry out other duties as usual." Moreover, "the drugs react differently with the body as they enhance fatigue and pain, thus affecting the activities performance of the individual" (RA, FGD Summaries, 14-15). According a key informant, in findings that corroborate the above sentiments, there are activities that can be performed and some that are no longer easy to be performed by the PLHIV. The KII participant noted that:

> Well, I can say that it depends on what someone is doing. Well there are some activities that are so hard and require a lot of energy. You may find that someone with the strength which he had during the times when he was HIV negative, so you realize when they turn positive you find his strength is slightly reduced (KII-003, 55).

Although they were not able to work with the capacities of the past, yet the realities of daily life require that PLHIV must still be busily engaged with their affairs since no one will fully take over their responsibilities. As the 36-year-old widow (R11) avers, she has to keep working to sustain herself and her family for lack of a viable alternative.

4.4 Effects on Perception of Self

This section reports findings on how knowing one’s HIV status as being positive affects beliefs and thoughts about self, including who the PLHIV believe they were or had become in comparison to the past; what they thought about their self-worth and value to the community and family; and how they conceived of their health and well-being. The findings are clustered under three main domains, namely: perceived sense of disrupted self, perceived sense of stable self and perceived sense of restored or enhanced self. These domains are presented in the following subsections. The list of these domains and how they were mentioned by the study participants and disaggregated by gender is presented in Table 4-3.

Table 4-3: Effects of being HIV positive on perceived sense of self by gender

Effects of HIV on sense of self	**Female (N=30)**	**Male (N=19)**	**Total**
Perceived sense of disrupted self	11	3	**14**
Perceived of sense of stable self	7	6	**13**
Perceived sense of restored/enhanced self	13	10	**23**
Total Responses (multiple responses)	**31**	**19**	**50**

4.4.1 Perceived Sense of disrupted Self

A number of participants viewed themselves as living an essentially new type of life, or as having joined something new or having acquired a new status. The following statement by a 47-year-old widow emphasizes that she is now in a totally different phase of life.

> When I was still well is different to what it is now. When I was still well, I did not know that I am anaemic. But since being put on medication, I have come to know that I am that way. Yes. Sometimes I can grow very pale, is when I go and purchase the medications for the blood booster and I use them to boost my blood (R39: 47-year-old widow, 65-69).

A 36-year-old widow expressed this being in a new state well when she said that “it depends on the fact that when someone [a friend or acquaintance] has not known their status so they think that the way you were in the past [is the way you still are] but now you are like someone who has joined something new…” (R11: 36-year-old widow, 124,125). For these participants, they were in a totally new phase of existence unlike the case in the past.

A disrupted sense of self was also construed to mean having an altered bodily condition such as inability to gain weight and being ever light weight whereas this was not the case before. A 33-year old married female participant had this to say:

> The changes that HIV has brought to me, first, I have been...the fatigue I was talking about is part of the changes, and then should I fall ill, I really go down. Then another one I see that I cannot grow fat. I am forever thin. Those are some of the main changes I am noticing mainly (R15: 33-year-old married woman, 47).

Another participant, a female aged ≥46 years and living separated added that:

> In fact, I realize that my body, I have reduced in weight and I do not see my weight increasing because I had a big body when I was in Naivasha and when I came back to Kisumu when I lost my job, I lost weight and I started regaining weight in 2004/5 it was okay. So, 2006/7 when I came to live with that friend of mine. I saw again that I was losing weight (R35: separated woman aged ≥46 years, 45-57).

In this regard, perceptions of self were seen as being linked to the capacity of the body to be in a normal condition or to behave as expected.

Others expressed an insecure sense of self, whereby any negative discussions or information about PLHIV, even if not about themselves directly, would affect the way they thought or felt about themselves. A female participant aged 26-35 years and living alone having separated from her husband had this to say:

> Or when you hear someone saying that there are some people who are taking medications. I become shocked in my heart and ask myself “from where did this thing get me if some people are still remaining who are not infected” (R41: separated woman, aged 26-35 years, 83-87).

One participant no longer viewed himself as being of much worth to the society. The 35-year-old married man remarked that “Now I see myself as useful but not so much as in the past (R10: 35-year-old married man, 73). He considered himself to have lost something that he knew he could never recover, hence his current condition could be considered disrupted.

One other way through which being HIV positive affected the perceived sense of self of some participants was by making them to drop their future plans. A number of people mentioned momentarily having doubts about their future. However availability of ART helped them review their prognosis. However, some dropped these plans altogether. One male in-depth interviewee gave the following account:

> In 2004, I was planning to go to college and as I was preparing for my college, organizing a way of getting money, it found when my parents -both parents died. So when they died...they died when I...I didn't know about HIV. And according to how I was seeing them, it's like HIV was the main source of their death. So when I realized that this is what has happened to me, I dropped almost all the things that I had in my plan. I said let me now get what I can eat, what I can wear, what I can maybe having my daily routine then I stopped the rest. And since then, the work that I can do… So I became desperate and everything was left. I leave everything to the hand of God, "now God it is you. If you can give me what to eat (...) and I am told that I can live positive, let me live positively" (R22, 41-year-old, married man, 53).

Some FGD participants, especially the youth, also noted disruptions with regard to their future plans. Among the in-depth interviewees, there were only a few who mentioned that being diagnosed HIV positive made them to abandon their plans or lose hope for the future. On the contrary, the key concerns among the youthful FGD participants seemed to revolve around either having to give up a career, or not being able to fulfil other social expectations such as being able to marry. One male youth had the following to say:

> I can say that it affects the future plans a great deal. Like me, today I am supposed to have a family but I do not have that family. Not because I am not trying to have it, but I have been trying to have it [but without much success so far] (FGDMY-003, 219).

Another youth FGD participant noted that:

> Changes occur in life. On my side, the way I did discover I was like that, issues to do with marriage were completely forgotten. Because when I look at the future where I am headed and the income I get, so I see that "will I abandon those that I bring to the world?" So that has completely affected my mind (FGDMY-004, 211).

One key informant seemed to lend credence to the perceived sense of a lost future when he indicated that: "okay, well, there are some who feel that during this time when they are now on medication, that they no longer have a future" (KII-003, 73). Another informant commented that: "the future plans, it is not easy to pursue." He added that: "You know once you are tested HIV [positive], it is just like you just see the grave is this one. You see. You just imagine that this is the end of all, all things. This happens to everyone" (KII-002, 59).

The study findings evidently show differences in perceived sense of self with regard to future plans when the responses of the unmarried youth infected with HIV were compared with those of the other participants who had already established families of their own and had children.

4.4.2 Perceived Sense of stable Self

Perception of self as stable was evidenced among participants who considered themselves to be okay, normal, healthy and who averred that nothing had changed in the way they viewed themselves. A 32-year-old female participant put it nicely when she said that:

> I had love for myself since the past even before I knew my status. I love myself. Even if I have it [HIV], I would like to love myself. I would not like to abandon myself. You see. But what I want, I love peace. So long as I have that peace, then I have no stress of money. I know how I can get money and get something to eat and how I can dress myself and how I can take care of myself the way my heart likes. Then I just feel that I am okay. So I am just proud of it. My work which I can do and get money to enable me to live without stress (R40: 32-year-old divorced woman, 51).

A male participant said that "[s]o there is no change in my heart in any manner…You know…the way human beings perceive others you may not know. But for me, though me I perceive that I am not badly off" (R8: a widower aged ≥46 years, 57-59).

A stable sense of self could also exist even in cases where the participants indicated that they had experienced some changes and that living with HIV was a totally new experience. A widow in the aged 36-45 years acknowledged a gap between the past and the present but still felt normal. She had this to say:

> When I still did not have the infection, I was just okay, I was just good (this was before being tested)…I just look at myself as normal. I have just taken everything as normal because nowadays I find that this thing is something for all people. I am not the only one who is infected. So I just take life as normal (R14: widow, aged 36-45 years, 53-55).

Despite acknowledging these changes, this lady still indicated that she felt okay and took life as normal as she possibly could. The participant mentions that she takes it normal because she is not the only one. She finds safety in numbers (R14: widow aged 36-45 years, 53-55).

Another variant of a sense of stable self was expressed by one participant, who, like many others, manifested a sense of being totally immersed in the 'HIV world.'

> Like me, I don't know how it is with other people but with me I feel very proud. I feel very proud of myself. This is one thing that gives me the encouragement. Every morning I wake up. Most people have a time-table or maybe a wall-clock to alert them, when the time for their drugs reaches. Well with me I don't keep any, I don't keep watch, I don't keep anything, but every time I wake up, I feel great about myself and that is what tells me…Even if I oversleep, I just wake up it's time for me to take my drugs, I go pick my drugs, take them and then I can go about my business as usual (R21: married man, aged 26-35 years, 38).

One married man (R21) reported that he took life as normally as possible and was contented with life as it was at the moment. He carried out his activities as normal after taking his medication. To stress the fact that for him life was normal, he mentioned not using any technical aids (such as an alarm clock) to wake him up for his medications. According to his account, he woke up naturally and even if he overslept, he did not consider that a big issue.

According to the study findings, a number of participants reported that their future plans, a key component of perception of self, remained unchanged. One in-depth interview participant had the following to say: “I see that there is nothing it [positive HIV status] has interfered with even one. My plans can still proceed. I can still proceed” (R10, 35-year-old married man, 79). One female in-depth interviewee, answered in the following manner:

> No. (Emphatically). I can say that the plans that I have… What I had in my life, the thoughts that I had since my husband had already died I have three children. The thoughts I had is that if God grants me life that I enable them to go to school. So when I got to know my status the fear that engulfed me is that now I would leave these children of mine like this (without help). But now, I am confident and I tell them every day that whoever reads [studies diligently and passes her classes] well will be able to study as much as they desire even up to university. I would cater for them. So I do not see any change that this disease has brought into my life which I can say that it has spoilt for me for instance that I was working hard but this illness has drawn me back (R1, married woman age-group 26-35, 87).

A number of FGD participants and key informants also noted that being diagnosed HIV positive did not have much impact on the perceived sense of self of PLHIV. As one key informant put it: “It is just that you are HIV positive but still, you can still just carry on with the activities that you used to do (KII-003, 67).

4.4.3 Perceived Sense of restored/enhanced Self

Participants who demonstrated a restored or enhanced sense of self had experienced a marked improvement in their lives because they no longer had problems with recurring sickness, were able to perform their daily chores normally and could be able to work harder than those who they considered well (HIV negative). The fact that they were living in peace with themselves and had little stress was also considered valuable. A female participant whose story epitomizes this perspective had this to say:

> The situation is just as it was in the past. I currently even live better because the problem of falling sick I no longer have. That after every short while, someone is coughing, after a short while—for me it is feeling fatigued that I used to feel fatigued that I could not work the way I used to work in the past. I [currently] do my chores as usual. I just perform my chores. I am even better because…now I work more and my farm does not lie fallow. I get bountiful harvests—I still have the harvest of the past year in my house in a sack. So I find that myself I am glad because if a disease overwhelms you in the house, there is nothing you can do. So I see that I am living well. I am well (R12: 31-year-old married woman, 51).

The participant expresses a renewed sense of vitality and vigour that makes her even surpass her previous output in terms of harvest and gives evidence in the fact that she still has surplus grain from the previous year's harvest.

The ability to perform one's daily tasks and fulfil social obligations successfully was indeed a powerful component of a restored sense of self because it enhanced a person's capacity for independence. A widower aged ≥46 years supports this view when he comments that:

> You know the moment you are not able to perform your duties, you will be a beggar and a person whom others are tired of. The goodness is that you are able to perform your duties, you do not become a beggar and you do not become a parasite. So, a parasite means someone who depends on…on others. So I am not a parasite. I do my things so knowing my status has helped me because now I can do my own things so it has helped me a lot, a lot (R31, widower, aged ≥46 years, 51-56).

The above case illustrates one of the obvious benefits of knowing one's HIV status and being enrolled into care. For the widower (R31), knowing his HIV status has enabled him to recover his perception of self which seems to be intertwined with his ability to be self-reliant as opposed to being dependent upon on others (R31, widower aged ≥46 years, 51-56). Enhanced and restored sense of self due to ability to be self-reliant made possible by better health is further reinforced by a 48-year-old married man who quipped that:

> In fact, currently, I can say that I have a more elevated sense of self. Because the things, that is the joy that I have is that I can maneuver my ways. My things I can perform with joy. That is, independently (R36, 61-63).

Apart from strength in the body and ability to perform daily chores, the appearance of the body was also a key factor in defining restored sense of self. Some participants not only considered their bodies as smart looking, but also rejoiced in the fact that they had gained weight and regained a well-built physique. A typical case in point is a married female participant aged 36-45 years. She remarked that:

> I am very smart, I am very beautiful, [and] people admire me. Nobody can know that I am living with HIV, compared to the days when I was living without knowing my status. At that time I had stress, I had lost weight, and so on. But after knowing my status, my life changed because I know how to live with HIV, I know how to eat, I know how to get money. My life has changed. Even the photos I had before are different from the photos now. So I am living a good life with HIV before the life with HIV (R47: married woman, aged 36-45 years, 53).

The fact that they had bodies that were presentable and admirable and which disguised the possibility of their status being made public was a source of satisfaction that enabled these participants to express an enhanced sense of self. In contrast, those who could no longer gain weight and have smart bodies perceived a disrupted sense of self as has been seen previously.

Ability to resume active participation in social life and engage meaningfully in daily events was considered a valuable aspect of self whose recovery had been made possible by enrolment into care. A 44-year-old widow had this to say:

> When I survey myself in the past, my status in the past that even perhaps people were going for some journey somewhere. I would not personally go because I was unwell. But currently, anytime you can call me, I will just pick my bag, as long as there is money. And even if it found when I was well, but where people are, I would always just be to myself. You know when you have lost weight, your body is also paining and you are weighed down with worries. But this case you are healthy, even though you may not be heavily built like myself (R38, 31).

The acquisition of new and valued social roles or status, such as that of ‘health consultants’, was hailed as a benefit of knowing one’s status. It was often the case that other families who had a member suspected of having HIV-like symptoms would approach someone known to be living positively with HIV for advice. A 51-year-old separated female participant put it nicely when she said that:

> The change is great, because currently in the village, you can find that someone approaches you to ask you about something. Even if the person has some problem, you could just find that they just stop you. Even where we are taking care, sometimes there is someone who knows you but you do not know them. You could just find them stopping that “please let me talk to

> you. I am also there." And I am normally very free to talk to them. And I am also free to inform them that "me whom you see talking to you, do not think that I am not like you" (R46: 51-year-old separated woman, 46).

The participants in the study who were thus considered as 'health consultants' felt that they were valuable and that they still had something useful to contribute to society.

Ability to acquire new things, qualities, characters traits and perceptions of self that one did not have in the past were features of a renewed sense of self resulting from knowing ones HIV status and deciding to live positively. One female participant who had acquired a new perception of herself quipped that "I started to appreciate myself. In the past, I came to a point when I really despised myself and resolved that it would be better if I died. (Laughter). But later, I came and loved myself" (R34: married woman, aged 18-25 years, 51-53). Another man had this to say: "Well, I can say that I respect myself more than before because I want to live. So I must just adhere to the instructions I am being given so that I may live" (R44: 36-year-old married man, 79).

A 21-year-old married man who had acquired a new sense of life and who was able to accumulate property and achieve some material progress from the new experience said that, "I have built, I have bought three livestock and my wife has also bought two animals. So even her when I informed her that I was HIV positive, I did not see her develop any fear" (R23: 21-year-old married man, 71-77). Some participants also considered life after knowing their status and enrolling into care and treatment as a new lease of life. It was as if someone was getting his life back again. One man remarked that "It is only that rising and walking again. So you just be faithful to your wife. So you avoid wanton sexual relations" (R3: married man, aged 26-35 years, 77).

4.5 Chapter Summary

In this results chapter, findings on the effects of HIV on the social relationships, the capacity to fulfil social obligations and the perceptions of self of PLHIV have been presented. Four main effects were noted on social relationships. These were the first category of participants whose relationships remained normal. The second category experienced stigma and discrimination due to their new status while the third category restructured their interaction patterns whereby most of their new associates were those living with HIV as themselves. The final category of participants experienced enhanced and improved social relationships.

Three main themes emerged with regard to effects of being diagnosed HIV positive on capacity to fulfil social obligations. The first theme encompassed those who noticed no meaningful effect on their capacity to fulfil social obligations and consequently felt that their capacity remained relatively intact. The second theme involved those who reported regaining their capacity to perform their daily activities. In most cases, these are individuals who had lost their physical strength due to prolonged and recurring illness episodes and had been bed-ridden for some time. The final theme was diminished capacity to perform their duties. These participants reported that their strength was ebbing and they could not match their former strength in performing their daily chores and fulfilling their social obligations.

The final theme captured the effects of HIV on perception of self. Three main effects were constructed from the data. The first category included those who perceived their sense of self as having been disrupted by being diagnosed HIV positive. The second category involved those who indicated that their sense of self remained relatively stable. This group considered themselves to be normal and to be the same ones they were pre-diagnosis. The third and final category comprised those who experienced a restored or enhanced sense of self. Those experiencing a restored sense of self were mostly those who had either regained their lost capacity to perform their duties, had acquired bodies considered smart, had acquired a cherished social status and wider acceptance in the society and those who were able to resume active participation in social life.

The next chapter will consider the coping strategies adopted by PLHIV in adapting to life with HIV and the difficulties they faced in coping.

5 RESULTS III: COPING STRATEGIES AND DIFFICULTIES FACED BY PLHIV

5.1 Chapter Overview

In the current chapter, the concern of the PI is to present findings on the coping strategies PLHIV adopted in order to adapt to and live successfully with HIV. The chapter also examines the difficulties faced by PLHIV in their coping efforts. The first question being answered is: *Through what ways do PLHIV cope with and adapt to their HIV status*? The question was operationalized by asking the participants some of the things they did in order continue with their lives in spite of their HIV status. The question had inbuilt probes to identify some of the adjustments they had made in their lives, the activities they engaged in, the activities they avoided and the precautions they took.

Due to the semi-structured nature of data collection methods, themes pertinent to the questions were also found in other places throughout the transcripts. As a result, the coping strategies have been arrived at both deductively, by following up the order of the interview questions and inductively, by reading through the other sections and by making inferences from the responses. The coping strategies PLHIV adopted were grouped under six main thematic categories: psychosocial and emotional strategies; relying on faith and religious beliefs; social strategies; adherence to medication and good nutrition; livelihood enhancement strategies; adoption of safe sexual behaviours; and abstinence from and minimization of the use of alcohol and drugs. These strategies were what PLHIV reported doing either by themselves or through support from others, especially in instances where they were not capable of fulfilling their specific needs. These strategies are presented sequentially in the subsequent sections.

5.2 Psychosocial and Emotional Strategies

PLHIV adopted a number of psychosocial and emotional strategies as a way of coping with HIV. The strategies included disclosure of HIV status, acceptance of HIV status and enrolment into care, avoidance of stress and contentment with life, and access to psychological counseling (Table 5-1).

Table 5-1: Psychosocial and emotional coping strategies

Psychosocial/Emotional Strategies	**Female (n=30)**	**Male (n=19)**	**Total**
Disclosure of HIV status	23	13	**36**
Acceptance status and enrolment into care	22	10	**32**
Avoidance of stress & contentment with life	17	10	**27**
Access to psychosocial counseling	12	3	**15**
Total Responses (multiple responses)	**74**	**36**	**110**

5.2.1 Disclosure of HIV Status

Disclosure of HIV status was a key strategy adopted by PLHIV in the coping process. In reviewing the responses of the participants, disclosure was considered beneficial in at least four key ways. First, disclosure acted as a form of security or insurance in the cases of medical or other emergencies. One female participant underscored this benefit of disclosure in the following words:

> I just informed them because I could possibly fall sick and there could be no one to pick my medications for me. So I could even send my sister that “go and collect for me my medications”…I thought it was good to inform your [her] relative that you are unwell, so that even at an instance of illness, they will quickly reckon that “so and so is suffering from this kind of illness. So let us take her to the hospital” (R26: 31-year-old single woman, 51-55).

Because disclosure could provide security in emergencies, most of the participants found it necessary to have at least one trusted person whom they gave information about their HIV status. Similar sentiments were shared by some male participants as well. One man commented that:

> I became free with them [family members]…due to illness. It could be that due to illness, you could be stranded in the house [in case of a strong attack]. Sometimes your wife may be at home and the person you could inform is perhaps your brother who is living close by. You could tell him that I use these types of medication and they can be collected at such a place or he could remind me that at particular times, I should be taking my medication (R20: married man, aged 26-35 years, 33-34).

The participants who stated that disclosure was useful in cases of emergency, as in the cases quoted above, felt that HIV comes with some uncertainties and a PLHIV may not be sure of the course of the illness. As such, it was important to share this information with some close person.

Secondly, disclosure was considered instrumental in helping create an atmosphere conducive to adherence as one would not need to hide anything. Such a free atmosphere was believed to act as a barrier against stigma and discrimination as it could be used as a preemptive strategy to disarm any person who would think of stigmatizing the PLHIV. According to one female participant, her motivation for disclosure was the need for a free environment.

> So I wanted that they know my status so that we find an easy way of staying together with them in the house. Secondly, after I had been diagnosed, after I had been given the drugs, I was told that if I knew that I might forget [to take medication in time] then I should tell the people who are close by to remind me. So I tried to tell the children…that "my children, when I was tested, it was found that I have HIV. Now these drugs are the drugs I take, and anytime that you see that I'm about to forget, then remind me because they are my life now." So that is the main reason why I tried to inform my children (R15: 33-year-old married woman, 23).

As an example of protection against stigma and discrimination, this excerpt from a female participant is instructive:

> I inform everyone; especially my brothers-in-law…even cousins. Me I have told them, I do not hide because I realize that it has helped me. Being that I had disclosed, I am free and it has made me live in a free environment. I do not have stigma, because I reckoned that stigma would make me have worries. I felt that once I had made a public disclosure, no one would backbite me (talk behind my back) (R2: widow aged ≥46 years, 53).

The above statement indicates that this female participant did not want to be an unwilling victim of ridicule due to her status. So she preempted any possible cases of being discriminated or stigmatized by taking the initiative to inform all those who were close around her. Because of this disclosure, as her statement indicates, she has benefited greatly for she finds that she lives in a "free environment".

Thirdly, and as has been highlighted in the previous quotation, disclosure was viewed as an appeal for social support. It embraces the realization that for success in coping, the support of others is needed. A man who disclosed to his wife after being tested positive mentioned that:

> Yes. It forced me to inform her. After informing her she told me that it was okay…that there was nothing problematic because those are things that are part of life, that befall humanity. So she tried to comfort me and then I just started using the medications that I was given at the facility. So that is what I began on immediately till it reached a point when they enrolled me on antiretroviral drugs (ARVs) (R28: 25-year-old married man, 21).

As the case of this 25-year-old married man indicates, his disclosure attracted very ready acceptance from his wife and this was important in helping him to start the journey of living positively with HIV. Here we see an example of how disclosure clearly helped not only make it possible for adherence but also evoked social support from the spouse. The importance of disclosure in soliciting social support is additionally supported by the views of another female participant. This lady was informed during counseling that disclosure was vital as it would be useful in making it easy for others to support her and for positive living to be possible.

> Depending on how the doctor counseled me, he told me that for me to be able to find it easy in life, for me to have an easy life, I must inform the people…some among those with whom I am living, that I be with them… I inform them about my life, [and that] is when they will understand my life, and is when it will make it easy for them to support me. So it was forcing me to inform them (R41: separated woman aged 26-35 years, 31-33).

The fourth way in which disclosure was found to be a useful coping strategy was in the desire to help others. Some PLHIV felt a sense of moral responsibility to the rest of the community that motivated them to inform others of their status. In this case, disclosure was aimed at convincing the community members of their risk of being infected with HIV and encouraging them to go for testing. The overall goal was to motivate community members to know their HIV status and to adapt their behavior appropriately.

> Later, I became free with the village where I am and the whole village knows that I am living with HIV. Even where I am living they know me even today that I am living with HIV. Being free to let them know has made people to really go for testing [encouraged the uptake of voluntary counseling and testing (VCT)]. Even if I see one of my fellow human beings having problems or even when they are unwell, then I give advice. I have even taken time with some of these people and brought them for testing and they have even been enrolled on medication. And considering the way I am strong, they see the importance of being diligent to follow the treatment plan [adherence to medication]. And I have brought many to Nyabondo Hospital and they have been receiving medication in a proper way and they are well (R25: 37-year-old widow, 21).

In the case of this 37-year-old widow, disclosure of her HIV status has been a great benefit to the community for through this, many people have been motivated to know own their status and many have ended up being enrolled on medication. Perhaps some of the people she encouraged to get tested would still have been ignorant of their status were it not for her decision to disclose.

As can be deduced from the above foregoing statements, disclosure makes the task of coping with HIV a collective and collaborative effort that goes beyond the PLHIV to even include their family members and the immediate community. Disclosure is therefore a good avenue for calling forth the support of others to help with the various issues related to the management of HIV and a tool for overcoming stigma and discrimination.

5.2.2 Acceptance of Status and Enrolment into Care

Acceptance of HIV status and subsequent enrolment into care and treatment was considered a key turning point to living positively with HIV. Acceptance was seen to serve as the fulcrum around which a positive experience with HIV revolves. As such, the ability to live a long life, to successfully cope with stigma and discrimination and to regain normal functioning all depend on whether a person diagnosed HIV positive has accepted their status or not. When a person accepts their HIV status, the next logical step would be for them to be enrolled on treatment where they can benefit from the life-extending benefits of anti-retroviral therapy (ART). A female participant and a mother of young children commented that:

> Later, I changed my mind that, “is it the end of the world; the fact that I have HIV is it the end of the world? I [should] accept, I [should] start medication and if God wills, I [will] live. How about those who get involved in accidents, did they have HIV?” Sometimes, I would sit down and you would find me crying. Me I even bought *Rat & Rat* (a poison for killing rats); but I found that it would not help me. My children would remain in trouble (R7: married woman, aged 26-35 years, 55).

As has been indicated in the previous quotation, acceptance was an important point of departure in ensuring that this female participant could live a long life. It provided for her a critical starting point for enrolling into care and medication. Through adherence to medication, one would be assured of more years of life. The next statement by a separated woman aged ≥46 years buttresses this perspective.

> So, I also wondered that “this knowledge that someone is positive may be the people who have studied it are the ones who understand; the counselors are the ones who understand how to talk to someone who is positive, HIV positive.” In fact it was really difficult for me. But I

> had to accept. So it is acceptance which has made me to be alive till this moment (R35: separated woman, aged ≥46 years, 5).

The female participant, R35, commented in very clear terms that it was her decision after counseling that made her to accept her status and attributes her being alive till the present time to the decision to accept her status. It can be deduced from her statement that had she not accepted her status, she would not have been alive as at the time of the interview.

In FGDs, the participants also highlighted the centrality of acceptance as being key to successful coping. One female FGD participant corroborated the significance of acceptance in the following terms:

> What one should do, first, you accept yourself. After accepting, it will be easier for you to cope with it [HIV]. Because you know the moment you deny, in the first place you would have discriminated, the self-discrimination. When you see people, you think they are talking about you. You think, you imagine they had known. So in that condition of accepting oneself, it is the key to everything (FGDFY-012, 159).

Stigma and discrimination are constant living realities that PLHIV have to contend with. The fact that HIV has no cure coupled with the moral implications surrounding its transmission makes it a condition amenable to stigma. Because stigma is a social reality, a deliberate and brave decision by PLHIV to embrace an HIV positive identity is essential for successful positive living. Otherwise, life within such a society would be too difficult. Hence for a number of PLHIV, acceptance was important as a stigma fighting or reduction strategy. The following statement was typical for a number of participants.

> The names they have given us, you are called...aren't you just called a person of HIV...a person with HIV. But once you have decided and accepted, that you are a person with HIV, even when someone refers to you as a person with HIV, you will not have a problem. Because at the moment they are referring to you as someone with HIV, perhaps they may also be having HIV unawares. So that one [being referred to as being HIV positive] does not bother you (R9: widow, aged ≥46 years, 111).

According to R9, as can be deduced from the above quotation, acceptance was important as a counterstrategy for confronting ridicule and branding by others. The PLHIV may be confident that they at least already know their status whereas those branding them may be HIV positive but ignorant of this. So in a sense, the PLHIV saw themselves as being in a better situation.

Finally, acceptance was the basis for being able to regain normalcy and to continue with the daily affairs of life. According to R47:

> It is only that first of all, the main method that can make me go on with my life, is accepting my status. After accepting my status, then I will do anything to make my life go on. I must know that if I have children, then children must go to school. If I am living in the town and I am renting a house, I must pay rent. And if I have a business, I must ensure that this business goes on. That is when I can pay rent and is when the children can go to school. You must be a person who has a plan (R47: married woman, aged 36-45 years, 63).

According to R47 therefore, acceptance is the key to ensuring that everything goes on as usual. Acceptance helped the participants to recognize the need to go on with life and ensure that social obligations, such as taking children to school, paying bills, and engagement in gainful income-generating activities (IGAs) are fulfilled. As one KII participant observed: "Okay, the methods someone can use, is to accept yourself as you are. Admittedly you would initially be shocked but accept yourself as you are" (KII-002, 67).

As has been eloquently narrated by the participants, acceptance was a key prerequisite for coping and for successfully encountering the difficulties one faced due to being HIV positive.

5.2.3 Stress Avoidance and Contentment with Life

Another key psychological and emotional coping strategy is learning to avoid stress and worry and contentment with life. According to some of the participants, excessive stress was considered dangerous to health and well-being especially given that PLHIV already had a compromised immune system. Some of them believed stress could reduce their CD4+ counts (R35, 63; R40, 51) and compromise their immune system thereby effectively cutting short their lives (R11, 129). Due to its potential threat to health, stress was something PLHIV were counselled to avoid at all costs. Consequently, as R47 notes, she was trying to deal with and manage stress:

> Okay, I have stopped many things. First of all, the thing that was bothering me that would even have resulted in my demise was stress. It was the stress that I was undergoing. But stress is the first thing I dealt with thoroughly. I try to avoid…okay you cannot eradicate stress but I manage it. I am trying to manage stress (R47: married woman aged 36-45 years, 65).

Because completely eradicating stress is not possible, PLHIV mentioned that they were trying to creatively manage and handle it. PLHIV tried out a number of mechanisms in order to deal with stress. Among these was the endeavour to stay joyful even when confronted by potentially stressful situations. Some efforts at staying joyful were buttressed by faith in God and were in some cases expressed through reading the Bible to gain comfort. As one widow narrated:

> What can I say, (prolonged laughter) when I get some issue that can scare my life, I see how to manage it. I stay joyful [calm] then I see how to handle this situation. More often than not—I am a Seventh-day Adventist—I can go to the Bible and open some verse, and it can help me so that I do not develop stress (R2: widow aged ≥46 years, 101).

Another stress-avoidance strategy was ignoring stressful thoughts and worries that often flooded their minds. With regard to their status, there were some participants who indicated ignoring the fact that they were HIV positive and assumed that they were just normal like the uninfected people. According to one female participant: “Okay, I try to subdue the thoughts and I do not...I assume even the issue of being HIV [positive]…I do not talk about it. I assume I am just like any other person (R24: 36-year-old widow, 83). A similar sentiment was expressed by R27 (28-year-old single woman): “You should not have a lot of worries…you should just be like those who are alive [HIV negative].”

Another mechanism used by some of the participants was keeping themselves busy with the affairs of everyday life and avoiding moments of idleness. According to one participant, idleness would provide great room for worries and stressful thoughts to engulf one’s mind. One female participant epitomized this perspective as is captured in the excerpt below:

> So the people who have been training us emphasize that you need to have something which you are doing to keep you busy. Every PLHIV must get something to do so that you do not have an idle mind. An idle mind will inevitably lead to worries. When you have such thoughts, you will get stressed and when you get stressed, your CD4+ will go down (R35: separated woman, aged ≥46 years, 63).

Another strategy discernible from the transcripts was the practice of letting life flow normally, whereby some of the participants let things take their own natural course. They did not want to overburden themselves with things over which they had little or no control. According to R39: “Nowadays I do not force anything. I just do what I can. If it goes too much, it can give me stress and then I hurt myself.” This mechanism, for some, also included living a contented life within the capacities and opportunities that one still had at their disposal and staying as much as possible within one’s means and not striving for things that were not feasible. According to R50, a widow:

> I try to limit the impact of the difficulties in gradual measures. Even if it comes to renting a house, I try to get a house which I think I can easily afford. Not a house for display, which will then give me stress when the landlord is seeking his right [monthly rent]. I can rent a house for Kshs. 4,000 (EUR 36) instead of renting a house of Kshs. 1,000 or some Kshs. 800. So, it would be better to rent a house which I know I can pay for, that will not give me conflict. Conflicts is one of the difficulties. If someone is in conflict with you, you will not have peace in that house (R50: 52-year-old widow, 75).

According to the preceding comment by R50, living within one's means was a safety mechanism as it helps one avoid a lot of potential for conflict, considered a source of stress.

5.2.4 Receiving Psychosocial Counselling

Counselling was a fundamental component of treatment, care and support for PLHIV. Through counselling and education on various health issues, PLHIV were sensitized on other means of coping. During counselling sessions, PLHIV were given information on pertinent issues such as adherence to medication and good nutrition. They were also informed about the importance of positive living and disclosure of their status to family members. In the accounts of a number of PLHIV, counselling played an essential role in helping them accept their status. One in-depth interview participant had the following to say:

> When I initially got to know my status, first it really bothered me. Another counsellor advised me and counseled me to even play music as a stress-relieving mechanism. It necessitated that at sometimes as I was relaxing, I would play some music and get absorbed in my things, so that I can forget. When the time for taking my medications came, I take my medications and swallow them. I can see changes. I have come to get used. Initially, it really disturbed me (R34: married woman, aged 18-25 years, 51).

The coping strategies discussed in this chapter are not to be seen as being mutually exclusive but as mutually reinforcing. Each strategy is to be seen as helping make it easier for others to be adopted. For example, during counselling they were taught how to deal with stress; but counselling itself was also critical for acceptance. During both pre-test and post-test counselling, they could also be given information on how to successfully live with HIV, and be encouraged that they were not the only ones infected. For instance, one male participant had this to say:

> The way the doctor talked to me. He talked to me calmly. He counseled me and told me that "the test will be done today and the following day, you will get the results." So when I went, before that I had informed some brother of mine that "I had gone for that test". He told me that

> "my sister just go and do the test. Those things people live with." So at least, when I was going, I was expecting both. Either a bad one, or a good one. So when I got this bad one [a positive HIV test result], so I had just to accept it (R39: 47-year-old widow, 33).

The participants received counselling from a number of sources. The most important sources were trained patient support centre (PSC) counsellors from where they received the main counselling. Trained community health workers (CHWs) also provided counselling to PLHIV within their communities and residential neighbourhoods. CHWs also functioned as an important link between the communities and the health facilities (PSC). Counselling was also offered informally by family members who, though not necessarily trained, nonetheless provided encouragement and were available to discuss the challenges that arose in the day-to-day lives of their HIV-infected members. Some of the family members included spouses, children, siblings and other relatives. A female participant who received counselling from her siblings gave the following account:

> So you know that they [children] would remind me of the time when I am supposed to take my medication. They were encouraging me. Even when I am stressed, they counsel me thoroughly. They have really stood by me…She [her sister] has been with me very much because whenever she sees that I am down, when I am stressed or when sometimes my finances are not good, she comes in and tells me, "sister we are joyful about you. We are proud of you being our firstborn. Whatever it is that is troubling you let us know so that we can help sort it out." So I have seen that they have been very close to me (R2: widow, aged ≥46 years, 49 & 63).

As has demonstrated in this sub-section, psychosocial counseling was very important in helping the participants accept their HIV status, disclose their status to their family members, adjust to taking medication and ensure good adherence. Counseling was received from different sources and not only from the trained professional counselors. Family members and CHWs also participated in counseling their members diagnosed with HIV.

5.3 Faith and Religious Activities

In this section, findings related to spiritual dimensions of the lives of PLHIV as human beings are presented. The PLHIV demonstrated that faith in God had a role to play in their lives. This faith in God was also evidenced in their engagement in religious activities.

5.3.1 Faith in God

As part of their coping strategies, the participants exhibited an acknowledgment of the role that God plays in their lives. A good number of respondents in both FGDs and in-depth interviews exhibited implicit trust in God's ability to grant them length of life. The following excerpt from an in-depth interview participant illustrates this trust in God:

> "But I will not die. I know that I will take my drugs well and if all goes well, God will give me a bonus of living to enable me care for you [assuring her children]. You are the ones who I now desire that you do not get into the same situation that I am in" (R7: married woman, aged 26-35 years, 21).

The following case of a 52-year-old widow is also a typical example of those who believed that it was God who had willed that they have length of life.

> Things that are of value in my life? I see that the greatest benefit in my life is that God is the one who has given me life and it pleases me that my life is prolonged under the grace of God as I take care of my children. My life would have ended long time ago (R50: 52-year-old widow, 65).

Others expressed their trust in God's intervention by way of the expectation that God would grant them life. Theirs was not expressed in very concrete terms as the previous cases suggest. An example would suffice to demonstrate this view.

> Me, I just pray to God that if he extends my life a bit, then I can reach a stage where I can help my child and leave him/her at a good stage. So I had taken my thoughts and committed to God. That a lot of thoughts like "I am sick, or I am this way, I did what, I abandoned. So there is no change in my heart in any manner to make me have some shock (R8: widower, aged ≥46 years, 57).

For some of the participants, God was seen as a source of comfort in their difficult circumstances, who granted them a good state of health. They trusted God to make it possible for an HIV cure to be found. They expressed their trust in God through prayers for healing when sick, prayer for length of life, and through getting saved. Generally they trusted God with their lives and waited for His intervention in their lives.

The participants had a desire to live long so as to enjoy life for themselves and particularly to be able accomplish unfinished projects. The most mentioned among these projects was the need to raise up their children who were still not mature to depend upon themselves.

> I view myself in the sense that if time can...if medication -because the government is giving us free medication, so I just want to do my things the way I can. When it reaches time that I die, then I will die, and even my children, I know that if God grants me life, then I would find means of educating them, so that even them they find out means of how they can take care of themselves (R20: married man, aged 26-35 years, 50).

So, as has been shown above, the participants had faith in God's intervention in their lives and trusted that He would grant them length of life to enable them accomplish their life projects and to live to the end of their allotted days. One of their most important projects was the upbringing and education of their children.

5.3.2 Engagement in Religious Activities

As part of their coping strategies, some of the participants indicated that they engaged more intensely in Church and religious activities. This engagement included joining church-related groups. One lady stated that she had stopped associating with groups she considered disadvantageous and had instead joined among others, church-related groups. She had this to say: "But since knowing my status, I joined groups that are church-related, those that are development-minded…" (R38: 44-year-old widow, 37).

For yet another participant, regular attendance at religious meetings, like the weekly worship services, and guiding her children to God's way was a manifestation of her engagement in religious activities. The following excerpt from a widow aged 36-45 years is illustrative:

> The things that are of value in my life are…the thing that I see as being beneficial to me more is going to worship God. I can organize myself so when it reaches on Sunday, I will go and worship my God and I have also placed the children on that way of God (R48: widow, aged 36-45 years, 79).

Being involved in undertaking religious activities such as singing in the Church choir were other ways through which some participants engaged in church activities. One female participant found music therapeutic, as it helped relieve her difficulties. In describing her coping strategies, she had this to say:

> Apart from eating and the work I do as a community health worker, I move/walk a lot; that is good for exercise. I also talk with people. Singing, music is therapeutic. After I have walked a lot and I am tired or even when I feel that something is not proceeding smoothly, when I go to Church, when we sing as a choir, when I participate in practice during the trainings, when I go back home I feel refreshed. So singing is also therapeutic (R35: separated woman, aged ≥46 years, 57).

As the case presented above indicates involvement in singing was found to be therapeutic. It helped this particular participant to cope with stress-related symptoms. For these particular individuals, faith in God and involvement in church-related activities were important coping strategies that helped them overcome some of their difficulties and live successfully with the realities of being HIV positive.

5.4 Social Strategies

The main social strategies employed by the participants in coping with the implications of living with HIV revealed three main patterns. These patterns included: maintaining active social engagement, joining support groups, and changing interaction patterns. The strategies reveal the importance of human relationships to the health and well-being of PLHIV.

5.4.1 Maintaining active Social Engagement

PLHIV tended to remain socially engaged as evidenced by the fact that they maintained existing social relationships. Even in cases where they dropped non-beneficial relationships, they tended to form new ones. They maintained social engagement with their family members, support groups, and with new avenues for social expression including active participation in religious activities and religious groups. A married man aged 26-35 years who valued his engagement with his parents noted that:

> Okay, I keep a good relation with them [family members]. Yes. First in that line are my parents. I keep a very good relation with them. I give them the respect they deserve and I talk to them. I discuss with them anything that is necessary to be discussed with them, and I do not go against them. If they tell me that this thing you have done is not right, I have to refrain from that, because if I do not do that, we are going to fall out and I do not want to fall out with them. They are the people who are holding me together. They support me, they support my wife and we like it. We do not want to lose it [the support]. So even my wife has to follow in the same line (R21: married man, aged 26-35 years, 68).

A 42-year-old widow in discussing the strategies she uses to cope highlighted the importance of maintaining good relations with members of her support group when she indicated that: “I maintain the interactions with the support group” (R37: 42-year-old widow, 67). A female participant living separately from her husband added that: I also talk with people…when I participate in practice in the trainings [Church choir trainings], when I go back home I feel refreshed” (R35: separated woman, aged ≥46 years, 57).

Data from FGDs and discussions with KIIs also indicated that PLHIV maintained their social relationships, especially those with family members, relatives, neighbors and friends. Since PLHIV also lost some social relations because of their status it was important for them to always seek to find other modalities of still remaining socially engaged. This was not always within the context of the family or the circle of friends. More often than not, most PLHIV indicated finding meaningful relationship within the context of their support groups. In this regard, the support groups occupy a very prominent role in the lives of PLHIV in Kisumu County and it would not be an exaggeration to say that support groups are the fulcrum around which the lives of PLHIV oscillate.

5.4.2 Joining Support Groups

The most important of the social strategies employed by PLHIV was joining and participating in support groups. Almost all PLHIV were members of some support group since it is recommended to them from the PSCs to join support groups.

> After knowing my status, the counselor released to me my result. After that she introduced me to some support group and I joined that support, support group. So after joining the support group, I started coping with life (R47: married woman aged 36-45 years, 27).

By policy, the PSCs help in the formation and management of various support groups catering for the needs of the PLHIV based on considerations such as gender and age. Examples of support groups include those for male adults, female adults, and for male youth, female youth, discordant couples, and for CHWs by themselves. According to one PSC coordinator, “apart from that, we are forming support groups. Like in this facility, I have 15 support groups. And at times, I am forced to form support groups according to the nature of the people” (KII-001, PSC in-charge).

Support groups were instrumental in helping the participants to not only overcome powerful stigmatizing notions but to also find a place where they could feel at home. Within these support groups, PLHIV also found people with a similar condition with whom they could share their experiences and obtain mutual support. As the following quotation from a 36-year-old indicates, support groups were used as avenues for providing support with income-generating activities as a way of strengthening livelihoods of PLHIV.

> We have support groups. There we have Income-generating activities (IGAs), and there we learn. We were given some goats for milk. The milk can be taken at home to support nutrition and can also be sold and if the goats get young ones, these are given out to members (R24: 36-year-old widow, 127).

Support groups also provided a forum where PLHIV learnt from the experiences of others who had lived with HIV for long periods. They had the chance of knowing some of the methods these fellow group members have used, the challenges they have faced, and how they have overcome such challenges.

> Okay, the support group members, just as I have informed you that it was a support group of PLHIV, the members of the support group…By then sometimes I would disclose while crying because those days, what was happening. But in that place I found that those who were there are the same. I found people saying that they got to know their status in the nineties [1990s]. So that gave me courage. When they were saying that they got to know their status in the nineties, and when I look at him without him telling me, there would be nothing to show that he had HIV. So this gave me courage that if someone has already lived [with HIV] for 8 years, 10 years, then I can also live. Coupled with the teachings that we were getting there, we were being treated equally like the children of one family (R37: 42-year-old widow, 13).

As can be seen from the above quotation, the support group context provided a safe environment where PLHIV could easily and freely disclose their status to people who share the same status with them. Disclosure within the group is considered therapeutic and as some of them indicated, it had enabled many PLHIV to bravely embrace positive living.

> Support group is what has made it possible for me to talk to you the way I am talking to you. Because before I joined the support group, I was a shy man and stigmatized and whenever I was coming to the clinic here, I would cover, I would try even if I did not have money, I would buy...I would look for something like a newspaper to block my face [demonstrates]. But through the support group, I can come into this place to discuss with you confidently. Because I know that the fact that I am HIV positive, it has happened so I have to accept it. So the support group has helped me through many different teachings and counseling. I could not even get into this place (R31: Widower aged ≥46 years, 66).

Support groups also enabled the PLHIV to find new friends. Most of them mentioned having gained new friends by joining support groups. So they did not feel worried or bothered when some friends deserted them after learning of their HIV status.

Support groups enabled PLHIV to meet other people who were in similar circumstances. Consequently, support groups were important in helping PLHIV to develop the right attitude useful for overcoming and resisting stigmatizing attitudes from the community. They also found a home where they could feel a sense of belonging and meet friends from whom they could obtain mutual support and with whom they could share experiences. Additionally, they met individuals who had lived longer with HIV from whom they could learn how to successfully cope with HIV.

5.4.3 Changing Interaction Patterns

Another important social coping strategy was the restructuring of social interaction patterns. The PLHIV deliberately took a proactive step in creating a social network that worked best to advance their interests. They were involved in rational calculations to find out what relationships worked and what did not work and discarded those that no longer worked. In other words, they engaged in a simultaneous process of diminishing the significance of certain friendships or associations and of enhancing the role of other sets of relationships. This strategy was also considered as one of the effects of HIV on social relationships. One female participant commented that:

> Before I knew my status, I was in some groups even for gossiping, gossiping, gossiping, varieties of gossip, gossip such as that so and so has HIV. I knew that HIV kills, you hear my mum. But since knowing my status, I joined groups that are church-related, those that are development-minded and concerning someone especially with regard to his health I would not want to delve into. And if I want to talk about it, I would go to him straight and settle it with hi….him (R38:44-year-old widow, 37).

The case of R38, is a clear indication of a complete change of interaction patterns where one set of interactions which did not serve a constructive purpose are discarded for more constructive ones. This aspect of restructured social engagements was reflected in the kinds of groups the PHIV engaged with. For R37, a 42-year-old widow, her new identity as someone who is HIV positive has become the more salient in her life since even her choice of social relations is largely from among members of the support group of PLHIV.

> No, till now since I joined the ‘HIV world’, most of my friends, they are people who are HIV positive. The reason, this is the person, who even when I am not feeling well, I can share with them; because they know what I am. So I can share with such a person deeply. And then me, also since I lost my husband, I did not have many friends. First, I did not want friends…So when I joined the ‘HIV world’ it made all my friends had to be people with whom we are in the support group. These are the people I can leave to go and visit; we can share stories concerning our life, and how we are faring on (R37:42-year-old widow, 33).

The other vital theme within the change of interaction patterns was the notion of selection of friends. This came out clearly when some indicated that they were actively involved in sifting who could belong to their social circles. Those who would be friends were vetted by proving them to see if they could keep information confidential.

> Secondly, I select the people from whom I can seek advice, who can...can give advice. Okay a group geared towards development, which even if I want to initiate something “you say this and this” and then they give you some advice. Because you know, you must have a goal, you know you must now have a goal…I share a lot with the people we are living with HIV. I do not hold my things to myself. When I have shared the things that bother me or what I want to do, then you find that you get advice. Yes, advices come. Yes advices come... I do not keep silent with the things that I want to perform (R47: married woman, aged 36-45 years, 65).

According to the accounts presented above, PLHIV realized the importance of social engagement in coping effectively with HIV. PLHIV recognize and take advantage of the potential of social relationships to help them make meaning of their HIV status and adopt pragmatic coping strategies. They maintained social engagement, joined support groups and changed their interactions patterns. All these efforts helped keep them socially connected and receive mutual support from others.

5.5 Health Strategies

In this section, findings on what PLHIV do with regard to medication are reported. Three main sub-themes were identified. These were adherence to medication, observing clinical appointments and reduction in the use of alcohol and drugs. These themes ought not to be construed as being mutually exclusive. On the contrary, the participants often mentioned them as part of the broader theme of adherence. They logically belong together in treatment and care of HIV. However, in the interest of conceptual clarity, they will be presently in different sub-sections.

5.5.1 Adherence to Medication

Enrolment in and consistent and proper use of ART were mentioned as the most important things the PLHIV could do so as to continue with their life and ensure a return to normalcy. Indeed, adherence to medication, which means taking the medicines according to the prescribed dosage and at the correct times, was invariably mentioned as the first strategy towards adaptive coping with HIV. Adherence is broader and includes sticking to all the instructions of the doctor and the health personnel. A female participant whose experience epitomized the importance of adherence had the following to say:

> Okay, the thing of the greatest and of first priority in my life, as a person living with HIV, first number one is the drugs. Number one is drugs. In fact if you forget even for a minute, you just feel that there is something lacking in your body. I must take the medication. After taking the medication, I must eat well...So the greatest thing in my life right now is that I must take my medication because with drugs, is what will prolong my life, with food is what will make the drugs to help me (R47: married woman, aged 36-45 years, 71).

The participants indicated their commitment to taking their medications with dedication because non-adherence could mean annulling the dose and perhaps having to start all over again. This was the sentiment expressed by a 35-year-old married man who indicated that:

> So I just take my medications. So I just take them with commitment that "I now would not like to miss my doses because if you miss them your strength goes down. You will be like someone who has annulled the dose that you were on. So you continue with that dose without fail and at the right time (R10: 35-year-old married man, 99).

The importance of adherence to medication is highlighted by the 44-year-old widow who indicates that even when going on a journey, she must ensure that the first thing she packs is her medication.

> Yes the things that I must do so that my life continues, the first one is medication. The issue of medication is something I give first priority. Even if I want to leave for a journey, even before I pack my clothes, in adherence we were taught that you first pack your medication. You registration number must also be in your brain (R38: 44-year-old widow, 57).

In the context of FGDs, adherence was also mentioned as one of the key pillars of coping with HIV. As the following excerpt illustrates, adherence is more than adherence to drugs.

> Someone found with HIV to be able to cope with life, number one, there are some key points you are supposed to consider. One of them is adherence. Adherence you are not just adhering to your medication and that. Adherence is adhering to everything around what supports your life (FGDMY-001, 238).

As the above cases illustrate, the PLHIV indicated that they would not want to miss their drugs. They noted that they wanted to adhere well in order to prolong their lives and thus realize the benefits of ART. They expressed the determination to strictly abide by the prescriptions and advice of their clinicians and to not let anything distract them from realizing this goal.

5.5.2 Observing Clinical Appointments

Going hand-in-hand with taking medications at the prescribed terms and in the correct dosages is the strict observance of clinical appointments. Clinical appointments serve as opportunities for the PSC personnel to determine the progress the PLHIV are making in their path to recovery and normality. During such appointments, the clinicians check key health indicators such as CD4 count, viral load, body weight and the presence of any OIs. Any adverse incidents such as side effects are also noted. Observing clinical appointment was often mentioned as a co-event with adherence to medication.

> The methods I am using? First, I would like to adhere well to drugs. Yes. I adhere well to medication because in the past I did not know how I should be using medications. But after getting counseling, I know how to take my ARVs on time. So I do not miss medication, I also do not miss clinical appointments and then stress, the way I had been informed that stress lowers CD4+, I would like that if all is well, that I should not have stress (R40: 32-year-old woman, 63).

A male participant indicated that he needed to be consistent not only with his medication but also with his visits to the clinic on the appointed dates. He had the following to say: “I continue with visiting the health facility, I continue taking the medications they give me and the porridge for which I was given flour” (R19: married man aged ≥46 years, 85).

Coupled with visits to the clinic as per the appointments is the significance the participants attached to the instructions or advice of the health personnel. They indicated a willingness to do all it takes to abide by the instructions of the PSC personnel, especially the clinicians. For example, in giving the authority for why they have to pack their medications as the first items when going for a journey, the participants cited the instruction of the medical personnel. A 44-year-old widow indicated that:

> The issue of medication is something I give first priority. Even if I want to leave for a journey, even before I pack my clothes, in adherence we were taught that you first pack your medication. Your registration number/care number must also be in your brain (R38: 44-year-old widow, 57).

Closely tied to and as important as adherence are the other issues of observing clinical appointments and following the instructions given by the health care personnel.

5.5.3 Reduction of use of Alcohol and Drugs

Some participants who had been taking alcohol and other drugs such as cigarettes reported stopping their use. One female participant had stopped taking alcohol. She had the following to say: “In the past, I would take alcohol without lying. Those are things which I have stopped doing” (R46: 51-year-old separated woman, 80). One male participant who had been taking alcohol and smoking as well, reported stopping both when he stated: “I have stopped taking alcohol, I have stopped using drugs” (R43: married man, aged 26-35 years, 84).

Participants in FGDs and KIIs also mentioned abstinence from alcohol and other substances of abuse as a key plank in coping with HIV. Commenting on what a PLHIV needed to abstain from, one FGD participant commented thus, “If you used to drink like me—before I started taking medication, I used to drink—you stop. So issues like that (FGDFY-012, 163). A key informant also indicated that the use of alcohol and other drugs are things PLHIV should refrain from. He stated that:

> Okay we have things such as drugs, alcohol, cigarettes, you get it. Those now you must forsake so that –because things like alcohol, they contain, they contain chemicals and these chemicals will suppress the medication and therefore medications will not be beneficial to you. So you will be adding to the, you are using medication and you will be adding the chemicals in drugs (KII-003, 85).

Whereas some participants had succeeded in stopping the use of drugs such as cigarettes, they were still struggling with the habit and trying to stop the use of alcohol. One male participant indicated that: “The things I have stopped doing, I used to drink severely, I am now minimizing it; I used to smoke, and I no longer smoke now” (44: 36-year-old married man, 101). Another man still struggling with alcohol mentioned that: “What is still giving me difficulties very much is alcohol. That is what I am struggling with because I had stopped smoking, but alcohol, I am still struggling with” (R29: single man, aged 18-25 years, 115). Another participant had changed the brands from very strong ones such as locally brews to milder ones. In his words, “I used to take *changaa* [local, traditional brews] but that one I abandoned and I now use keg.”

Among the major reasons for stopping their drug and alcohol use included the fear that these substances would end their lives prematurely (R11:36-year-old widow, 137); that it was not compatible with the medications and the treatment regimen they were placed under (R20, married man aged 26-35 years, 76); that they had lost interest in alcohol and no longer found such a habit useful, neither did it make meaning in their lives (R37, R48).

5.6 Livelihood Enhancement Strategies

The participants mentioned engaging in a number of activities to attain and maintain a relatively normal and acceptable standard of living. In spite of living with HIV, the daily activities of PLHIV—e.g. providing for the basic needs of the family and meeting other obligations of daily life—had to be performed. The activities mentioned were clustered into three major categories. First, they mentioned carrying on with everyday life activities, such as continuing either in self-employment, paid employment or in other daily activities. Second, they mentioned being engaged in producing their own food, either by working in the farm or in employed service. This was to ensure they had access to good and adequate nutrition. Third, they also mentioned being actively involved in income-generating activities (IGAs). These themes, although interrelated and apparently difficult to disentangle, represent three distinct domains. First we begin by looking at carrying on with life's activities.

5.6.1 Carrying on with Life's Activities

For some study participants, carrying on with life's activities meant continuing to participate in the regular occupations of life geared towards providing their basic necessities. They mentioned either taking up employment in their areas of training, or engaging in farm work. As part of their daily occupation, CHWs engaged in health promotion among fellow PLHIV or provided education to the community to urge them to be tested for HIV. A 48-year-old married man had the following to say:

> Yes the things I do daily also help me to prolong my life. Mostly as I had already mentioned, I had informed you how I am an electrician in a construction firm. In that instance I am exercising myself. That is, I am keeping myself in movement everywhere because sometimes I am going up story buildings, I go up ladders, I must go something like hammer, chiseling, that is hard work (R36: 48-year-old married, 82).

As the above statement indicates, it was important for this participant to stay actively engaged and to keep in constant movement as these provided opportunity for exercise. A female participant put in nicely when she said that:

> You are not supposed to just stay idle because even if you are not working [paid employment], you should strive to even do cleaning [doing their own household chores]. There are others who just stay and they are not going to work. Like me, I can chat with a customer till evening and when it reaches a particular time, I will say I am going to collect a packet of milk. I continue doing my work. I am used to working. Because, I normally wake up, by six I am normally awake let's say five o'clock. I have a small baby, so I need to wash the clothes, clean

> her, take her to the place where she is being taken care of, clean the house, and if the house is clean, after taking a shower, then I leave and go to work. At the place of work, I may find a customer waiting for me—I am a saloonist—sometimes I am called while still in the vehicle [in the public transport to work]. When you arrive, you start being busy with your work (R34: married woman, aged 18-25 years, 67).

In the statement above, the female participant emphasizes the need for one diagnosed to be actively engaged as opposed to staying idle. She contrasts her case with other PLHIV who just stay idle, whereas they could be meaningfully occupied with something positive.

An FGD participant, commenting on the necessity of continuing with one’s occupations and keeping on with what one used to do before diagnosis had the following to say, “Once you have been found to be HIV positive, you are not supposed to abandon what you were doing in the past. Even if it is employment, continue doing it. Even if it was exercising such as jogging in the morning [continue doing it] (FGDMY-004, 254).

The participants’ accounts emphasize the importance they attached to continued engagement with the normal everyday occupations as a coping strategy. According to their narratives, these occupations could provide a means of earning a livelihood and of keeping them busy.

5.6.2 Producing own Food and ensuring good Nutrition

Being on medication with ARVs is important for PLHIV because ARVs help contain and reduce the spread of the HIV in the body. Food is an essential component in complying with treatment regimen. Therefore as part of coping strategy, the PLHIV mentioned struggling to ensure they could provide for their own nutritional needs.

Nutrition played a very important role among the PLHIV regarding adherence to medications. PLHIV are counselled and trained that nutrition is one of the key elements of effective HIV care and management. As such, the PLHIV were advised to make every effort to ensure they had proper nutrition. The response by one of the male participants is a good case in point:

> The methods I ought to be using appropriately, I must maintain the use of my medications… Thirdly, I must try to get good food and eat food that is relevant and at the correct time so that the medications do not get when my body is weak (R43: married man, aged 26-35 years, 80).

The following quotation, still emphasizing the primacy of good nutrition, talks about it in terms of an indispensable aspect of the care and management practices whose neglect is considered tantamount to destroying one’s life. As the participant in the next excerpt puts it, it was something over which one cannot afford to be careless.

> [What] I am cautious about, to not destroy my life? I must be careful about food. I must look for good food to eat, a balanced diet to eat so that I use it to take care of my life. And also medication to take my drugs in good time (R12: 31-year-old married woman, 83).

According to discussions in FGDs and with KIIs, nutrition was critical to proper coping. One male youth FGD participant, commented thus on the importance of nutrition:

> Then apart from the most basic things is positive living. What is positive living? You should do the right thing at the right time. And also balance diet, nutrition. You should eat, if it is proteins, you make sure you eat a well-balanced diet. Vitamins should also be there. It is not only ARVs and that is all? Apart from that, food is also contributing. Because drugs can't work,—if you are taking ARVs alone, you cannot survive. Also nutrition is a very important thing. That is positive living (FGDMY-002, 242).

The participants clearly understood what it meant to eat well or what the components of good nutrition were. They expressed good nutrition in terms of a balanced diet, sufficient amounts of food, and eating at the right time. In describing what she understood by good nutrition, one female participant had this to say:

> I must eat well. Eating well does not mean eating flesh. When I get vegetables, I cook that vegetable of mine well and then eat. Habits like skipping lunch, I must at least look for something small that can keep my stomach. I must also just carry water. Every time I go on a journey, I must just carry my water (R39: 47-year-old widow, 83).

Having good nutrition was also defined in terms of having access to a variety of foods. It was therefore not enough to eat a balanced diet. The balanced diet needed to consist of a wide range of foods. For example, one man talked elaborately on different varieties of fruits, vegetables and proteins as the following quotation suggests:

> I can get some fruit and eat, avocadoes, mangoes, oranges, beans. These little things I eat them like that. Sometimes also if I come across carrots, I eat. I eat with all my children because whatever I eat they must also eat. Even eggs when they are available, I eat. Chicken also if I get, I eat. Fish, I alternate them like that. But if those are not there, even vegetables, the bitter ones like *mto, dek, bo, osugah,* [these are traditional vegetables] if we get milk, we put in it, we just proceed like that (R4: married man, aged 35-46 years, 55-61).

The above statement also suggests flexibility to know that there will be times when there will be no food that one may desire. The most important point however is to eat what is readily accessible and take advantage of foods that are locally available.

Various reasons were advanced as to why they needed to ensure that they had good nutrition. Among the reasons mentioned was the compromised immunity of the body due to the activity of the virus. As such, good nutrition was important in equipping the body to successfully fight off OIs and for the medications to work effectively. The participants also wanted to ensure that the condition of the body was maintained in its equilibrium so as to ensure a good life. The other reason they advanced was the potency and toxicity of medications and their adverse effects if taken on an empty stomach. According to the lessons they learnt from the PSC, lack of good nutrition may limit the therapeutic benefits of ARVs.

They achieved self-reliance in providing food either through self-employment, full-time paid employment or as volunteers with the PSC. A married man aged 26-35 years had the following to say:

> The things I do–because I have some plot I was given as I am the eldest son I was given some plot there–I can sometimes plant maize, beans. So sometimes the harvest can help me, like when our pay delays. So sometimes I get some eight tins [a tin is the equivalent of two kilograms] of maize and this can help in the house here (R20: married man, aged 26-35 years, 68).

The value of providing their own food by working in the farm was echoed by a female participant who stated that:

> I still work in the farm, like [growing] vegetables or on a small plot I can grow maize. Potatoes also I can grow in a small way. So these are the means by which I can get to feed myself…What I find of a greater…the farm because it is from where we get our daily food (R13: 51-year-old widow, 59, 77).

Capacity to produce their own food and to meet their own nutritional needs and that of their families was an essential plank in the coping strategies adopted by some of the participants. As a good number of participants had access to arable land, and given the benefits of nutrition in adherence to medication, producing one's own food was a useful avenue for increasing access to good nutrition. Even for those who were in employment, produce from the farm went a long way in augmenting their sometimes insufficient incomes.

5.6.3 Developing Income-Generating Activities

A number of participants indicated having saved and invested in various types of IGAs so as to secure for themselves a means of livelihood. The IGAs were in various fields such as agribusiness, small-scale businesses, bricklaying and welding. Some who were still in active employment also had some investments that they managed on the sides. Others saving portions of their incomes with a view to getting into self-employment in the near future. A female participant underlined the importance of having a source of income when she said that: "In the past, I would relax, I would not work very hard. Currently, I work very hard to have a means of sustenance so that my life can continue in a good way" (R17: Widow aged 26-35 years, 117). A married man aged 26-35 years also emphasized the necessity of an income-generating activity (IGA) when said that:

> Now, you must have something [crop] which you can plant so that even when you have a problem, or you want to look for some money then you can sell it, and then you get some money or clothing. Something you can even sell to get food to eat. You need to also have a programme for your household (R3, married man, aged 26-35 years, 89).

According to these participants, it can be seen that in spite of being HIV positive, and perhaps because of this, they now had to alter their pattern of living and had to deliberately assure themselves of a source of income and livelihood support.

The most popular form of IGA for these participants, however was agribusiness. Those who practiced this form of IGA not only grew food for consumption but also for commercial purposes. One lady had this to say:

> Even *mto* and *dek* I have already bought. If I prepare some ground and plant them, then I will water them so that they grow because I will not be able to buy vegetables. When I sell the bananas, I would like it to take care of cooking oil. Tomatoes I have to buy because tomatoes does not do well here. Because even if I plant it will require someone who has prepared something [greenhouse]. Yes, that is what can manage tomatoes because you [referring to herself in the third person] do not have ability to go buying insecticides all the time (R12:31-year-old married woman, 97).

The vegetables (*mto* and *dek*) mentioned by the participant in the preceding excerpt are very high-value traditional vegetables in very high demand and are not very demanding in terms of labour input.

Whereas agribusiness is undertaken by both male and female participants, some investment areas were mostly male-dominated, given that they are more labour intensive. These included bricklaying and light industrial activities like welding. A 41-year-old married man who was engaged in bricklaying had this to say:

> I think that the adjustments that I can make, if I can get a better job that I can earn [well], and I plan myself well with whatever is needed for my life, then I will be just very okay…Activities, Now what I am doing apart from that voluntary work, I am a brick maker. I [also] do small farming. Those are the things that keep me moving on (R22: 41-year-old married man, 65, 67).

According to the preceding quotations in this sub-section, participants often engaged in more than one IGA. Participant R22, for instance, was engaged in farming, voluntary work at the health facility and bricklaying. Engagement in IGAs, particularly producing their own food from their farms, were important coping strategies that helped the participants to earn a decent livelihood and ensured adequate nutrition necessary for enhanced ARV effectiveness.

5.7 Adoption of Safe Sexual Behaviours

The adoption of safe sexual behaviours, by some interviewees, was mentioned as a key component in coping with HIV. Five distinct changes in formerly habitual sexual behaviours are presented. First, subjects ceased having sexual intercourse with multiple partners. Second, most participants vowed to practice faithfulness to one spouse/partner whose HIV status they knew. Third, they also mentioned using protection during sexual intercourse, except during occasions when they were seeking to get a child, which had to be done in consultation with their health care provider. Fourth, a number of women were abstaining from sexual relations with men altogether.

Fifth, some women who were involved in commercial sex work reported losing interest and finding no benefit in this kind of work. As most of the risky sexual behaviours normally transpired in the context of pursuit of pleasure, a number of participants mentioned ceasing the pursuit of pleasure. This cessation was to act as a barrier against relapsing into the risky sexual behaviours. Findings on cessation of pursuit of pleasure are presented first. The participants also gave concrete reasons as to why they adopted such safe behaviours. The reasons for adopting safe sexual behaviours are presented at the end of this section.

5.7.1 Cessation of the Pursuit of Pleasure

There were various forms of pleasure in which some of the PLHIV had engaged before knowing their status and before being enrolled into treatment. These pleasure activities were often connected to sexual behaviour not considered socially acceptable and to taking of alcoholic beverages. The findings show that pleasure often comprised of going to dances both within the villages in a rural settings, and in the town for those from an urban setting. As part of their efforts to live positively, PLHIV now deemed it imperative to cease or minimize their involvement in such pleasure activities. One female participant stated that:

> OK, in the past, in my past life, I was a person who loved pleasure. I was a person who used to drink. But currently, all those I do not do.” She added that: “Currently, I do not go out in pursuit of pleasure, I do not take alcohol (R37: 31-year-old widow, 57, 71).
>
> And a male participant indicated that:
>
> Yes I was a lover of pleasure. I would go dancing, I would drink, I would dance and I also had women—beautiful ones that I had selected—because when I was doing second hand clothes business I had good money. Money was available. But those ones [habits] I reduced” (R33: married man aged ≥46 years, 127-133).

5.7.2 Sexual Abstinence and Faithfulness to one Partner

Some of the recommended means of preventing HIV infection include abstinence and mutual faithfulness between partners who know their status (Mathers *et al.*, 2010; Mbizvo and Bassett, 1996; Oladepo and Fayemi, 2011). These two are among the options that some of PLHIV practiced in order to keep themselves safe from getting re-infected with other strains of HIV. In this study, those who reported adopting abstinence were all women. A total of eight women stated that they would not have much to do with sexual intercourse and with men. They had therefore decided on living their life without interruption from male partners. One female participant said that: “I take care of unwanted sex. That one [having sex] I left, I refer to myself as someone who is abstaining.” She went further to add that: “The things I have stopped doing, I have stopped sexual intercourse as the first one and now I abstain” (R15: 33-year-old married woman, 65-69). Another participant indicated that: my mind has settled on the fact that I want to live. I abstain, and I just want to live without any other issue. This has helped me.” She makes this more emphatic when she says that: “I have taken precaution that I do not want any man in my life” (R2: widow, aged ≥46 years, 99).

Generally, those who were abstaining were mainly widows, and had known their status for relatively longer periods of time. Of the participants that indicated they were abstaining from sexual intercourse as a coping strategy, six out of eight were widows with the youngest being 31 years old and the oldest being 52 years. Of the two female participants who were not widows, one was married while the other, who was 51 years old was separated from her husband due to her HIV status. Her husband turned out to be HIV negative when he was tested. More than one-half of them (5) had known their HIV status for more than 10 years (the longest was since 1992, the latest since 2002). The remaining three had known their status for at least 4 years. Even though there were other options such as widow inheritance, which is common in this community, these women decided to remain totally abstinent and to concentrate on their own affairs.

The other important practice reported in the study was mutual faithfulness between two partners. Once the PLHIV got to know their status and were counselled about positive living, most of them resolved to live less sexually risky behaviours by only having sexual relations with one trusted partner. In most cases, these partners were their spouses. However, not all were married. Some were separated and so they opted to be faithful to one partner. This was a logical consequence of ceasing to have indiscriminate sex with multiple partners. The participants realized the meaninglessness of pursuing a promiscuous lifestyle as highlighted in the quotation by a male participant below:

> Once I got this illness [and got to know about it] so I decided that issues of sexual promiscuity, I had to now cast aside. That I should only have one partner whom I can stay with. Because I realized there is no point of cheating somebody's daughter that I am interested in her and then later infect her. I see that having one person has made my body to remain constant the way it is. (R23: 21-year-old married man, 95-97).

Similar sentiments were expressed by some female participants as is expressed in the following except:

> The changes I have carried out in my life is that having multiple sexual partnerships, I decided that I would like to follow a straight path so that I control my life. Things that I would not like to befall me in my life are things like… meaningless relationships. Before I got diagnosed with HIV, I had many friends before I knew my status. But now after knowing my status, I now know that those many partners can endanger my life. So I maintain only one friend (R48: widow, aged 36-45 years, 69-73).

According to the findings, pre-diagnostic sexual attitudes and behaviours of some participants favorable to maintenance of a chain of sexual partners seemed to have radically changed. As exemplified in the two excerpts quoted above, the participants viewed such practices as being fraught with many dangers that they were keen to avoid.

5.7.3 Reduction in Sexual Partners and engaging in protected Sex

A number of the participants, both male and female, reported having many sexual partners before knowing their status. This was expressed in different concepts. Some of the terms included sexual affairs, indiscriminate sex, and sexual promiscuity, walking with women outside marriage, widow inheritance, and extra-marital affairs or just simply as seeking after women. There was a tendency for most of them to have had many sexual partners. However after getting to know their status and receiving counselling and enrolling on medication, most of them reported stopping these kinds of activities. A male participant had the following to say:

> Okay, I used to have many girlfriends. Nowadays I do not feel like…The activities that I am now avoiding, once somebody is married, and again you found yourself positive, so those other extra-marital affairs, you stop those ones; try to avoid such. And if I must, then I have to prepare for using the (protective) measures to avoid re-infection (R22: 41-year-old married man, 83 and 69).

Having many sexual partners was not only a preserve of the male participants but was also engaged in by some of the female participants. One female participant commented that:

> The fact that I am coming into contact with men (sex) so I try to avoid. Even if I have one person, it is only one person whom I stick to. You know in the past, I was...you would roam [have affairs] the way you want to. But at the moment you know even those many affairs you no longer desire. So you just stay to mind your affairs, and avoid a lot of issues. Since 2010 to date, the things I now do, I no longer have affairs indiscriminately. That if you find this man you go with him, and if you find this man, you go with him. So I am just staying the way that you can see (R9: widow, aged ≥46 years, 75, 7-79).

As the two cases indicate, coming to know that they were HIV positive prompted them to implement changes in their sexual behaviours. They came to the realization that they could not continue the way they had been doing and as part of their coping strategies, opted to transform their sexual behaviours.

The most adopted sexual practice among both the male and female participants was protection though using condoms during sexual intercourse. As their statements made clear, the participants would never contemplate the having sexual intercourse without protection even with their spouses or partners due to the risk of re-infection. During post-test counselling, positive living is emphasized, including the need to strictly use protection during sexual intercourse. Hence protection, alongside other strategies was a key component of sexual behaviour change among the participants. A male participant remarked that: “Like in the past, I never used to use a condom whenever we were making love with my lover, but now it forces me to use a condom (R43: married man, aged 26-35 years, 86). A key informant in emphasizing what PLHIV should do to cope effectively with HIV commented that, “they should not have sex without protection. That is behaviour change" (KII-003).

Looking at the findings of the FGDs, emphasis was laid on protected or safe sex by most of the groups in addition to other sexual behaviour changes. An FGD participant had the following to say concerning positive living:

> Positive living also includes sex. For example if you want to play sex, do you use protection? When you want to play sex, you must use protection to avoid re-infection. Maybe you do not know the status of that person you are going to have sex with. Maybe he/she is also HIV positive; maybe she/has another strain. If you go there unprotected, either you will infect her or she will re-infect. So to avoid that one, use CD [condom], you see (FGDMY-002, 242).

The following quotation by a female participant is equally illustrative of the practice of using condoms during sexual intercourse.

> When having sex with someone, I can use condoms…So we can only engage in sex when we have protection so that my life gets prolonged. Because you know if you do so without protection, that person can infect you with the strains he has. Sometimes the one I have is a bit better, but the one he has may have a higher concentration and that can cut my life short (R5: widow, aged 26-35 years, 177).

In the instances mentioned above, as in most of the cases, PLHIV had to adopt the practice of using protection during sexual intercourse as a component of positive living advocated by the care and treatment providers. The government provides the condoms which are distributed freely and the PLHIV get them as part of their care packages.

5.7.4 Stopped *Parking*

In Kenya, *parking* is commonly used as an unofficial expression for being engaged in the exchange of sex for money as an occupation; or commercial sex work. At least two women who had been commercial sex workers before knowing their status resolved to abandon this work in order to extend their lives. Asked about what her past occupation prior to knowing her status was, one female participant had the following to say: "Yes, earlier, me earlier I used to go for parking [commercial sex work]. I used to go for parking." On being pressed further concerning what other habits she had changed, she retorted that: "those ones only. It was just having sexual affairs and going for parking [commercial sex work] are the things I used to partake in. Nowadays I lost interest in those things" (R26: 31-year-old single woman, 93-99).

The other female participant who shared in this kind of life prior to knowing her status indicated that: “Earlier…before getting somebody to live with, I could do prostitution. But nowadays, I see that prostitution cannot help me” (R17: widow, aged 26-35 years, 139). These two female participants had resolved to quit commercial sex work due to its implications for their lives. The information they had received, and the desire to live long and normal lives, had made them lose interest in this type of occupation.

5.7.5 Reasons for Change in Sexual Behaviours

The overriding reason why PLHIV adopted safe sexual behaviours was to avoid either endangering or shortening their lives. As PLHIV, they had compromised immunity and therefore, a delicate life. Thus they desired to do all that they could to protect their lives. They understood the link between their CD4+ counts, their immunity and their health status. They knew what decrease in CD4+ count meant; that this was indicative of a depressed or weakened immune system that reduces the capacity of the body to fight off infections. According to the following statement by a male in-depth interviewee:

> Adjustments are that, that leisure life you must now stop. The sex where you had many sexual partners, you do not have that time for leisure now. Because your life is delicate, your CD4 is compromised in the first place. So we must ensure that we live positively, so that we live longer. So that these children of ours who are still young, we can leave them somewhere if they have a place in life (R30: married man aged 36-45 years, 143).

Moreover, as is indicated in the excerpt by R25 below, they had been informed of the dangers of being re-infected with different strains of HIV than those they already had. They had been taught in counselling that acquiring new strains could accelerate the development of resistant strains not responsive to the current treatment regimens available. Thus they were very diligent to either stop engaging in sexual activities, reduce the number of sexual partners or use protection in cases where they had to have sex.

> Because, why I am saying so, if I engaged with many sexual partners more than two and above, I may have problems in the future because we had been taught that you could get strains of HIV which are different from yours and this may be harmful to your life. This is information that I had got earlier after being initiated on medication (care). Because that I would have done before but now, I cannot do. That is a kind of life that if I engage, I would be a bad person. And I would also be endangering the life of someone who would get the virus from me, who may have been negative, who may get HIV from me. So that is another thing over which I am very cautious and has put off (R25: 37-year-old widow, 95).

As indicated in the preceding quote, some participants also indicated not wanting to transmit the virus to others. They felt morally obligated to take precautions to not indiscriminately infect innocent people by engaging in irresponsible sexual relations such as unprotected sex or having multiple sexual partners. Instead, they vowed to be faithful to their sexual partners, to use protection and to avoid extra-marital sexual liaisons.

5.7.6 Summary of Coping Strategies adopted by PLHIV

The coping strategies and the corresponding activities carried out under these strategies are outlined in Table 5-2. As Table 5-2 shows, there were six main coping strategies and 21 activities related to the various strategies.

Table 5-2: Summary of coping strategies adopted and things done by PLHIV

Coping Strategies	**Components**
Psychosocial and emotional strategies	Disclosure of HIV status Acceptance of status and enrolment into care Avoidance of stress and contentment with life Receiving psychosocial counseling
Faith and religious activities	Faith in God Engagement in religious activities
Social strategies	Maintaining active social engagement Joining support groups
Health strategies	Adherence to medication Observing clinical appointments Reduction of use of alcohol and drugs
Livelihood enhancement strategies	Carrying on with life's activities Producing own food and good nutrition Developing income-generating activities
Adoption safe sexual behaviours	Cessation of the pursuit of pleasure Reduction in sexual partners Faithfulness to one sexual partner Practicing protected sex Sexual abstinence Abandoned parking (commercial sex work)

5.8 Difficulties faced in Coping with HIV

In this section, findings are presented to provide answers to the fifth research question. This question sought to establish the difficulties that PLHIV in Kisumu County encountered in their efforts to cope with and adapt to a life with HIV. An analysis of the findings revealed that the study participants faced several difficulties. Five main difficulties were synthesized from the data. First, the participants lacked adequate resources to provide for the needs of their families. Second, they lacked access to sufficient food and nutrition. Third, they faced stigma, discrimination and cultural challenges. Fourth, they lacked the means to effectively provide education and training for their children. Finally, they often experienced health-related problems. The difficulties are summarized in Table 5-3.

Table 5-3: Difficulties PLHIV faced in coping with their status

Difficulties faced by PLHIV	**Female (N=30)**	**Male (N=19)**	**Total**
Livelihood and income related	18	13	**31**
Food and nutrition	10	6	**16**
Stigma, discrimination & culture	10	4	**14**
Children's education	9	2	**11**
Health-related	2	1	**3**
Total Responses	**49**	**26**	**75**

5.8.1 Livelihood and Income-related Difficulties

One of the main difficulties the participants experienced was lack of reliable incomes and proper means of earning their livelihoods. Often, they considered ability to earn an income—in terms of money—a key aspect of successfully meeting their obligations. The participants indicated that they needed money and other resources to purchase food, and to pay rent and school fees for their children. They also needed money to pay for levies charged at the health facilities, which were mostly minimal. The means for securing a proper livelihood was expressed differently but revolved around money or other non-monetary resources. According to one female participant: “The challenges that are there are the means of earning a livelihood” (R17: widow aged 26-35, 143). Another female participant remarked that “it is just these means of support which I see that sometimes I experience difficulties because at times, I find it hard to earn an income” (R40: 32-year-old separated woman, 121). The following statements from a married, male participant and a widow respectively, highlight income as their greatest difficulties.

> The most difficult is on how to get money that I find most problematic, because I find that if I can have some reasonable amount of money, then I could carry out my things the way I desire (R20:married man, aged 26-35 years, 94).
>
> When I go and line up there [PSC], I will have to pay the charges levied there. But sometimes my income does not make it possible for me to be able to pay these charges. This is a big challenge for those PLHIV. Yes. It is a bit challenging for those PLHIV because sometimes someone may not even be able to get this money, but truly they are unwell (R37: 41-year-old widow, 75).

Participants in FGDs and KIIs also cited lack of proper and sustainable sources of income as one of the key difficulties PLHIV contended with. According to one FGD participant,

> I would say that the challenges the PLHIV face are maybe in terms of income, their income… You find that they do not have any source of income. So this one is also a stress in them that "how can I get somewhere that I can get a living." You stress yourself with this at the same time, maybe if you get that work, or you don't get that work, it forces you to do a work that now you use a lot of energy in doing (FGDMY-003, 280).

A KII participant, a PSC coordinator had the following to say:

> Another challenge I was talking about is this still level of poverty. Our level of poverty. We still cannot manage so much as clients because HIV is quite demanding. And even people who have those, today it is so good that somebody is taking care of the drugs, and laboratory tests. But if it was left for the clients, then we would have no clients here (KII-001, 59).

Lack of a stable source of income, or incomes that were considered insufficient resulted in inability to meet financial obligations. Hence, one of the difficulties most mentioned by both male and female participants had to do with lack of or inadequate income. In both cases as exemplified above, access to sufficient income was viewed as being critical for one to meet their obligations.

According to some of the participants, income for secure livelihoods could be earned in a variety of ways. These ways included paid employment, self-employment, and business. For the majority, earning an income was mostly in context of employment and if they could secure a stable employment opportunity, they would have secure livelihoods. One man commenting on the challenge of getting employment and thus means of livelihood said:

> One major challenge that I face is that now I have not... since I was into the ...I mean I was...I took up the responsibility of having a family, I have not got, I have not got a sustainable job. So this is one thing that worries me so much. And that is why I have made a decision that self-employment is the way to go and am right now saving towards the same (R21: married man, aged 26-35 years, 74).

In some cases, the PLHIV realized that lack of proper qualifications were barriers to getting better job opportunities. They did not access proper career training due to lack of finances and were themselves now caught up in a trap of poverty. The experience of one female participant is illustrative:

> The greatest difficulties I am confronted with, first, the income is low. Our income is very low. Number one, I am not employed. I also went to school but school fees could let me reach only form three. So I have no certificate with which I can look for a job. So you find that our income is low and we have brought forth children into the world and we would like these children to go to school. So we find that we have a lot of burden. So many other issues about the family require a financial resolution (R47: married woman, aged 36-45 years, 81).

In the above case, the participant clearly locates the interconnections that exist between low income, lack of employment and proper academic qualifications. She traces her lack of employment to low qualifications and subsequently, her low incomes to lack of employment. This kind of situation makes it difficult for her to fulfil the social obligations including paying school fees for her children.

For a number of participants, the ability to have a secure livelihood and thus to provide for themselves and their families was linked to their capacity to effectively perform their daily tasks. Consequently, incapacity to fulfil these expectations was largely attributable to diminishing physical strength. In their own terms, their diminished physical health therefore compromised their ability to have secure means of livelihood. Most of their daily activities included working in the farms or in casual labour. The following statement, by a female participant represents this view.

> The challenges I face -because you know me now I am not in full strength- so food, I do not get in an easy way only if we work hard. And also paying school fees for the children (R13: 51-year-old widow, 81).

The above statement was corroborated by a male in-depth interview participant in the following terms:

> The need to earn an income. It becomes difficult for them [PLHIV] because first of all, there is some weakness that sets in because sometimes you are weak. Because people who are in the early stage of their lives, you find that they are having some weakness in their bodies. Because for you to now do something difficult/hard as a means of earning an income, you find that you are stressed. This is the greatest. That is they become weak (R36: 48-year-old married man, 90-92).

For those who rely on self-employment as a means of livelihood and especially working in their farms, one other reason that jeopardized their livelihoods was bad weather conditions. Even though this was not a permanent condition and even though it affected those not infected with HIV as well, its impact on PLHIV was much greater because of the circumstances under which they found themselves. Often, poor harvests occasioned by adverse weather conditions worsened the food scarcity in households having someone living with HIV and made them more vulnerable.

> I am just okay, only that managing the daily life is what is difficult because of the means of getting an income. Like now, after we planted, it shone [a dry spell] that there is nothing we are going to harvest. So we still do not know how it is going to turn out. But where we are, we grow sweet potatoes, cassava. But now that is not possible. We do not know how things are going to be here ahead of us. What lies ahead we just believe that God is the one who knows. Because *piny otho* [the harvest has failed] and that is where our hopes are grounded; is where my hopes are normally laid; that is the source of my help. That if I work well in the farm, then I may find a way of feeding my children and myself (R25: 37-year-old widow, 129).

Living alone without support from a spouse or a partner was also a difficulty. However, this invariably effected female than it affected male participants. The three female participants who mentioned living alone as a presenting a difficulty in providing for their households were either widowed (2) or were separated (1) from their spouses.

> Okay, there are difficulties since now as a single parent, you find that sometimes, the harvest is not good. You are the one to look for food. You are the one to do everything. A child is also going to school. Sometimes one is unwell—like one is now unwell [she had a sick child admitted at the time of interview]. So these must be there (R24:36-year-old widow, 113).

Lack of the means for a sustainable livelihood and for meeting other obligations was perceived as one of the greatest difficulties. A number of participants either lacked the relevant qualifications for securing formal employment, did not have sufficient strength to work in their farms or in the case of widows and separated women, lacked the support of a life partner with whom they could work together to support themselves and their families. A good number who wished to be self-employed lacked the financial resources to do so. As such, life for these participants was a struggle since they could not comfortable afford food, school fees and levies charged in the health facility.

5.8.2 Access to Food and Nutrition

Access to adequate and nutritious food was a major problem that a great number of the participants encountered. Even though it has been mentioned in the previous section in relation to lack of means of livelihood, food and nutrition is isolated here for special treatment as it forms a fundamental component of HIV care (UNAIDS, 2008; World Bank, 2007; World Health Organization, 2013). During the time of conducting the field research (July-August 2013), the respondents indicated having suffered a crop failure in Nyabondo area. Nyabondo is a rural, agricultural district compared to Kisumu, which is to some extent urban and peri-urban. The crop failure compounded the task of finding food for the family. The following is a statement from a male participant who had difficulties accessing good nutrition.

> There are challenges of getting food. Like for example now when there is total crop failure. Food that can be eaten is not there. Like now me in my own house, proper food to be eaten is not there. So, sometimes I may only afford a tin of maize [2kgs] and I have children and their mother. So these children, after I get one tin of maize, then we eat. But when I get some of my money like when I am paid, then I am able to buy more and we can eat well…But when that is over, so we go back to getting by. And I start to wonder where to turn to in order to get some food. So I get insights that I just go and talk to the people who sell the grains, they will not deny me and truly, they help me like that (R4: married man, aged 36-45 years, 73-75).

Under normal circumstances, the participants from this area do not need to rely on the market for their food supply. They are normally able to produce their own food in their farms. But in instances of crop failure, they have to rely on the market. As participant R20 states:

> Things are indeed difficult. Indeed food is now difficult to come by because there was no good harvest because there was too much rain which then suddenly disappeared. So currently, people must just rely on the market. Everything now must be purchased (R20: married man, aged 26-35 years, 92).

Participants in FGDs also underscored the difficulty they faced in terms of accessing adequate food. As one FGD participant commented:

> But I just struggled with life. So there I just continued like that but now what the challenge that is there has made me to stay home with the parents because it appears you are a burden. Because now the way they have known, they understand that you need to have good nutrition.

> And you know good nutrition they know is money. But according to me eating well is life. Even if it is vegetables which you get, life continues. Even if it is some sardines you add to it, life continues (FGDMY-004, 194).

At times, and as can be seen from the some of the accounts, the matter of the being able to have a variety of food sources was important for some PLHIV. It is recommended that PLHIV have a proper and balanced diet. This involves having a good mix as well (World Bank, 2007; UNAIDS, 2008). But they were not able to get this kind of variety and this was perceived as a difficulty. One lady commented that:

> Sometimes, you may desire some kind of food but may not be able to afford that kind of food. So one may try by all means, but sometimes like even breakfast must be a balanced diet. Sometimes, you have taken porridge only and sometimes for lunch you only come across *ugali* (staple food made of maize flour) and vegetables. So the current difficulty is with regard to food. Concerning my life, it may only be that issue of food but if I consider my life, then, sometimes it is only to request God. If He is willing—because if you are alive, if He gives you life—then nothing is difficult (R1: married woman, aged 26-35 years, 143).

The participants considered access to a well-balanced diet and in sufficient amounts important as the medications they were using were very strong and may not work well a proper diet. One participant observed that: "You must have eaten well. Otherwise, it [ARVs] will make you fall like a drunkard. So sometimes, the challenge that I may have is that if the nutrition is not good…it can overwhelm me" (R31: widow aged ≥46 years, 72-78). This statement effectively summarizes the importance of nutrition in HIV care and treatment.

5.8.3 Stigma, Discrimination and Cultural Rites

According to some participants, societal attitudes towards PLHIV are still very hostile and morally judgmental. PLHIV are still perceived to be responsible for having acquired their HIV status. According to the interviews and discussions, PLHIV are perceived as sexually immoral and of having engaged in morally prohibited sexual liaisons. As such, they are seen to deserve being infected. According to one participant:

> What I find to be very challenging is that sometimes, when I hear how people are talking about people with HIV, and I feel I am also in that bracket, I really feel very hurt. The way they consider PLHIV as those who are not morally upright. That is people who are romantic. People just know that HIV is acquired through illicit sexual intercourse. So I just conclude that I am also within that bracket (R42: married woman, aged 36-45 years, 115).

This all-inclusive perception that PLHIV are sexually immoral could also lead to other forms of treatment such as discrimination and stigmatization that PLHIV are exposed to. Even though they perceived that levels of open stigma and discrimination were declining—a condition they attributed to high HIV prevalence—some participants still felt that PLHIV experienced subtle and overt stigmatizing and discriminatory treatment. One female participant, in giving a response concerning the difficulties she faced, stated that “Secondly, people do not love me depending on the status of my life. And thirdly, it is that, I think that it is the love, that is if you touch somebody’s items and somebody feels that you should not be touching such items” (R15:33-year-old married woman, 91). These are all indicators of stigmatizing and discriminatory treatment.

Some participants indicated experiencing insensitive treatment from others. One female participant said that: “The second challenge I see, the people who are in our village, the way they regard my life, even though I am still alive, they consider that my time upon this world is up” (R17: widow aged 26-35 years, 147). This was an instance of being insensitive and not being aware of the difficulties involved in having to live with HIV. Consequently, some participants adopted practices that could end up leading to self-stigma as they isolated themselves from the others. One lady commented that: “You feel that you should not even sit with those people. Also, the place of work, if it is these places that are exposed, sometimes it may be difficult to take your medication among people because you are fearful” (R32: separated woman, aged 26-35 years, 171).

Traditional and cultural practices such as *levirate marriages* (the practice requiring that widows be remarried within the clan to either a brother-in-law or to a male kin at the same level as her former husband) was also noted as a challenge. Other traditions required, for example, that sexual intercourse be engaged in before certain activities (e.g. planting) are performed.

> Like women who are still young like me—I was left when I was still very young, you see. Sometimes, the home where you were married, they would want you to accomplish the traditions of that home. But you feel that no, me I will not be inherited. Me I will live the way I am. And someone will say that “this young wife, it means that when she goes back there to the city. She is going to engage in prostitution, you see. So that is the way things are (R39: 47-year-old widow, 101).

The problem with the fulfilment of these cultural rites and traditions are more pronounced especially when the widows are still considered to be young. Some in-laws, often motivated by nothing more than the desire to seize control of the property that the widows have inherited, normally instigate problems and make it difficult for these women to live in peace. Failure to comply may lead to one being labelled rebellious or as having decided to engage in illicit sexual activities such as commercial sex work.

5.8.4 Children's Education and Well-being

Providing education for their children was one of the difficulties some of the participants experienced. As has been seen in the section on livelihood and income related difficulties, PLHIV often lacked sufficient finances to pay school fees for their children—especially for those proceeding to the secondary school level. For some participants, this was reckoned as the greatest challenge among other challenges. This problem was more compounded in cases where the PLHIV was a widow, having lost her husband and being left to deal with these issues alone. Following is a statement from a 51-year-old widow concerning the difficulty of being able to get the required resources for their children.

> The greatest [difficulty] is school fees because food, I can work in the farm, because working me I can work in my farm…So the greatest challenges...food is a challenge admittedly, but of the two, the one with the greatest weight is the education of the children (R13: 51-year-old widow, 83).

Those whose children had completed secondary school experienced difficulty securing sufficient funds to enable them pay for their tertiary education. One female participant whose son had finished form four (the necessary qualification to join university or other higher levels of professional training) but was not able to proceed to a college had the following to say:

> The other challenge has to do with the child. He has finished form 4 and so the issue of college is required, fees is not there. Even if it is there, he can only be able to go to school for a short time, then he pulls out as we wait for money. You cannot also push your relative that "please help me". You just have to plead (R39: 47-year-old widow, 103).

The problem of educating children was also experienced by male participants. As one male participant stated: "The challenges that are there are like now, I have school fees [to pay], so the difficulties are on the means of getting these funds. I try to work hard, that is, that is a difficulty, a difficulty on getting money (R33: married man, aged ≥46 years, 141).

As has been noted in the previous sections, concerns with their children's future well-being (as seen in terms of education and a proper training in preparing them for future careers and for self-reliance in the future) was a key concern for the parents. Children's future including their education was one of the major reasons that prompted some PLHIV to resolve to accept their HIV diagnosis and get enrolled into treatment and care. Therefore it became one of the key issues perceived as a difficulty in coping with and adapting to a life with HIV. Since they were struggling with other issues, this was really a burden for some of the PLHIV.

5.8.5 Health-related Problems

As can be noted in Table 5-3 above, it is somewhat surprising that difficulties related to health are mentioned by only three participants and therefore do not seem to be a serious concern. For one female participant, one of her challenges was what she described as "some small illness that just emerges unexpectedly and when they appear, they are very serious and sometimes overwhelms you" (R15: 33-year-old married woman, 91). This participant seemed to be bothered by the unexpectedness of these illnesses as well as with the fact that they could become serious.

Another participant, a 41-year-old married man, mentioned the "on-and-off" diseases that never used to afflict him in the past. In describing these illness episodes, he notes that: "Some came strangely that maybe make me think that "how, what are these that are happening to me in my, my life" (R22: 41-year-old married man, 85). This also seems to point to the unexpected and strangeness of the experiences he was having on his body. These are new experiences that he never used to have in the past. Some of the symptoms of these illnesses were lack of strength in his limbs and occasional chest pains. He described these signs thus: "Sometimes I can wake up and see that I cannot, maybe, step even down. My feet are like they are paining, sometimes I have chest pains, but eventually after sometimes, it disappears again." These are changes that he attributed to his status as being HIV positive since according to him, "these used not to be. So it is a challenge to me that 'is it this thing, this positivity that brings about all this into your body.'" In trying to understand the reasons for these experiences he tried to interrogate whether they could be as a result of "the side-effects of the medication" (R22: 41-year-old married man, 85).

It seems possible that the muted mention of health problems is related to the benefits of ARVs and the changes the PLHIV have implemented in their lives. These could be some of the reasons as to why in comparison to the period during or immediately after diagnosis, many of them did not mention health as a big problem currently. As was presented in the section on coping strategies, the PLHIV had implemented a lot of changes, adopted new healthy practices and abandoned old health-risk behaviours. Additionally, they strictly adhered to the prescriptions and other instructions given by their health care providers, especially with regard to taking their medication at the times indicated. They also mentioned avoiding worries and stressful situations. Additionally, they made every effort to eat well-balanced diets in addition to being participants in support groups and other socially supportive environments. The participants also reported experiencing accommodative social atmosphere in their neighbourhoods. All these are conditions necessary for health and well-being and could explain the apparent state of good health as at the time of the study.

5.9 Experiencing no Difficulties

In somewhat surprising results, nine (9) in-depth interview participants (6 female and 3 male) mentioned experiencing no difficulties. As a way of triangulation across response items, especially on the effects of HIV on their lives, it was noted that these six participants had perceived themselves as either having a stable or restored sense of self, had their social relationships remaining stable, or had retained their capacity to work and fulfil their social obligations. In cases where they had been disabled and not able to work due to some sickness, they had regained their capacity to work. The six (6) women who reported having no difficulties were either single (2) or widowed (4). However, the two male participants experiencing no difficulties were married. The responses by one female participant is instructive:

> No, me the issues I encounter that can make me despair, I do not see because I am someone who lives alone and mostly I also do not like coming into social gatherings. This is because sometimes, some heart of mine tells me that if I can sit with someone discussing issues then I tend to imagine that someone may backbite me or talk to me about HIV. So something which lead to a disagreement with others, which may lead to someone mention to me about HIV is what I do not want. So mostly, I stay at my home with my friends. Someone may visit and may give me some advice on HIV, we can discuss issues such as merry-go-round, things that may bring us help or development going forward (R25: 37-year-old widow, 121).

Part of the possible explanations for R25 not experiencing much problems seems to be the fact that she had adopted a pragmatic coping strategy that helps her avoid situations that could lead to stress or such related outcomes and present her with existential difficulties. When probed further as to whether she was not experiencing problems even at the level of her relatives, she had the following to say:

> None. Because even in our extended family, they now take me to be just as they are. Because even if something comes up to be done within the family, I work with them in one accord without any drawback. I just work with them in one accord without any problem (R25: 37-year-old widow, 127).

Peaceful coexistence and acceptance within the nuclear and larger family seems to be an important point in ensuring that PLHIV have a less troublesome experience. Another female participant attributed her not experiencing difficulties to her attitudinal disposition. According to her, she was “a person who is ever jovial” and who likes “interacting with other people.” So according to her, she does not experience any challenges (R27: 28-year-old single lady, 166). Yet another lady explained that she does not experience any challenges that are unique to her being HIV positive but only those she considered normal for all people, such as the difficult economic times. She noted that: “I do not see any challenges on a serious note except that as now life is a bit difficult.” She notes that generally in her life, “I do not experience any difficulty.” As is evident in her account, her experiencing no difficulty could be attributable to her capacity for self-reliance, as opposed to being totally dependent upon others. In her own words, she quips that: “I find it extremely simple for me because in the past I would be constantly seeking support from relatives. But currently, no one can see me at their doorstep.” She further mentions being able to collect her medications every three months and asks the rhetorical question as an emphasis “Isn’t it simple?” (R38:44-year-old widow, 89).

Of the three male participants, their ability to fend for themselves and their families was viewed as an important reason as to why they indicated not experiencing any difficulties with their lives. One of the male participants stated that: “Whatever the children want, I will provide. If I will not be able, I tell them to wait; that I will organize” (R49: 35-year-old married man). The other man, in discussing that lack of certain things could not deter him from living positively indicated that: “those are things which if they are missing you can go and look for them. And if you get some little money of yours, won’t it be possible to eat that thing you desire?” (R3: married man aged 26-35 years, 137-139). He also caps of his statement with a rhetorical question to emphasize that as long as one can work and get some income, they can be able to meet their basic needs which he symbolizes with food. According to him, lacking something does not mean that one cannot get it if one wants it. He indicates that whenever he gets his income, he can access whatever he needs. He adds that “whenever I get that money of mine, I can go and purchase that particular thing and eat. I do not eat it with the thought that my life now… (R3: married man, aged 26-35 years, 137-139).

Generally, those who had no serious difficulties in adapting to and coping with a life with HIV were those who had stable social relationships, a stable sense of self and who had retained or regained the capacity to fulfil social obligations and could therefore fend for themselves and their families. The relationships PLHIV had with their families, friends, relatives and neighbours were also instrumental in limiting difficulties faced.

5.10 Chapter Summary

In this chapter, the strategies PLHIV adopted to cope and live successfully with HIV and the difficulties PLHIV faced in coping with HIV have been presented. The strategies identified are: (1) psychosocial and emotional strategies, (2) relying on faith and religious beliefs, (3) social strategies, (4) health strategies, (5) livelihood enhancement strategies, and (6) adoption of safe sexual behaviours. The difficulties faced by PLHIV related to inadequate livelihoods and incomes, lack of access to adequate food and nutrition and stigma, discrimination. The other difficulties identified in the illness accounts of the participants included inability to provide for their children’s education and current and future well-being and health-related difficulties. There was also a category of participants who indicated experiencing no coping-related difficulties. This brings to a completion the presentation on the findings of the study.

In the next chapter a detailed discussion of all findings in the context of both methodological, theoretical, and empirical literature is presented.

6 DISCUSSION

6.1 Chapter Overview

In the first three sections of this chapter (6.2 through 6.4), the methodological considerations of quality and trustworthiness, and strengths and limitations of the study are discussed. Next, the substantive findings as outlined in the objectives and research questions are discussed. Thus the main themes discussed are: (1) being diagnosed HIV positive; (2) effects of HIV on the lives of PLHIV; (3) coping strategies adopted by PLHIV; and (4) the difficulties PLHIV faced in coping with a positive HIV status.

The study, embedded within an interpretivist scientific tradition, adopted a qualitative research methodology. A hermeneutic phenomenology study design was employed to collect data to unearth the subjective meanings that PLHIV attached to their condition in order to get insights into their experiences of living with HIV. Data was collected at two health facilities in Kisumu County in western Kenya with the help of three research assistants. The methods of data collection were semi-structured in-depth interviews (49), focus group discussions (FGDs) (8) and key informant interviews (KIIs) (6). The participants were both male and female ranging in age from 18 years and above. Except for two (2) of the key informants who were the PSC coordinators, the rest of the research participants were PLHIV. Ethical clearance was obtained from the Kenyatta University Ethical Review Committee and the Jaramogi Oginga Odinga and Teaching Referral Hospital (JOOTRH), both in Kenya. Research authorization was granted by the National Commission for Science, Technology and Innovation (NACOSTI)[8]. Data was digitally recorded, personally transcribed by the PI, and subjected to thematic coding employing both deductive and inductive approaches.

6.2 Quality and Trustworthiness of the Study

The assessment of quality and trustworthiness of a qualitative research is based on a different set of criteria than those used in quantitative studies even though the intended purpose of these criteria is the same. Among the accepted criteria for establishing the trustworthiness of a qualitative study are credibility, transferability, dependability and confirmability (Hansen, 2006; Lincoln and Guba, 1999; Pope and Mays, 2006). In this section, a discussion is given

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[8] As research authorization was being sought, the organization was known as the National Council for Science and Technology (NCST).

on how each of these criteria for scientific rigour and trustworthiness have been fulfilled within this study.

6.2.1 Credibility

Credibility in qualitative studies is concerned with showing the “truth value” of the findings; the idea that the findings and interpretations can be shown to correspond to the underlying reality being investigated (Lincoln and Guba, 1999). According to Lincoln and Guba, establishing credibility involves two related steps. The first step is the production of a complete and sufficient account of the varied perceptions of social reality espoused by the social actors. The second step is to avail the reconstructed accounts to the participants (originators of the accounts) for authentication and validation. Credibility requirements can be achievable, broadly speaking, through a *thick description* of the participants’ accounts and through *member checking*. The authors of qualitative texts have mentioned a number of undertakings that can enhance the credibility of a qualitative inquiry. These include “prolonged engagement”, “persistent observation”, “triangulation”, “peer debriefing”, “negative case analysis”, “referential adequacy”, and “member checking” (Lincoln and Guba, 1999:407). A detailed discussion of these undertakings is beyond the scope of this study, but a short account will suffice to explain how credibility concerns have been addressed.

Peer debriefing, which implies subjecting a study to peer review is one of the mechanisms that was utilized to help realize credibility. Preliminary findings of the study were presented to the teaching staff and postgraduate students at Kenyatta University. This forum provided an opportunity for subjecting the work to a dispassionate and disinterested critique from persons who could objectively evaluate the work. The other way through which truthfulness of the findings have been assured is the concept of triangulation. In the study, the PI was assisted by three research assistants. And even though all the four investigators including the researchers had different personalities and unique ways of carrying out the interviews, the results still pointed to relatively coherent accounts across the cases and sites. Apart from investigators, triangulation also took the form of study sites, sources and methods. Taken together, triangulation helped ascertain the trustworthiness of the findings.

The other criterion according to Lincoln and Guba (1999) relevant for this study is prolonged engagement. Prolonged engagement requires that a researcher spends a good deal of time in the study context and with the participants. One of the goals of prolonged engagement is to equip a researcher with an in-depth understanding of the cultural and social context of his participants. Intimate knowledge of the cultural environment of the study is paramount if an investigator is to understand the meanings of actions, statements and events within the research context. Being a native of this culture, the PI did not need a long time to understand the culture. Similarly, the PI has been involved with HIV activities in that region of the country, has lived in that area for some time and has been involved in research activities in the two research sites in the past. As such, his familiarity with the culture and past involvement with the sites and participants of similar nature provide a basis to believe that prolonged engagement can be demonstrated. Additionally, a one-month preparatory field visit was conducted one year prior to data collection, during which contact was made with the facilities and informal discussions held with a PSC coordinator of one of the sites.

6.2.2 Transferability

The equivalents of *transferability* in quantitative methods are relevance, applicability or *generalizability*. The main dimensions of this criterion include the applicability with which the findings of a qualitative research can be used to address some practical problem either of policy or programming (Mays and Pope, 2006). According to Hansen (2006), transferability means that the research process is clearly described in terms of the study sites, sampling procedures, methods of data collection, and the analysis of findings. Such description could help determine whether the findings could be considered relevant to some other situations, and hence the idea of transferability. Transferability is equivalent to replicability in quantitative research.

The other dimension of transferability has to do whether the findings of a particular study can be generalizable to the wider population or whether they can be replicable in similar contexts or with similar target groups in a different setting. This is also linked to the concept of representativeness, whether the sample was representative enough to allow for generalization and replication (Lincoln and Guba, 1999; Mays and Pope, 2006; Pope and Mays, 2006). In this study, the generalizability dimension has been achieved by ensuring that the sample was purposively selected and represented a wide range of participants. The participants included both men and women, young and old, single and married / widowed, rural and urban. Similarly, in the analysis, care was taken to ensure these varying perspectives are represented through the quotations selected. Transferability or relevance has also been ensured by providing a thick description, which gives a detailed elaboration of the experiences of PLHIV with regard to the study objectives and research questions. Based on this thick description, any researcher interested in replicating this study elsewhere or applying its findings to other populations may judge its utility for their specific purposes (Holloway, 2005b; Lincoln and Guba, 1999; Mays and Pope, 2006; Pope and Mays, 2006).

6.2.3 Dependability

Dependability as a criterion for measuring trustworthiness of a study is seen to correspond to *reliability* in quantitative studies. Indeed a number of qualitative authors use the term reliability in their works. So for this purpose, the two terms are used interchangeably even though they do not mean the same things (Lincoln and Guba, 1999). The concept of reliability in quantitative research seeks to assure that the research process would produce the same results if conducted by other researchers, or perhaps in different settings by different people. The concern is with whether the findings are consistent, dependable and accurate (Lincoln and Guba, 1999). Dependability has identical concerns with reliability, as it is interested to establish whether the manner in which the research was conducted is acceptable. In this respect, it seeks to assess the “suitability of methods, and transparency of methods and analysis” (Hansen, 2006). Thus, the decisions that were made including the sampling decisions, the research design decisions, and data collection decisions should be scientifically justifiable.

Because the product is as good as the process, quality assessments determine whether the process is justifiable. The dependability criterion is closely related to the confirmability criterion for if a process is dependable, then it is to a certain level confirmable as the research products (findings, interpretations, conclusions and recommendations) will be seen to be based on sound principles. In this study, dependability is assured by accurate records and availability of source documents (audio recordings, transcripts, field notes, ethical review documentation, the research proposal containing all methodological decisions and records of all choices), which are well kept. All methodological and other decisions have been justified in the report. The PI ensured that all the basic assumptions of the different methods of data collection were met. Sampling was also stratified and was purposive.

The report was written based on triangulation from a multiplicity of sources and methods that included analytical notes made along the course of the study. Therefore, the report has benefitted from exhaustive analytical procedures. An audit trail could ascertain that records of all the processes, the decisions made, and of the entire research process have been kept and can be relied upon to reconstruct the process. Additionally, it can be shown that the report is based on transcripts of interviews, FGDs and KIIs as well as on field notes backed up by a detailed journal (Lincoln and Guba, 1999).

Due to time constraints, not all the required steps in ensuring dependability were followed. For instance, *member checks,* whereby stakeholders and participants are given a peek preview into the results and interpretations and their opinion sought as to whether these corresponded to their statements was not feasible. However, attempts have been made to ensure that the steps available to the researcher are exhaustively appropriated (Lincoln and Guba, 1999)

6.2.4 Confirmability

Confirmability, on the other hand, is concerned to ascertain that the findings, interpretations and conclusions are based on the data, that they are grounded in the data and not products of the ingenious imaginations of the researcher (Lincoln and Guba, 1999). In this research, the codes used to categorize the responses were based on the objectives of the study and research questions as well as directly from the data collected. As such a balance of both inductive and deductive coding approaches was used. This was to ensure that the codes, and therefore the categories, were informed both by the literature and theory as well as by the data.

In the coding, analysis and write up of the research report, triangulation of methods was used to ensure that the findings reported and interpretations made were derived directly from the data and represented all the possible diversity of responses across all the three methods of data collection (in-depth interviews, FGDs and KIIs). The discussions and conclusions have also been derived from what was said by the participants with theoretical and analytical input of the PI. The data on which the analysis and hence the interpretations and inferences as well as conclusions have been drawn were based on raw transcripts of audio-recordings of interviews, FGDs and KII data, field notes, research journal, analytical and theoretical notes. These were augmented by other source documents such as ethical review documents, research authorization documents, participants' records, informed consent forms, and researchers' field itinerary (Lincoln and Guba, 1999).

6.3 Strengths of the Study

The study has a number of strengths. First, the study was conducted in a natural setting, which made it possible for relatively authentic information to be collected. It was conducted in the very health settings where the PLHIV were receiving services and with the cooperation and assistance of the PSC coordinators and personnel. It was thus conducted in an environment of trust and relative relaxation. The research meetings were also arranged to coincide with the regular support group meetings and schedules and to fit within the normal clinic visits of the PLHIV. Such a design was to help avoid interrupting the regular routine of the PLHIV and to ensure that a relatively normal environment as possible obtained for the carrying out of the study. Such an environment helped to reduce obtrusiveness of the research process and thereby helped minimize any possible biases to the responses obtained.

Secondly, the study relied on triangulation of methods, sources and settings. The study employed three different methods of data collection, namely; in-depth interviews and FGDs with the patients and KIIs with those who took care of them. Another aspect of triangulation were the different categories of respondents involved (youth and adults, males and females, different marital status, and different economic and education attainments). Whereas FGDs helped gather information on the collective experiences of living with HIV and generate richer data through the group dynamics, the in-depth interviews and KIIs made it possible for the unique experiences of PLHIV and the opinions of service providers to be captured. Use of a variety of methods allows researchers to see the social world and understand social phenomena from a broader perspective. In addition, triangulation allows for the multiple accounts to mutually reinforce each other and thus generate a more elaborated account (Holloway, 2005a; Kalof *et al.*, 2008). The study utilized a hermeneutical phenomenological approach, which gives priority to the interpretations, meanings and the stories of participants, allowing them to narrate their experiences in their own words and in a way that makes sense to them. In other words, the data is the voice of the participants and can be relied upon to represent meanings of life with HIV in relation to the objectives of the study (Barbour, 2008; Kitzinger, 2005; Taylor, 2005).

Third, the study benefitted from a preparatory field visit during which time the PI familiarized himself with the study setting, created rapport with the gatekeepers, established the ethical and research authorization procedures and delineated the potential pitfalls that could hamper the study. The preparatory visit provided insights that guided the formulation of next steps of the study. Moreover, the actual research process benefitted from the collaboration of the health facility personnel. They helped with the recruitment of participants, provided resources and spaces for conducting the interviews and also gave their time in helping organize for the interviews (Green and Thorogood, 2009).

Fourth, the PI and his research assistants are from the cultural milieu within which the study was conducted. As such, they understood the language and all its nuances including idioms, proverbs, metaphors and other linguistic devices. They are also exposed to the societal perceptions and attitudes towards HIV within the Luo community of western Kenya (Lincoln and Guba, 1999). Moreover, the PI has experience in this area, having been engaged as a PI within a study that evaluated services provided for PLHIV in selected facilities in western Kenya. The facilities included the two facilities in which the present study was conducted. The PI has also lived and worked in the region in a project with a related theme but focusing on community-based approaches to HIV prevention.

Fifth, the PI personally transcribed the audio-recordings all by himself, thus eliminating as far as possible, errors and biases that may have arisen through the process of data transformation, otherwise several errors may have arisen in the case of different transcribers. Moreover, through this process, the PI became immersed and grounded in the data and could thus clearly articulate the broad outline of the findings. This process made it possible for the PI to comprehend the general feel and direction of the responses and to develop a clearly accurate picture of what the various stages of the illness trajectory meant for the PLHIV (Gibbs, 2007).

6.4 Limitations of the Study

The study findings were probably influenced by a number of limitations that are inevitable in any research project of this nature. First, the study relied on the subjective accounts of participants regarding their experiences of living with HIV. These accounts may have been influenced by factors beyond the control of the study and may be limited by certain cultural and historical factors having been conducted in one county in western Kenya among a people sharing the same cultural identity – the Luo. This means that the findings may not be directly transferrable to other study populations in different geographical, cultural or social settings. However, the sample for this study was purposively selected and represented a cross-section of people infected with HIV. As such, even though the findings may not be immediately generalizable and transferrable to other contexts, the insights gained from it may help inform the design of such a study (Hansen, 2006; Lincoln and Guba, 1999) .

Secondly, the study was based on the accounts of the PLHIV and their health providers, and did not get opinions from other members of the communities in which these people lived. As such, the findings may not provide a complete picture upon which to draw conclusions regarding the experiences of living with HIV. The study would have benefitted from the accounts of a number of community members. However, due to constraints of time and financial resources, the sample size was limited to those living with HIV and a selected number of service providers. Additionally, since the concern was to provide a hermeneutical phenomenological account of the lived experiences of PLHIV, it is the view of the PI that the study achieved this aim, even if the accounts of the community are missing (Green and Thorogood, 2009; Holroyd, 2007).

Thirdly, the study did not get the opportunity to implement some of the other recommended mechanisms of ensuring dependability and confirmability of findings such as member checking. These were not possible within the temporal scope of the study. As such, there could be a possibility of researcher-bias in the interpretations and conclusions. However, other methods of ensuring trustworthiness and reliability were used. These included triangulation of methods in data collection and analysis. The PI also ensured methodological rigour throughout the entire process, providing clear justifications for every decision made with regard to the design, the methodology, the data collection methods and methods of data analysis. Moreover, the PI located the findings within the context of both the theoretical and empirical literature. As such, the findings can be considered accurate and reliable (Hansen, 2006; Lincoln and Guba, 1999; Mays and Pope, 2006).

6.5 Being diagnosed HIV Positive

6.5.1 Circumstances of knowing HIV Status

Being knowledgeable about one’s HIV status, especially in an environment with higher HIV prevalence, is an important element of public health for two main reasons. First, knowing one’s HIV status provides a critical turning point for it is through diagnosis that a person can be enrolled into anti-retroviral therapy (ART) and start the journey to living positively with HIV. It is the gateway to care and treatment services aimed at suppressing the viral replication and preventing opportunistic infections (OIs). A suppressed viral load ensures that the immune system remains robust enough to fight off infectious diseases thus ensuring that the body remains healthy and enabling a PLHIV to live a long and relatively normal life (World Health Organization, 2013; Maina *et al.*, 2014; Government of Kenya, 2007).

Secondly, early and prompt diagnosis has benefits for the society at large being an integral component of measures to prevent new HIV infections (Anand *et al.*, 2009; WHO, 2003; Ng’ang’a *et al.*, 2014). Through appropriate health education and counselling, PLHIV can be equipped to adopt less risky behaviors such as protected sexual intercourse and reduced number of sexual partners. Adoption of such practices can make PLHIV to be effective partners in minimizing cases of new HIV infections. These HIV-infected persons will take steps to not pass on the infection to others. Moreover, health behaviours such as having protected sex could have benefits for reducing cases of mother-to-child-transmission and transmission within discordant relationships. For these reasons, it is essential that as many people as possible get to know their HIV status early enough before much damage is done to the body's immune system (Maina *et al.*, 2014; Government of Kenya, 2007; World Health Organization, 2013).

In Kenya, HIV testing is offered under a number of contexts. According to discussions with one of the PSC in-charges, people are tested for HIV under provider-initiated testing and counseling (PITC), prevention of mother-to-child-transmission (PMTCT), voluntary counselling and testing (VCT) and home testing and counseling (HTC). The Kenya government—with the support of its development partners—seeks to ensure that information is given to the public and that the necessary facilities and infrastructure is provided to facilitate the national HIV response (National AIDS and STI Control Programme, Ministry of Public Health and Sanitation, Kenya, 2010).

Though each participant's diagnostic experience was unique, the findings of this study revealed four main circumstances that led to the respondents knowing their status. First, most participants (61%) of this study knew about their status after they had suffered personal illness or experienced some suspicious but disturbing symptoms. A remarkable feature of the illnesses, whether of a spouse or of self, was their protracted nature. Most of the respondents had suffered from recurring illness or a series of illnesses. They would be sick on-and-off for extended periods of time, seek medical attention but these illness could neither be effectively nor conclusively treated. In most cases therefore, diagnosis tended to come at moments when the respondents or their spouses were admitted to hospital and an HIV test was recommended by a doctor as a way of helping determine the underlying cause of the recurring illnesses. This finding is in agreement with those of Tarakeshwar *et al.* (2006), Wekesa and Coast (2013), Morin *et al.* (2006), Liamputtong *et al.* (2012), Jürgensen *et al.* (2012), Thomas *et al.* (2009), who found that personal illness was one of the main circumstances leading to a diagnosis with HIV among their study participants.

Secondly, a number of participants (14%) knew their HIV status due to the illness and hospitalization, or death of a spouse, child or other close family member. In the context of illness and hospitalization of a spouse, an HIV test was often recommended by the health care providers as a way of delimiting the course of illness. Under these circumstances, the participants, who in most cases had accompanied their ailing spouses to the hospitals, were asked if they too could be interested to know their status. Even in cases where the participants did not immediately accede to testing and counselling, they could later seek this option due to suspicions they had developed about their own condition given that their spouses were already infected. Following death of a spouse, some participants thought it logical to be tested. It is noteworthy that the majority of those knowing their status due to the illness or death of a spouse were women. In findings similar to those of the present study, Olsen *et al.* (2013), Tarakeshwar *et al.* (2006), Rapport (2005) and Paulson *et al.* (2002) also found out that some of the women in their studies learnt about their HIV status when their partner or husband or close family member became seriously ill or died.

Thirdly, diagnosis with HIV for some women (5 women or 10% of all in-depth interview participants) and for a number of female FGD participants, occurred within the context of ante-natal care. These expectant women neither suffered ill-health nor suspected themselves to be HIV positive. They only got to know their HIV status when they attended a clinic for ante-natal care. These findings correspond to those of Maman *et al.* (2014), Liamputtong *et al.* (2012) and Tarakeshwar *et al.* (2006), where in each case, some of the women became aware of their status in the context of antenatal care. A study by Anand *et al.*, (2009) found that one-third of HIV-infected women in Kenya and two-thirds of HIV-infected women in Malawi received information on their HIV status during their last pregnancy. The Kenyan health system implements a policy requiring routine testing for pregnant women who present at ante-natal clinics (ANCs) for ante-natal care. According to findings from the 2012 edition of KAIS, this policy has helped increase the rates of testing to over 90% for women who gave birth over a period of five years to 2012 (Ng’ang’a *et al.*, 2014). However, some mothers are not getting tested during pregnancy and therefore there still remains the risk of them transmitting HIV to their children either during pregnancy, at birth or during breastfeeding.

Fourthly, some clients were persuaded to get to know their status from public health campaigns aimed at promoting uptake of voluntary testing and counselling (VCT). VCT is promoted as an essential entry point to HIV care, treatment and prevention services (McArthur *et al.*, 2013; Maina *et al.*, 2014; Odhiambo *et al.*, 2014). However, as the findings of this study show, only about 10% of the participants voluntarily visited a VCT site or a patient support centre (PSC) for testing. Only a few people were getting to know their HIV status by self-choice for the sake of knowing their status. It was thus the least popular condition of learning about one’s HIV status. As such, most people are not taking a proactive step to get tested. In similar studies conducted elsewhere, voluntary testing, where individuals of their free will opted for testing, was found to be one of the possible circumstances of knowing ones status, albeit not the most popular one (Tarakeshwar *et al.*, 2006; Paulson *et al.*, 2002; Treloar and Rhodes, 2009; Rapport, 2005; Olsen *et al.*, 2013; Butler-Kisber, 2010).

Currently, more than half (53%) of HIV-infected people in Kenya aged 15-64 years do not know they are HIV positive (Ng’ang’a *et al.*, 2014). It is thus inevitable that the levels of new infections will continue to be significant as the proportions of HIV-infected people who do not know their status, and who are probably not using protection whenever they have sexual intercourse, will continue contributing to new infections. This study produced findings that corroborate the findings of a great deal of pervious work in the field.

Consistent with the chronic illness trajectory model, PLHIV often have some pre-trajectory experiences with symptoms of HIV in their own lives or in their experiences with illness of their spouses or children. In some instances, they could be exposed to circumstances that could expose them to risk of contracting HIV such as engaging in risky sexual behaviour, being commercial workers, and in occupations such as that of traditional birth attendants (Jürgensen *et al.*, 2012).

The findings of this study have revealed that most of the participants involved (76%) knew about their HIV status during times of personal health crises or illness and death of other family members such as a spouse or child. This could be after their bodies became affected by the virus, after the occurrence of some monumental events such as the sickness or death of a spouse or loss of a child, after experiencing some abnormal physical symptoms like illnesses or opportunistic infections, or during antenatal care. They are also tested due to some pragmatic considerations such as before getting married. These findings suggest that before the need for testing in such dramatic circumstances arises, most participants had no idea they might be infected with HIV and could have been unknowingly infecting other individuals.

Such a scenario, consistent with the findings from the Kenya AIDS indicator survey (KAIS) 2012, which shows that more than half (53%) of HIV-infected people in Kenya do not know their HIV status (Odhiambo *et al.*, 2014; Government of Kenya, 2007; Maina *et al.*, 2014) has very dire implications for public health, especially with the incidence of new HIV infections. Admittedly, progress has been made over the 5 years since the time of the last KAIS (National AIDS and STI Control Programme, 2009) when more than 83% of HIV infected people did not know their status. However, programmatic action still needs to be taken to encourage people to know their status and to take advantage of the benefits of early diagnosis, care and treatment and to be an integral part of prevention efforts (Maina *et al.*, 2014; Government of Kenya, 2007).

6.5.2 Decision making for Testing

Findings of this study show that the decision to take an HIV test is to a large degree a personal decision even though it can be influenced by significant others. In some cases, however, the decision can be made on behalf of the person needing it, especially if such a person is incapable of making a decision due to debilitating illness. This was mostly the case for people taken to the health facilities by family members. In the case of recurring ailments that defy treatment, the decision to get tested can also be influenced by friends, relatives, (such as spouses and siblings), or be prompted by health care workers. This may be the more necessary when the symptoms or ailments a patient is suffering from give the health care personnel reason to suspect infection with HIV.

Other studies have reported the influence of social networks in testing decisions. Musheke *et al.* (2013), have noted that individuals experiencing disturbing symptoms normally consult their social networks and seek their opinions with regard to HIV testing. These social networks mostly comprise of family members, peers or relatives. Since these people normally act as important sources of economic and psychosocial support, they tend to exert considerable influence on health decision-making. Denison *et al.* (2008) found that friends and family members were crucial in adolescent HIV-testing decision making. In many cases, the opinions of these significant others determined whether the adolescents went for testing or not. In a study done to assess factors affecting acceptability of VCT in Bushenyi, Uganda, Nuwaha *et al.* (2002) found that the influence of spouses, sexual partners, fiancés, relatives, friends, health-care workers and others who had tested and known their status was influential in HIV testing decisions.

Parrott *et al.* (2011), argue that close relatives and family members provide a form of confidential support and encouragement. On the basis of this support and encouragement, they may help people in vulnerable circumstances to overcome their fears and go for testing. In findings identical to those of the present studies, relatives, especially women's natal relatives actively encouraged and persuaded their affected loved ones to go for testing and counselling. It can be argued that the existence of trust and confidentiality can help calm the fear of and encourage testing decisions. The support, anticipated sympathy and concern can also help make the prospects of a positive HIV result less scary for the potential testing clients. Individuals can thus reason that whatever the test results are, they would be accepted and not discriminated against.

6.5.3 Facilities where Testing was done

The respondents to this study were all enrolled into care and treatment at Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) and St. Joseph's Nyabondo Hospital. Most of the respondents had also known their HIV status at either St. Joseph's Nyabondo or JOOTRH. These two facilities are among the major treatment facilities in Kisumu County. St. Joseph's Nyabondo lies in a rural district in Nyakach sub-County whereas JOOTRH lies within the city of Kisumu. Another seven participants were tested at Liverpool VCT. The VCT is located within Kisumu City Centre and is not attached to any major health facility. It mainly offers VCT services and refers those tested to JOOTRH or other health facilities nearest to their places of residence for enrolment into care and treatment.

The findings of this study are consistent with other research findings, which indicate that most people in Kenya get to know their status in institutions where HIV testing is domiciled within an integrated health institution that offer a wide range of services and not in standalone VCTs. Evidence suggests that this trend has not changed much between the KAIS of 2007 and that of 2012. According to KAIS 2007 about 55% of men and 48% of women had reported having had their last HIV test in a public facility. Other testing sites including private health facilities, stand-alone VCTs and mobile clinics, and other locations accounted for between 10%-24%. In terms of gender differences, more men (18%) than women (11%) were likely to have had their last HIV test at either standalone VCT or mobile clinic sites.

According to the KAIS 2012, the results showed that 44% of respondents were tested in outpatient clinics, and 30% in standalone VCT settings. In these findings, men were similarly more likely to have had their last HIV test in standalone VCTs (41%) compared to women (22%). In outpatient clinics however, the rates ware comparable (men 44% vs. women 44%) (Ng'ang'a *et al.*, 2014). It can be argued that most of the testing in Kenya takes place in the context of health facilities where services are integrated as opposed to in stand-alone VCTs. However, the HIV care and treatment services in these facilities are not conducted as part of the overall health provision framework. There are designated HIV clinics (PSC) to which people are sent for testing and those found positive are enrolled in these clinics and henceforth are managed by the PSC personnel. This may have implications for retention in care for it may be viewed as a form of stigmatization or discrimination.

Research done to compare HIV testing in four African countries (Burkina Faso, Uganda, Malawi and Kenya) found that whereas a majority got tested in standalone VCT centres compared to integrated facilities in Burkina Faso (55% vs 26%) and Uganda (47% vs. 38%), the case in Kenya and Malawi was the inverse. In Kenya and Malawi respectively, the majority were tested in the integrated facilities (70% and 65%) as compared to standalone VCT centres (9% and 8%) (Obermeyer *et al.*, 2013). What these findings seem to suggest is that most people in Kenya do not take the initiative to know their status. It is likely, as the findings of this study suggest, that most people wait for adverse circumstances such as death or sickness of a spouse or personal illness to know their status. In such circumstances, the knowledge may not be really by choice but out of necessity.

6.5.4 Initial Reactions to a Positive HIV Diagnosis

The initial reactions a person diagnosed with HIV manifests could be seen as forming part of the process of sense making, and of trying to attribute meaning to what being infected with HIV entailed. This process of meaning making begins the moment a person realizes that something is not right with the body, especially in the case of those who were diagnosed based on personal illness or during the illness and death of a spouse. As has been demonstrated in the findings, nearly all participants of the present study expressed some degree of fear, shock, pain, worry, stress and sadness to the news of their HIV status. In most cases, the participants reported having experienced two or more of these emotions.

The findings of this study are consistent with other research on how people initially react to being tested HIV positive. Consistent with these previous studies, fear (Baumgartner and David, 2009; Gardner, 2013; Ribeiro Nobre *et al.*, 2012; Žydžiūnaitė and Vainoriūtė, 2011), shock (Anderson *et al.*, 2009; Baumgartner, 2007; Baumgartner and David, 2009; Gardner, 2013; Liamputtong *et al.*, 2012; Ribeiro Nobre *et al.*, 2012; Tsarenko and Polonsky, 2011), stress (Anderson *et al.*, 2009; Gardner, 2013, Žydžiūnaitė and Vainoriūtė, 2011, 2011), denial (Anderson *et al.*, 2009; Baumgartner, 2007; Baumgartner and David, 2009; Tsarenko and Polonsky, 2011), sadness and grief (Baumgartner and David, 2009; Goudge *et al.*, 2009), hopelessness, fatalism and thoughts of committing suicide (Anderson *et al.*, 2009; Baumgartner and David, 2009; Liamputtong *et al.*, 2012; Ribeiro Nobre *et al.*, 2012; Tsarenko and Polonsky, 2011; Wekesa and Coast, 2013) were found to be the main initial reactions.

These psychological and emotional reactions were common to all participants. Consistent with literature on chronic illness, such reactions are to be expected in cases where an individual is experiencing a traumatic or drastic event that disrupts their taken-for-granted realities of everyday life (Bury, 1982; Charmaz, 1983). The reasons as to why they demonstrated these initial reactions were similar to those found in other studies. These reactions were related to the nature of the disease, its mode of acquisition and its practical, moral and social implications (Žydžiūnaitė and Vainoriūtė, 2011). Prior to diagnosis, some of the participants believed that HIV was for a particular class of people such as prostitutes and the sexually promiscuous and therefore did not expect to be tested HIV positive. Moreover, some participants indicated that they had not engaged in activities that could expose them to HIV infection. Such individuals mentioned that they did not have affairs with other people and were faithful to their spouses. As such, it came to them as a big surprise that they could be diagnosed HIV positive. Similar findings were obtained by Baumgartner and David (2009), Liamputtong *et al.* (2012) and Tsarenko and Polonsky (2011).

Another reason was the perception that being infected with HIV is a death sentence (Anderson *et al.*, 2009; Baumgartner and David, 2009). HIV is often associated with certain death, a lack of cure and with being perpetually on ART (Žydžiūnaitė and Vainoriūtė, 2011). It has been shown from the findings that these ideations of immediate or imminent death preoccupied both the male and female participants. When one becomes diagnosed with HIV, death becomes a key preoccupation because as yet, there is still no known cure for HIV/AIDS. As such, even though medications to suppress the viral activity exist and despite the prospects of longer and productive lives due to the benefits of HAART, the fear of death is still a very real one. Other studies have found results linking the certainty of death with emotionally-laden initial reactions of fear, shock, worry, denial and suicidal ideation (Anderson *et al.*, 2009; Baumgartner and David, 2009; Liamputtong *et al.*, 2012; Zhou, 2007).

Societal attitudes towards HIV and PLHIV and how PLHIV expected to be received by their social contacts was also an important influence on the way people would initially react. The society views HIV as a condition that results from a want of moral correctness and lack of adherence to accepted standards of sexual behavior. As such, the integrity of someone known to be HIV-infected is immediately brought into question (Wekesa and Coast, 2013). The result is that such people are often ridiculed, rejected, or even ostracized by the society (Russell and Seeley, 2010). Therefore, the dread of their status being known to others instills fear (Ribeiro Nobre *et al.*, 2012), shock and stressful thoughts in PLHIV and some would rather die than return to the society where they will be accorded a less than human status. Indeed, it has been demonstrated in this study that some of the initial reactions also included suicidal ideations.

Some study participants did not believe the diagnosis, consequently denying the results. They therefore did not immediately allow themselves to be initiated into care and treatment. Nearly all the participants who disbelieved or denied the test results later sought to confirm these results in other testing centers. They visited as many as three or four testing facilities before finally coming to accept the results. Primarily, they believed they had not exposed themselves to behaviours that could lead to infection with HIV and they did not trust the initial test results and doubted the accuracy of the machines. Reasons for denial included concerns of how their lives post-diagnosis would be and how they were going to cope with HIV. Others denied because they perceived themselves as being healthy. They reported experiencing no symptoms associated with HIV, such as being emaciated, having scars on the skin or suffering from opportunistic infections.

Some participants, however, mentioned that they were neither shocked nor fearful but were satisfied to know their status and to be enrolled into medication. These findings corroborate those obtained by Baumgartner (2007), Ribeiro Nobre *et al.* (2012), and Wekesa and Coast (2013). There are several possible explanations for this result. First, it could be because they had been so down with illness that the medication provided relief. It could also be because knowing their status provided an explanation for the on-and-off illness they had experienced and that they could have a long-term solution in medication. Second, some participants, especially women, indicated not being shocked because of the nature of the husbands they had. These women were aware that their husbands were involved in sexually risky behaviors and were having affairs with other women. As such, testing provided answers to unclear questions of illness and confirmed their long harbored suspicions. Thirdly, the diagnosis (knowledge of status) was perceived as bringing about empowerment and freedom from the costliness of ignorance, such as seeking treatment for an undiagnosed condition. In these circumstances, where an HIV diagnosis was either highly suspected or expected, it is reasonable that some persons would react without much shock or fear, even though the reality is nonetheless still overwhelming and earthshaking.

Even though they expressed these emotional reactions, the majority of participants resolved to accept their status and to adopt positive living. A possible explanation as to why the participants readily accepted their HIV positive status could be related to someone’s past experience with illness. Past illness experiences could thus possibly influence the way PLHIV construct both their diagnostic and post-diagnostic worldviews. For most of the participants, the extreme difficulties and challenges prior to diagnosis, constant on-and-off sickness, and having to depend on relatives and friends for support with medical care could have made them to view their post-test experiences as a great relief and as a much easier lifestyle. The ability to be in control of their own lives and not being dependent upon relatives or being subject to unexplained illness episodes gave them a sense of meaning and self-worth instead of being perceived as a source of sadness.

6.5.5 Reconciliation to and Acceptance of a Positive HIV Status

The participants of this study put forth determined efforts to overcome the initial shock, fear and other emotional and physical reactions related to the results of their diagnosis. As has been demonstrated, not all participants readily accepted the test results when they initially received them. As has been discussed in the previous section, *Initial Reactions to HIV Positive Diagnosis*, a number of participants were sceptical about the results and went into denial. These clients proceeded to visit other testing facilities to do further tests. In all the cases, however, the test results were confirmed as positive and in all the cases the participants resolved to accept the results and be enrolled into care and medication. Reconciling with oneself to a positive HIV diagnosis starts another distinguishable though interconnected phase of making sense of illness. The key task in this phase is related to existential considerations of how a person would be able to live in the society with a positive HIV status. This section provides a discussion on the things that aided the process of reconciling or accepting to live with an HIV positive status.

First, psychosocial support was the foremost influence in helping the participants to cope with the information that they were HIV positive. They obtained different forms of psychosocial counseling and support from different sources. In findings that corroborate other studies, this support took the form of counselling provided at the PSC by health facility personnel and by CHWs (Baumgartner and David, 2009; Gardner, 2013; Medley *et al.*, 2009; Ncama, 2007; Wekesa and Coast, 2013). They also obtained mutual support and encouragement from support groups of PLHIV where they benefitted from the experiences, knowledge and testimonies of peer-counsellors, role models and from other PLHIV who had lived with HIV for a long time (Medley *et al.*, 2009; Wekesa and Coast, 2013). Family members, friends and relatives also provided support and encouragement thereby creating an accommodative atmosphere that made adjusting to living with HIV smoother (Baumgartner and David, 2009; Medley *et al.*, 2009; Ncama, 2007; Wekesa and Coast, 2013). These diverse forms of psychosocial support were intended to encourage the participants that being HIV positive is not the end of life, that HIV is not a death sentence and that there are medications to prolong one’s life.

Second, the unquenchable desire for a long life and the hope for an enhanced sense of well-being coupled with concerns about constant on-and-off illness episodes and deteriorating health conditions were equally important factors influencing the PLHIV's decision to accept their status. There are similarities between the findings of this study and those of others (Baumgartner and David, 2009; Gardner, 2013; Medley *et al.*, 2009) where the key concerns were the quest for longer life, the desire to avoid the fatal consequences of HIV and the deteriorating health status. In this study, it has been noted in a previous section that most of the respondents got to know their status in the context of serious and prolonged illness, either having been sick-on-and off for a long time or having suffered adverse health effects due to the effect of the virus. Therefore, their acceptance was related to their need for a solution to their constant on-and-off illness episodes. This desire to continue living motivated the decision of many participants to accept their status and to get enrolled into care despite the fact that knowing one is infected with HIV is difficult and painful.

Third, they were motivated by the availability of effective and affordable treatments capable of reducing the damage the virus could do to their immune systems. Through these treatments, the progression of the disease to AIDS could be slowed down. These medications could be accessed almost for free medication at public health facilities in Kenya including the facilities where this study was conducted. The participants had obtained the information about the availability of these medications either prior to being diagnosed or during pre- and post-test counselling. In findings similar to those of the current study, availability of treatment (ARVs) was a key element in promoting acceptance (Baumgartner and David, 2009; Gardner, 2013; Medley *et al.*, 2009; Ncama, 2007; Wekesa and Coast, 2013). In these studies, treatment allowed the beneficiaries to regain almost normal health status, helped eradicate the signs and symptoms of HIV, and made them regain strength and enabled them to continue with social roles and to maintain their social relationships. Therefore, the availability of the necessary medications and care and support options for positive living were very strong motivations in making one decide to be enrolled into HIV care and treatment.

Fourth, the PLHIV adopted a *normalization* strategy when they understood that HIV was a manageable condition with which someone could live comfortably. The availability of treatment helped reduce the fear with which HIV was held in the past. As opposed to the past when HIV was viewed as a death sentence, it was currently perceived by the participants to be just like any other chronic disease. This is due to the fact that through HAART, the effects of HIV to the body's immune system can be controlled. Moreover, the fact that opportunistic infections are the ones that do kill and not HIV itself was an additional motivation to get enrolled into care and to adopt positive living. Even though they were aware of the long-term effects of HIV and the lack of a cure for it, they believed they could control its progression to AIDS by good adherence, nutrition and adopting positive living (Baumgartner and David, 2009; Gardner, 2013; Ncama, 2007).

The other aspect of normalization was that PLHIV discovered they were not the only ones infected but rather many more people were already living positively with the condition. They often encountered PLHIV at the PSC, in support groups and within the community who represented the broad spectrum of society. Thus they noted that HIV did not restrict itself to only certain sections but affected individuals across different professions and from all walks of life such as doctors, nurses, teachers, policemen and farmers. Evidently, the participants viewed HIV as a wider human tragedy capable of infecting anyone in society irrespective of social status and not as a preserve of some unfortunate few. Normalization discourses are ideological stances that view adverse disease conditions as being like any other common disease and not as something out of the ordinary. These discourses, which have been made possible by HAART, thus seem to be crucial in helping to simultaneously demystify HIV infection and reduce stigma and discrimination. Through these discourses of normalization, the PLHIV have been able to recollect themselves and to put in place measures to improve their quality of life as made manifest in their coping strategies.

Finally, some of the participants were concerned about the present and future well-being of their children. In findings that echo those of other studies (Medley *et al.*, 2009; Russell and Seeley, 2010; Wilson, 2007), they reckoned that if they would live a little longer, they could provide the care and education necessary for their children to grow into self-reliant adults. Consistent with findings by Russell and Seeley (2010), the well-being of children was an issue that concerned women more than it did men. The preoccupations the women had about their children were based on the fact that most of the children were still young, going to school and wholly dependent on their parents. Therefore, the key concerns revolved around who would take care of the children should they (their parents), who had now been diagnosed HIV positive, pass away.

The need to be in a position to support their still very young children was an important element in the decision to accept the test results and to immediately enroll into care. Even some participants who found it hard to accept that they had indeed tested positive, realized the futility of being in a state of denial for long. In spite of the pain they felt about the diagnosis, they picked up the pieces and started a new phase of life. They recognized that they could only be able to support their children’s present and future security and well-being if they appreciated the fact that there was something they could do, in spite of their circumstances, to realize the dreams they had for their children (Medley *et al.*, 2009; Russell and Seeley, 2010; Wilson, 2007).

Women who had children had an overwhelming concern over what the future would portend for them. This concern gave them the motivation to muster sufficient strength to live positively instead of sliding into a morass of despair (Anderson et al. 2009; Medley et al. 2009). Some women reasoned that for their children to be able to cope with their illness, they themselves had to be able to cope and be in a right frame of mind. Since there was no guarantee that their children would be cared for by someone else, they had to be able to do it themselves in the time that they had to live (Anderson et al. 2009). Some of the ways they went about securing the future of their children was through opening bank accounts and saving for them, giving them a good education and putting up a good house for the family (Anderson et al. 2009; Medley et al. 2009; Russell, Seeley 2010). In that women needed to be alive in order to secure the livelihoods of their children, the presence of children was a strong motivating factor that gave women the inner drive to keep on with the business of life (Anderson et al. 2009).

6.6 Effects of HIV on the Lives of PLHIV

In this study, findings have been provided detailing the effects of being HIV positive on the lives of PLHIV with specific reference to their social relationships, their capacity to fulfil social obligations, and their perceptions of self. This information was intended to help identify the types of changes PLHIV have experienced in their lives and to provide a framework for capturing the meanings they attach to the experience of being HIV positive. First, the effects on social relationships are discussed and then the other two dimensions are addressed consecutively.

6.6.1 Effects on Social Relationships

The effects that being HIV positive has on social relationships are closely linked to either intentional or unintentional disclosure of HIV status to others. This is because it is only when other people get to know a person’s HIV status, by whatever means, that any subsequent changes can be observed. Findings presented in this study show that a majority of the participants reported not having observed any changes in their social relationships different from what they had before diagnosis. For this category, being diagnosed HIV positive and even disclosing their status to significant others, such as close family members, relatives and friends, did not have a significant impact on the way they interacted or related. Their social relationships to a greater extent, remained normal and they interacted with these significant others as they had done in the past.

Some participants noted an improvement in their social relationships. This improvement was seen in two main forms: more enhanced social relations and more love shown to them (PLHIV) by family members. Evidence from other studies show that PLHIV were often recipients of support, encouragement and acceptance from relatives and family members. They were counted as valuable family members and that being HIV positive did not diminish their worth as human beings (Ndou *et al.*, 2013). Campbell *et al.* (2011) also found that PLHIV received support from their family members once their status was confirmed and they were enrolled on medication. Their participants reported that their relationships within the family was okay. Participants in a study by Tarakeshwar *et al.* (2006) reported that their marital relationships provided them with a source of support. They also mentioned receiving instrumental and emotional support from their family members. According to Ndou *et al.* (2013), support from significant others often took the form of finances to help acquire medication and for transport to health facility to access treatment; reminders to the PLHIV of their upcoming clinical appointments; reminders to them of the time for their medications; help with preparing meals and provision of motivation and encouragement.

However, not every case was as rosy as what has been reported above. Some participants reported experiencing problems in their social relationships. The most common negative experiences were those of stigma and discrimination. Widows reported more difficulties in social relationships than the other categories of women. Findings from other studies show that PLHIV experienced treatment similar to those presented in this study. Most of the studies reported stigmatizing and discriminatory treatments directed to PLHIV (Anderson *et al.*, 2009; Majumdar and Mazaleni, 2010; Nattabi *et al.*, 2012; Ndou *et al.*, 2013; Selman *et al.*, 2013; Tarakeshwar *et al.*, 2006).

The stigma and discrimination expressed itself in several forms. Those who were discovered to be HIV positive were deserted, rejected or abandoned by friends and family members. The family members also distanced themselves, insulted and ridiculed the PLHIV. PLHIV viewed these insults and ridicule as lack of sensitivity to their circumstances by those who perpetrated them. The participants also reported being branded by those to whom they disclosed their status to or who got to know their status from other sources. In findings that corroborate those of the present study, PLHIV often noted either totally losing or only receiving minimal social and other forms of support from family, friends, relatives and the community (Anderson *et al.*, 2009; Majumdar and Mazaleni, 2010; Tarakeshwar *et al.*, 2006); being excluded from family activities by family members, with widows being particularly affected; widows often being blamed for the death of their husbands; receiving negative treatment such as rejection and being considered untouchable; and exposure to other forms of stigma and discrimination (Ndou *et al.*, 2013; Tarakeshwar *et al.*, 2006).

Besides cases of being deserted by friends, loss of trust of family members was a notable effect, particularly in the marital relationships where the women tested positive while the husbands tested negative. This loss of trust exhibited a clear gender dimension as it often resulted in the women being abandoned or put away. Findings from other studies, for instance, Ndou *et al.* (2013) and Tarakeshwar *et al.* (2006) show that an HIV positive status was often a course for marital conflicts leading to divorce and separation with women being more often the victims. Women were in these cases chased away by their suspicious husbands. However, in some cases, the marital conflicts and abandonment could be double-sided with husbands being abandoned by their wives in cases where the women tested negative.

As a way of reacting either to anticipated or actual stigmatization and discrimination, the results of this study showed that some participants restructured their interaction patterns based on the realities of their new condition. The most prominent theme in restructured interaction patterns was the creation of new social relationships with people of a similar HIV status. This included membership in support groups of PLHIV. The reasons advanced for interacting mostly with PLHIV were diverse and included the fact that these were the people with whom they shared many things in common and who were capable of appreciating their situation. Other notable changes included diminishing the importance of certain types of relationships while enhancing that of others. Some of the participants indicated limiting their interactions with others, some sort of self-isolation. Other studies reported similar strategies adopted by PLHIV in reacting to stigma and discrimination. According to Anderson *et al.* (2009), Nattabi *et al.* (2012) and Selman *et al.* (2013) social isolation, relating only to PLHIV and even seeking for sexual partners from among PLHIV and status disclosure were some strategies adopted by PLHIV.

6.6.2 Effects on Capacity to fulfil Social Obligations

PLHIV are not any different from those not infected with HIV since both categories of people are preoccupied with the same social obligations such as ‘doing ones things’, including ensuring that children are taken care of and fed and that the general cleanliness of the home is observed. According to Corbin and Strauss (1987), capacity to work is a crucial component of a person’s sense of self. Capacity to perform one’s duties was linked to the ability to be economically productive and seen as a guarantee of self-reliance, which is crucial for reciprocity in social interactions (Campbell *et al.*, 2011; Freund and McGuire, 1999).

Despite being diagnosed as being HIV positive, some PLHIV indicated that this did not in any way interfere with their capacity to perform their daily activities and to fulfil their social obligations. This group of participants did not experience any disruptions to their ability for normal functioning that could be attributed to their being HIV positive. In essence, they did not notice any remarkable changes to their capacity and after being placed on treatment and care and attaining full recovery, they were able to carry on with their activities normally. These participants seemed to emphasize their ability to perform the duties expected of them like any other person who is not infected with HIV as a way of underscoring the fact that they were really not experiencing any differences. As such, they considered themselves as normal.

The other major pattern reported in the study was regained capacity to fulfil social obligations. Some of the participants indicated that before knowing the reason for their on-and-off illness and before being put on ARVs, they were not able to perform many of the normal activities expected of them on a day-to-day basis. Due to constant illness, they had lost strength and stamina and were often fatigued. Improvements in health status after knowing one’s HIV status enabled many participants to resume their normal activities. Being on medication was therefore crucial in helping these participants recover to a state of normalcy and return to normal life. According to Campbell *et al.* (2011), knowing ones status and being enrolled on ARVs had enabled people diagnosed HIV positive to recover physical health and regain capacity to work. The theoretical literature support the hypothesis that regaining one’s physical health and capacity to work can make it possible for one to regain a semblance of normality, which is crucial for a healthy self-identity (Freund and McGuire, 1999; Nettleton, 2006).

The third pattern of effects on capacity to fulfil social obligations involved those who recognized that even though they were still able to perform some of their activities, it was not without certain limitations. Some participants reported experiencing diminished strength.

Others noted that they could not work for long periods of time like in the past. As argued by Corbin and Strauss (1987), inability or diminished ability to perform daily tasks is linked to reduced bodily function. Findings from other studies corroborate the present study's finding that health problems associated with being HIV positive such as fatigue, side effects of medication and occasional incidents of OIs, interfere with the capacity of PLHIV to perform their duties as expected (Ji *et al.*, 2007; Majumdar and Mazaleni, 2010; Selman *et al.*, 2013; Tarakeshwar *et al.*, 2006).

Consequently, it was evident that a good number of participants had lost their full strength and had to contend with reduced physical capacity to perform their mundane tasks. They were therefore forced to accept that they could not match their previous physical capacities. They had to be content with whatever they had left of their physical strength. Nevertheless, the realities of daily life required them to still busily engage with the affairs of everyday life since no one would fully take over their responsibilities. PLHIV had therefore to come up with strategies to go on with their lives which according to the study included giving up certain activities, reducing the amount of work they do; rescheduling certain activities or receiving support from friends and relatives. These findings are supported by those of Majumdar and Mazaleni (2010) and Tarakeshwar *et al.* (2006), and are consistent with the theoretical literature (Bury, 1982; Carel, 2008; Charmaz, 1983; Corbin, 2003).

6.6.3 Effects on Perception of Self

This section discusses how knowledge of one's status as being HIV-positive affects beliefs and thoughts about self, including who the PLHIV believe they have become in comparison to the past; what they thought about their self-worth and their value to the community and family; and how health and well-being are conceived. The findings of this study clearly demonstrate that most of the participants interpreted being diagnosed with HIV as living an essentially new type of life, or as having joined something new; having acquired a new status. Nearly all participants noted being in a totally new phase of existence unlike the case in the past. The three main patterns observed involved those who perceived a stable or constant sense of self, those who perceived a restored or enhanced sense of self and those who perceived a disrupted sense of self.

Perception of self as stable was evidenced among participants who considered themselves to be okay, normal, healthy and who averred that nothing had changed in the way they viewed themselves. A stable sense of self could exist even if participants had indicated having experienced some changes and that living with HIV was a totally new experience. Another variant of a sense of stable self was a manifest sense of being totally immersed in the ‘HIV world.’ Being immersed in the HIV world may be due to the need to meet the strict adherence requirements. It could also be due to isolation and sero-sorting due to real or anticipated stigma and discrimination from the community (Bury, 1982; Charmaz, 1983; Nettleton, 2006). This trend to concentrate on the HIV world, where ones main associates are friends or members of support groups of PLHIV is what Baumgartner (2007) refers to as *identity centrality*. *Identity centrality* with regard to HIV is a situation whereby HIV becomes the center of a PLHIV’s sense of identity, occupying the vast amount of ones thoughts, conversations and activities.

This identity centrality may not necessarily be a negative phenomenon as it is a response mechanism to discrimination and stigma. According the symbolic interactionist theory, which is one of the theories guiding this study, human beings are social actors who act a part in social relationships and are actively involved in meaning making. Human beings do not necessarily allow themselves to be restricted and restrained by wider structural realities of the society such as the definitions the society imposes on what it means to be infected with HIV. Based on the premises of this theory, it was anticipated that social networks, such as support groups of PLHIV, would provide the spaces where PLHIV as individuals would interact and corporately review their options. Through the process of social interaction, it was further expected that as a group, PLHIV would define their own meanings and realities of what it meant to live with HIV and subsequently work out pragmatic arrangements suited to their respective circumstances (Ferrante-Wallace, 2013; Ritzer, 2003; Wallace and Wolf, 2005). This hypothesis has been confirmed.

Theoretical literature is replete with evidence that the status of the body plays a great role in the perception of a healthy sense of self and thus has an influence on health and wellbeing. Both the ability of the body to be in a condition that can facilitate the performance of daily tasks as well as its conformity to societal conceptions of what constitutes a normal appearance in relation to the bearer of the body, are important considerations for the perception of self (Bury, 1982; Freund and McGuire, 1999; Nettleton, 2006). Because some of the participants had been affected physically by illness that rendered their bodies incapable of fully aiding normal function and presenting a normal appearance to the public, they exhibited a disrupted sense of self (Bury, 1982; Charmaz, 1983; Corbin and Strauss, 1987).

A disrupted sense of self for some of the participants of this study was construed to mean having an altered bodily condition such as inability to gain weight and being ever light weight whereas this was not the case prior to diagnosis. In this regard, perceptions of self were seen as being linked to the capacity of the body to be in a normal condition or to behave as expected. Others expressed an insecure sense of self, whereby any negative discussions or information about PLHIV, even if not about themselves directly, would affect the way they thought or felt about themselves. Similar researches conducted elsewhere, for instance Anderson *et al.* (2009) and Selman *et al.* (2013) report that participants exhibited a sense of biographical loss manifested in concerns about loss of their future, perception of the future as hopeless and dreams as shattered and feelings of doubt and despair.

However, being enrolled on ART and experiencing the therapeutic effects of ARVs can help restore an element of hope since ARVs have transformed HIV from being associated with imminent death to a chronic condition with which someone can live comfortably for long. Participants who demonstrated a restored or enhanced sense of self were largely those who had experienced a marked improvement in their lives because they no longer had problems with on-and-off sickness, were able to perform their daily chores normally and could be able to work harder than those who they considered well (HIV negative). The fact that they were living in peace with themselves and had little stress was also considered valuable. These participants expressed a renewed sense of vitality and vigour that made them to even surpass their previous capacities. This elucidates one of the obvious benefits of knowing one’s HIV status and being enrolled into care.

In findings echoing the theoretical literature, enhanced and restored sense of self seemed attributable in some of the cases to the ability to be self-reliant that arises from better health. According to the theoretical literature on sociology of health and illness, self-reliance and ability to interrelate with others in reciprocal terms as opposed to being dependent upon others, a key marker of an enhanced sense of self, evidently resulted from knowledge of their HIV status and from being enrolled into care and regaining a their physical health (Bury, 1997; Carel, 2008; Corbin and Strauss, 1987; Freund and McGuire, 1999).

Evidence from the study indicates further that apart from strength in the body and ability to perform daily chores, the appearance of the body was also a key factor in defining restored sense of self. Some participants considered their bodies as smart looking and rejoiced in the fact that they had gained weight and a well-built physique. The recovery of a normal body gave them the ability to resume active participation in social life and engage meaningfully in daily events. The PLHIV considered this a valuable aspect of self whose recovery had been made possible by enrolment into ART. Research in the field of chronic illness indicates that the body is an indispensable medium in the process of social interaction and identity formation for it is through the body that individuals present themselves to the social world (Carel, 2008; Corbin and Strauss, 1987; Freund and McGuire, 1999). According to symbolic interactionism, a person's sense of self is premised on his or her evaluation of what they believe others think about them. Consequently, positive evaluations lead to a positive sense of self (Ferrante-Wallace, 2013; Ritzer, 2003; Wallace and Wolf, 2005). In contrast, negative evaluations are linked to a negative sense of self. Therefore, a normal body will be a source of pride and joy (Bury, 1982; Carel, 2008; Charmaz, 1983; Freund and McGuire, 1999; Nettleton, 2006).

The acquisition of new things, qualities, character traits and new perceptions of self that one did not have in the past were features of a renewed sense of self as well. One particularly valued acquisition hailed as a benefit of knowing one's status was a new social role or status of 'health consultant'. It was often the case that other families with a member suspected of having HIV-like symptoms would approach someone known to be living positively with HIV for advice. This could only possible if one had known their status, had disclosed to others and was living positively. Other studies, for example Campbell *et al.* (2011), have found that being considered a community resource person is one of the outcomes of being on ARV and helps boost the sense of self of PLHIV.

6.7 Coping Strategies adopted by PLHIV

The participants were asked to share the activities they engaged in, the adjustments they had made in their lives, the practices they avoided, and the precautions they took. The various things PLHIV do and the strategies they adopt were grouped under five main thematic categories. These were: psychosocial and emotional strategies; faith and religious beliefs; social strategies; adherence to medication and good nutrition; livelihood enhancement strategies; adoption of safe sexual behaviours and abstinence from or minimization of the use of alcohol and drugs. These strategies represent what PLHIV reported doing either by themselves or through support from others especially in instances where they were not capable of fulfilling some specific needs. As is discussed in the subsequent sub-sections, coping strategies comprise yet another phase in the struggle to make sense of life with HIV. These various strategies are discussed sequentially below.

6.7.1 Psychosocial and Emotional Strategies

PLHIV adopted a number of psychosocial and emotional strategies to cope with HIV. The most commonly adopted ones included acceptance of HIV status and enrolment into care, disclosure of HIV status, avoidance of stress and contentment with life and receiving psychological counseling. Acceptance of HIV status and subsequent enrolment into care and treatment was considered a key turning point to living positively with HIV. Acceptance seems to serve as the fulcrum around which a positive experience with HIV revolves. As such, the ability to live a normal and long life and to effectively and successfully overcome stigma and discrimination depends on whether a person diagnosed HIV positive has accepted their status. Upon acceptance, the next logical step is enrolment on treatment where one can benefit from the life extending benefits of anti-retroviral therapy (ART). For a detailed discussion on acceptance, please refer to section on *How PLHIV reconcile to and accept a positive HIV status.*

Disclosure of HIV status was a key strategy adopted by PLHIV in the coping process. Several studies (Anderson *et al.*, 2009; Goudge *et al.*, 2009; Liamputtong *et al.*, 2012; Makoae *et al.*, 2008; Medley *et al.*, 2009) similarly reported disclosure as one of the coping responses. In reviewing the strategy of the participants, this study demonstrates that disclosure was considered beneficial and therefore a key coping strategy in at least four key ways. First, in findings echoing those of Liamputtong *et al.* (2012), disclosure acted as a form of security or insurance in the cases of medical or other emergencies. Secondly, disclosure was considered instrumental in helping create an atmosphere conducive to adherence as one would not need to hide their status from others. Such a free atmosphere was believed to act as a barrier against stigma and discrimination as it could serve as a preemptive strategy to disarm any person who would think of stigmatizing the PLHIV. These findings corroborate those of Liamputtong *et al.* (2012) and Makoae *et al.* (2008). Thirdly, disclosure acted as an appeal for social and other forms of support. It embraced the realization that for success in coping, the support of others is needed. Fourthly, disclosure was found to be a useful coping strategy in the desire to help others. Some PLHIV felt a sense of moral responsibility to the rest of the community that motivated them to inform others of their status. This in turn boosted their own social standing and perception of self.

However, as the experiences of the participants of this study show and as evidenced in other studies (Goudge *et al.*, 2009; Makoae *et al.*, 2008), PLHIV do not always disclose their status due to a number of fears and actual occurrences to such a disclosure. For instance, participants often found that disclosing brought with it certain risks. These risks included neglect, rejection and abandonment committed against them by close family members; verbal abuse, blame, physical abuse and being subjected to moral judgments (Goudge *et al.*, 2009; Makoae *et al.*, 2008). As such, people diagnosed with HIV exercised care with disclosure. They disclosed to a restricted circle of trusted friends and family members who they vetted thoroughly and in whom they had confidence and trusted that they would not betray the trust but would connive with them in keeping the information secret (Anderson *et al.*, 2009; Liamputtong *et al.*, 2012; Makoae *et al.*, 2008). Others opted to keep the information under lock and key in order to protect themselves and their family members. Moreover, as long as there was nothing in their bodies to indicate that they were HIV positive, they kept the information concealed except within the context of support groups and the health service providers.

Learning to avoid stress and worry and being contented with one's life was another key coping strategy. According to some of the participants, excessive stress is dangerous to health and well-being especially given that PLHIV already have a compromised immune system. In a similar study by Liamputtong et al. (2012), some of the women reported not thinking too much about their condition. Once they had confirmation they were HIV positive and had accepted their status, they had decided to go on to live positively with it. According to Anderson et al., (2009) the participants in their study endeavoured not to think about the diagnosis. They argued that giving prominence to their status would lead to depression. According to these participants, even though they acknowledged the existence of HIV in their lives, they did not let this be the defining feature of their lives.

In what she called a 'balancing act', participants in a study by Baumgartner (2007), avoided stress and reported being contented with life. This balancing act is what Baumgartner viewed as an outward manifestation of the *decentralization of identity*. Decentralization of identity is where being HIV positive is seen not as the dominant feature but as just one aspect of the self. Decentralization is further argued to be the future orientation of a life of HIV and is made possible by the availability of HAART.

Counselling was a fundamental component of treatment, care and support for PLHIV. Through counselling and education on various health issues, PLHIV were sensitized on other means of coping. During counselling sessions, PLHIV were given information on pertinent issues such as adherence to medication and good nutrition. They were also informed about the importance of positive living and disclosure of their status to family members. In the accounts of a number of PLHIV, counselling played an essential role in helping them accept their status. The role and forms of counselling have also been exhaustively discussed in the section on *How PLHIV reconcile to and accept a positive HIV status.*

6.7.2 Faith and Religious Activities

The narratives of some participants revealed that they exercised faith and trust in God and increased or renewed engagement in church activities. The participants demonstrated an acknowledgment of the role that God and faith played in their lives and hence exhibited an increased salience of their spiritual and religious identity (Baumgartner, 2007). In findings that corroborate those of other studies, a good number of the participants of this study exhibited implicit trust in God's ability to grant them length of life, to protect and guide them, to bring their hopes to fruition, and that with the right attitude they would be able to overcome the difficulties associated with their HIV status (Anderson *et al.,* 2009; Liamputtong *et al.,* 2012; Makoae *et al.,* 2008; Ribeiro Nobre *et al.,* 2012; Russell and Seeley, 2010). This faith and trust in God manifested itself in a variety of ways. Some of the participants indicated that they engaged more intensely in church and religious activities. This engagement, consistent with other studies, included joining church-related groups, singing and practicing in the church choir, and prayer (Makoae *et al.*, 2008; Ribeiro Nobre *et al.*, 2012).

The participants also acknowledged the supremacy of God and his ability to intervene in their lives. They thus decided to have hope and trust that their situation was not unknown to God. In similar studies conducted in Thailand, participants saw their status as being linked to their *karma*, a belief ingrained in Buddhism (Liamputtong *et al.*, 2012), and as having a definite purpose (Anderson *et al.*, 2009). The participants of the present study as well as those of other studies evidently benefitted from both a personal connection with God and as has been shown, from social interactions and connections made possible through being part of the corporate body of believers (Anderson *et al.*, 2009; Russell and Seeley, 2010). In general, there was an enhancement or salience of the spiritual or religious identity as evidenced in intensified engagement in religious activities and interactions with religious institutions and individuals (Baumgartner, 2007; Dageid and Duckert, 2008).

In this section, the role of faith and religious beliefs in aiding coping for PLHIV have been discussed. The PLHIV exhibited an enhancement in their spiritual identity expressed mainly through exercising faith in God's power to intervene in their lives and also through engagement in church-related activities.

6.7.3 Social Strategies

The main social strategies employed by the participants in coping with the implications of living with HIV revealed three main patterns. These patterns were: maintaining active social engagement, joining support groups, and changing interaction patterns.

PLHIV in general kept their social engagement active as evidenced in cases where they maintained existing social relationships. Even in cases where they dropped non-beneficial relationships, they tended to form new ones. They maintained social engagement with their family members, support groups, and with new avenues for social expression including active participation in religious activities. According to the evidence presented in the study, PLHIV recognized and took advantage of the potential of social interactions to help them make meaning of their HIV status and adopt pragmatic coping strategies. In results that corroborate the findings of this study, Makoae *et al.* (2008) found that their study participants remained socially engaged. For example, they chatted and talked with others on various topics of mutual interest. As several studies show, (Anderson *et al.*, 2009; Campbell *et al.*, 2011; Makoae *et al.*, 2008; Russell and Seeley, 2010), the PLHIV joined support groups, interacted with and disclosed their status to their family. This is an indication they valued the relevance of social interaction.

Perhaps the most important of the social strategies employed by PLHIV was joining and participating in support groups, a finding validated by other studies (Anderson *et al.*, 2009; Campbell *et al.*, 2011; Liamputtong *et al.*, 2009; Makoae *et al.*, 2008; Russell and Seeley, 2010). Almost all PLHIV had some experience with support groups. The PSCs spearhead the formation and management of support groups to cater for the needs of various categories of PLHIV under their care. As part of their procedures, PSCs recommend to the PLHIV to join support groups as part of care and support. According to the findings of this study support groups functioned as powerful instruments for creating alternative narratives of life with HIV to counter the prevailing social narratives.

Through these alternative illness narratives, the participants crafted strategies for fighting, resisting and perhaps overcoming powerful stigmatizing notions. Through such narratives, the PLHIV helped influence and change social perceptions and the understandings and meanings of being infected with HIV. It is through the bravery and resilience of PLHIV, supported by availability of ART services, and accommodative family and community members that the levels of stigma are seen to be declining and an enhanced sense of control over the disease is seen to be emerging. This observation is lent credence by a number of research findings

(Campbell *et al.*, 2011; Liamputtong *et al.*, 2012; Makoae *et al.*, 2008).

Within support groups, PLHIV found a sense of belonging and obtained mutual support (Baumgartner, 2007; Campbell *et al.*, 2011; Makoae *et al.*, 2008; Russell and Seeley, 2010). They met people in similar circumstances, some who had lived with HIV for long periods, with whom they could develop friendships, share experiences and from whom they could learn how to cope successfully with HIV. They had the chance of knowing some of the methods these fellow group members have used, the challenges they have faced, and how they have overcome such challenges. Consequently, support groups were important in helping PLHIV to develop the right attitude, and acquire the knowledge and skills useful for overcoming and resisting stigmatizing attitudes from the community.

Another important theme in social coping strategies was the restructuring of social interaction patterns. The PLHIV deliberately took proactive steps in creating social networks that worked best to advance their interests. They were involved in rational calculations to find out what relationships worked and what did not work and discarded those that no longer worked. In other words, they engaged in a simultaneous process of diminishing the significance of certain friendships or associations and of enhancing the role of other sets of relationships. The restructuring of social relationships also often included isolating oneself and avoiding social interactions for fear of rejection from others.

Others also believed they were no longer capable of keeping or maintaining social relationships. In some cases, isolation was necessitated by illness and not essentially a deliberate choice on the part of the PLHIV (Anderson *et al.*, 2009; Dageid and Duckert, 2008). Even though self-isolation could appear counterproductive, it was a nonetheless a strategy adopted by others and appeared to work for them, at least for the time being. PLHIV realized the importance of social engagement in coping effectively with HIV. Consistent with symbolic interactionism (Ferrante-Wallace, 2013; Newman and O'Brien, 2010; Ritzer, 2003), PLHIV were involved in a process of negotiating their own meanings of relationships and creating those social networks that worked for them.

In this sub-section, the various social methods that PLHIV utilized in managing life with HIV have been discussed. The PLHIV remained socially engaged, joined support groups and changed their interactions patterns. All these efforts were aimed at helping them keep socially connected and receive mutual support from others even as they struggled to cope with the reality of a life with HIV.

6.7.4 Health Strategies

In this sub-section, findings on what PLHIV did with regard to physical health are discussed. Three main sub-themes were identified namely: adherence to medication, observance of clinical appointments and reduction of the use of alcohol and drugs.

Enrolment in and consistent and proper use of ART was mentioned as the most important thing the PLHIV do so as to continue with their life and ensure a return to normality. Indeed, adherence to medication, which meant taking the medicines according to the prescribed dosage and at the correct times, was invariably mentioned as the first strategy towards incorporating an HIV identity into the self. In addition, it involved dealing with opportunistic infections (OIs). Other studies have found similar results. Campbell *et al.* (2011) and Dageid and Duckert (2008) reported that PLHIV actively took part in the management of their illness through taking tablets to boost their immune systems, observing doctor's appointments, and ensuring strict adherence to the instructions of the health care service provider, especially as it pertained to prescriptions and clinical appointments.

Adherence to medication as prescribed is important if the goals of viral load reduction, boosting of the immune system, and fending off opportunistic infections are to be achieved (Mweemba *et al.*, 2010; National AIDS and STI Control Programme, 2005; Shigdel *et al.*, 2014). PLHIV have interacted with the PSC personnel and they have been counselled on the importance of adherence. They therefore understood the connection between strict adherence to treatment regimens and their continued well-being. Clinical appointments served as opportunities for the PSC personnel to determine the progress the PLHIV are making in their path to recovery and normality. During such appointments, the clinicians check key health indicators such as CD4 count, viral load, body weight and the presence of any OIs. During such visits, any adverse incidents such as side effects are noted (Kitahata *et al.*, 2002; National AIDS and STI Control Programme, 2005). Observing clinical appointments was often mentioned as a co-event with adherence to medication.

Consistent with both the symbolic interaction theory (Ferrante-Wallace, 2013; Newman and O'Brien, 2010; Ritzer, 2003) and the chronic illness trajectory model (Kirkevold, 2002; McCorkle and Pasacreta, 2001; Robles-Silva, 2008), management of HIV is a collective effort involving the input of the patient, the family and the health care professionals. As such, success with medication, adherence and treatment requires the involvement of all these parties. In the management of HIV in Kenya, the MoH has endeavoured to put in place different strategies to ensure adherence, including adherence buddies, CHWs, community strategy and use of mobile technologies to ensure adherence (National AIDS and STI Control Programme, 2005).

A number of participants who had been taking alcohol and other drugs such as cigarettes reported stopping their use. They reported having received counselling and education in the PSC and in support groups to the effect that alcohol and other drugs of abuse were not compatible with the medications they were taking (World Health Organization, 2013). Moreover, they also recognized that using alcohol and drugs could increase their vulnerability to sexually risky behaviours, which could expose them to reinfection. Other studies have reported a reduction or abstention from alcohol consumption among people who have attended HIV testing and counselling (HTC) (Hahn *et al.*, 2014; Hendershot *et al.*, 2009; Samet *et al.*, 2004).

Several studies and reviews have documented the likely association between alcohol consumption and high-risk sexual behaviours such as multiple sexual partnerships, unprotected sexual intercourse, exchange of sex for money or other material goods, and increased sexual activity (Kalichman *et al.*, 2007; Mbulaiteye, 2000; Simbayi *et al.*, 2004; Weiser *et al.*, 2006). However, the participants are not always successful in these efforts. Whereas a number of participants had succeeded in stopping the use of drugs such as cigarettes, they were still struggling to stop the use of alcohol. Due to the counselling provided by the health care providers, it became clear to the PLHIV that if they had to adhere well and achieve viral suppression and realize significant clinical outcomes, they had to heed to the instructions of the PSC. For this reason, they put forth all efforts to forsake the habit of taking drugs and alcohol.

6.7.5 Livelihood Enhancement Strategies

The participants mentioned a number of activities they engaged in as a way of ensuring that they could either improve or maintain a relatively acceptable standard of living and live a normal life. In spite of living with HIV, the daily obligations of PLHIV such as providing for the basic needs of the family and meeting other obligations of daily life had to be performed. The activities mentioned were clustered into three major categories. These activities included carrying on with the normal activities of life, producing own food and engagement in IGAs.

Carrying on with normal Activities of Life

First, they mentioned the need to carry on with everyday life activities and to continue participating in the regular undertakings of life. Carrying on with life's activities, to a greater degree, meant engaging in life supporting endeavours including taking up employment in one's area of training, work at the farm, and continuing in formal or self-employment. It also meant continued engagement in other daily routine activities around the home. In their study involving five Africa countries, Makoae *et al.* (2008), found that carrying on with the normal activities of the day to keep themselves meaningfully occupied was one of the coping mechanisms adopted by their study participants. The idea behind this strategy could be to help the PLHIV maintain an appreciable level of normality. This could have bounce-off effects to help overcome some other challenges such as stress and worries as idleness can lead to worries and thoughts about one's situation.

In a study conducted among PLHIV in Uganda, Russell and Seeley (2010) reported that their respondents found a sense of being in control of their affairs and experienced a restored sense of normality and certainty of life by engaging in the daily affairs of life. The sense of independence and self-reliance brought about by the capacity to be in charge of one's own affairs as opposed to being totally dependent upon others gives a sense of liberation and empowerment and engenders a sense of equality with other 'normal' members of society. As elucidated by theorists on coping with chronic illness (Corbin and Strauss, 1987; Freund and McGuire, 1999), this can be a strong booster of the sense of self since it can enhance and reinforce the sense of reciprocity and engagement of equals in social interactions.

Production of own Food and Ensuring good Nutrition

Nutrition played a very important role among the PLHIV in the context of adherence to medical treatment. It needs to be noted that PLHIV are counselled and trained that nutrition is one of the key elements of effective HIV care and management (Kitahata *et al.*, 2002; National AIDS and STI Control Programme, 2005). As such, the PLHIV were advised to make every effort to ensure they had proper nutrition. The findings of this study show that the PLHIV took the issue of nutrition very seriously. They went to all lengths, in spite of the many challenges, to ensure they had a balanced diet and that they ate at least three times a day. In spite of their best efforts, some participants did not often have something to eat, a fact that made adherence to medication difficult. In studies corroborative to the current one, participants mentioned good nutrition as one of the key pillars of their coping strategies (Dageid and Duckert, 2008; Liamputtong *et al.*, 2012).

The participants mentioned providing their own nutritional needs by either by working in their farms, in business, in other IGA or in employed service. Being on medication with ARVs is important for PLHIV because ARVs help contain and reduce the spread of the HIV in the body. However, as had been seen in the previous section on adherence, good nutrition is an essential component in complying with treatment regimen. Therefore as part of their coping strategies, the PLHIV mentioned their struggle to ensure they could provide for their own nutritional needs so as not to suffer the deleterious effects of taking ARVs without adequate nutrition. Other studies, for instance Russell and Seeley (2010), report that participants in their study who were on ART engaged in hard work trying to reorganize their household livelihoods. In a context where subsistence agriculture was the main means of livelihood, many of them indicated working hard in the farm to both produce food and get resources for their children's education.

As some of the respondents were parents and spouses and thus responsible for their families, they felt socially and morally obligated to be in a position to provide food and other needs for their households. Even though PLHIV are not always successful in these efforts as will be seen in the section on difficulties, they still recognized the importance of food and nutritional security and the necessity of doing everything within their power to make sure they could provide for their own and their family's nutrition. Engagement in food production was part of helping them regain normalcy and sense of control over their lives, a very important component of a positive self-perception (Corbin and Strauss, 1987; Freund and McGuire, 1999; Russell *et al.*, 2007).

Engagement in Income-Generating Activities

The third activity the participants of this study mentioned was being actively involved in IGAs which were mainly in fields such as agribusiness, small-scale businesses and enterprises (such as bricklaying, welding, and selling of clothes and foodstuff) as well as other forms of self-employment. In a research conducted in Homa Bay County, Kenya, Odhoch (2008) found that besides the IGAs already mentioned, communities and PLHIV engaged in poultry and goat keeping and other handwork activities such as basket-weaving and rope-making. Production of tree seedlings was also another preferred activity. According to the findings of this present study, a number of participants indicated having saved some money and invested the same in some business while others mentioned being in the process of saving portions of their incomes to invest in various types of IGAs. The intention of the savings and investments was to capacitate them to provide for themselves and their dependents with what they considered the surest way of meeting their many needs and securing their livelihoods. Indeed other researchers have identified investment in IGAs as a popular way of helping provide for the needs of PLHIV. These are critical in helping secure means of accessing food and nutritional security and fulfilling other financial or material obligations (Odhoch, 2008; Russell and Seeley, 2010). The best way to support PLHIV is to help them be self-sufficient as much as possible in meeting their needs. This will help enhance their sense of self and their dignity as equals in social encounters with others (Freund and McGuire, 1999).

6.7.6 Adoption of Safe Sexual Behaviours

According to the findings of this study, adoption of safe sexual behaviours was a key component in coping with HIV. Five distinct changes in sexual behaviours were adopted. First, they stopped having sexual intercourse with multiple partners. Second, most participants vowed to be faithful to one spouse/partner whose HIV status they knew. Even where they stopped having sex with multiple partners and remained faithful to their spouses or partners, all who continued to be sexually active adopted the third method that involved the use protection during sexual intercourse. Exceptions to using protection were during occasions when they were seeking to get a child. In such cases, they had to consult with their health care provider. Fourth, a number of women mentioned having stopped having sexual intercourse altogether and were abstaining from sexual relations with men. Finally, some women involved in commercial sex reported finding the work no longer beneficial and thus lost interest in it. In a study conducted in the same geographical locality and which produced findings corroborative of the present one, Odhoch, (2008) found that PLHIV adopted faithfulness, abstinence, use of condoms (protection), and sticking to one inheritor as some of the sexual behaviour changes adopted as part of their coping strategies.

Changes in sexual behaviour are key to ensuring that the PLHIV do not get re-infected since reinfection may increase their viral load and thus hinder success in suppression of viral activity. Practicing safer sex also ensures that the PLHIV do not acquire other strains of the virus and that those who are not yet infected remain protected from contracting HIV. This is especially important in cases of discordant couples where only one spouse is infected and in cases where a person already infected seeks to protect their sexual partners whose status they may or may not be aware of. Other studies (Anderson *et al.*, 2009; Baumgartner, 2007; Gardner, 2013; Makoae *et al.*, 2008; Ribeiro Nobre *et al.*, 2012) have reported adoption of a range of similar adjustments in sexual behaviour to achieve the same or similar purposes.

6.8 Difficulties faced in Coping with a Positive HIV Status

In an attempt to cope and adapt to life with HIV, PLHIV were confronted by a number of difficulties. The main difficulties were subsumed within five main thematic areas: livelihood and income-related, access to food and nutrition, stigma and discrimination, children's education and well-being, and health concerns. These are discussed sequentially below.

6.8.1 Livelihood and Income-Related Difficulties

Lack of means for ensuring a proper and sustainable livelihood and ability to meet other obligations was mentioned by the participants as one of the greatest difficulties they encountered. Often, being able to earn an income in terms of access to money was considered a key aspect of successfully fulfilling ones social obligations. The participants indicated that they needed money and other resources to purchase food and to pay rent and school fees. They also needed money for transportation to the health facilities and for the levies charged there, although these levies are at best nominal. A number of studies identified poverty or lack of a secure source of livelihood as a key barrier to accessing ART or coping effectively with a positive HIV status (Cloete *et al.*, 2010; Groh *et al.*, 2011; Ji *et al.*, 2007; Kang'ethe, 2009; Liamputtong *et al.*, 2012; Nyamathi *et al.*, 2011; Russell and Seeley, 2010; Selman *et al.*, 2013).

The poverty or lack of livelihood resources could be attributable to a number of factors. A number of participants either lacked the relevant qualifications for securing formal employment or did not have sufficient strength to work in their farms or in the case of widows and separated women, lacked the support of a life partner with whom they could work together to support themselves and their families. A good number who wished to be self-employed lacked the financial resources to do so. As such, life for these participants was a struggle since they could not comfortably afford food, school fees and levies charged in the health facility. These findings are corroborated by those of other studies (Cloete *et al.*, 2010; Nyamathi *et al.*, 2011; Russell and Seeley, 2010).

6.8.2 Access to Food and Nutrition

The findings of this study indicated that access to adequate, healthy and nutritious food was a major problem that a great number of the participants encountered. Other studies (Groh *et al.*, 2011; Kang'ethe, 2009; Liamputtong *et al.*, 2012; Musumari *et al.*, 2013; Nagata *et al.*, 2012; Russell and Seeley, 2010; Weiser *et al.*, 2010; Young *et al.*, 2014), have also documented findings that corroborate those of the current study, showing that food insecurity is increasingly emerging as one of the key barriers to adherence to ART among PLHIV. Some of the documented ways through which food insecurity impacts on adherence include: intensification of hunger or increased appetite; deleterious effects of taking ARVs without adequate food or on empty stomachs; the emphasis on good nutrition as a key component of treatment and adherence by health service providers; competing priorities between food costs and health care costs and incompatible schedules of work making it difficult to look for food and to take medications according to schedule (Claros *et al.*, 2014; Groh *et al.*, 2011; Selman *et al.*, 2013; Weiser *et al.*, 2010; Young *et al.*, 2014).

The findings of this study further showed that a number of participants had problems obtaining adequate nutrition due to limited access to income and livelihood support mechanisms. In some places like Nyabondo, the vagaries of weather had also decimated crops and destroyed their only other possible means of getting food. This crop failure, although affecting even others not living with HIV, had more devastating impact on PLHIV who needed good and adequate nutrition due to their special circumstances. Some of the factors limiting access to good nutrition by PLHIV from other studies include lack of or inadequate monetary income (Liamputtong *et al.*, 2012; Russell and Seeley, 2010), being widowed if one is female thus limiting one's access to support from a husband, and poor harvests resulting chiefly from lack of access to productive resources such as land (Weiser *et al.*, 2010). Lack of access to food was more greatly felt by widows.

6.8.3 Stigma and Discrimination

The findings of this study indicate that stigma and discrimination are phenomena that kept coming up throughout the illness trajectory of the PLHIV. Stigma and discrimination manifested themselves before trajectory onset, at the initiation of care, came up as part of the factors informing the initial reactions of PLHIV after diagnosis and as one of the key effects on social relationships resulting from being diagnosed with HIV. As such, they kept coming up through every phase of life with HIV.

Even though a number of participants indicated that levels of overt stigma and discrimination were on the decline, a condition they attributed to perceived high HIV prevalence, they still felt that stigmatizing and discriminatory treatments to which PLHIV were exposed, still existed. Stigmatizing attitudes are outcomes of either intended or unintended disclosure of one's HIV status. According to the literature and treatment guidelines, disclosure is hailed as one of the key components of positively living with HIV (Greeff *et al.*, 2008; Li *et al.*, 2007). Disclosure has the potential of setting one free from the burden of having to keep one's HIV status secret and to open up opportunities for receiving help and support from one's social network and from other service providers such as NGOs, government agencies and FBOs (Greeff *et al.*, 2008; Medley *et al.*, 2009). However, disclosure may also prove to be a double-edged sword whereby in spite of the acknowledged benefits, it may expose the person disclosing their status to stigmatizing treatment (Liamputtong *et al.*, 2012; Medley *et al.*, 2009; Remien and Mellins, 2007).

Stigma and discrimination may hamper the PLHIVs' capacity to cope because of their impacts and outcomes. The impacts and outcomes and even the possible reasons for stigmatizing and discriminatory treatment have been extensively discussed elsewhere in this dissertation (see discussion section sub-sections on *Reconciliation to and Acceptance of a Positive HIV Status and Effects on Social Relationships*, and Literature Review section on *Challenges faced by PLHIV in adapting to a Life with HIV*). However, perhaps the explanation as to why stigma and discrimination present an important challenge in adaptively living with HIV are their implications for a person's reputation and the kinds of treatment that a person known to be HIV positive is exposed to. According to some participants and to the literature (Groh *et al.*, 2011; Ji *et al.*, 2007; Ndou *et al.*, 2013; Russell and Seeley, 2010), societal attitudes towards PLHIV are still very hostile and morally judgmental. HIV is generally viewed as only being acquired through sexual intercourse of the deviant kind. Thus, it espouses an all-inclusive perception that PLHIV are sexually immoral, having engaged in morally prohibited sexual liaisons. Consequently, PLHIV are often perceived as being responsible for having acquired their HIV status and are thus seen to deserve to suffer the consequences (Dlamini *et al.*, 2007; Majumdar and Mazaleni, 2010; Nattabi *et al.*, 2012). Due to difficulties experienced as a result of stigma and discrimination, some participants adopt practices that end up leading to self-stigma, such as isolating themselves from others.

6.8.4 Children's Education and Well-being

Concerns with their children's future well-being, as seen in terms of education and a proper training in preparing them for careers and for self-reliance in the future, was a key concern for those participants of the study who were parents with dependent children. As such, inability to meet the costs of providing an education for their children was mentioned as a difficulty. As has been described in the section on Livelihood and Income-Related difficulties above, the parents lacked sufficient finances to pay the school fees for their children, especially for those proceeding to the secondary school level and those seeking post-secondary education. For some participants, inability to meet the costs for their children's education was reckoned as the greatest challenge among a plethora of challenges. This problem was more compounded in cases where the PLHIV was a widow, having lost her husband and being left to deal with these issues alone. This finding resonates with those of other researchers in a variety of geographical and socio-economic settings (Adato and Bassett, 2009; Ji *et al.*, 2007; Miller and Tsoka, 2012; Selman *et al.*, 2013; Xu *et al.*, 2010).

Some studies have tried to identify the challenges that children affected by HIV and AIDS face in accessing education. The key circumstances making it difficult for children of PLHIV to access good education and realize positive educational outcomes have been identified as lack of money to pay for school tuition fees and other levies; poor academic performance; the need to take care of ailing parents or to take care of younger siblings; associational stigma and discrimination from peers within the school and within the community; psychological disturbances due to ill-health or death of parents and even lack of school items such as uniforms (Adato and Bassett, 2009; Ji *et al.*, 2007; Miller and Tsoka, 2012; Selman *et al.*, 2013; Xu *et al.*, 2010). The circumstances mentioned above make it difficult for such children to stay in school and develop successfully. As such these provide powerful barriers to an adaptive life for PLHIV.

In two studies that examined the role of social cash transfers for families affected by HIV, it was established that before the cash transfers, children were missing school due to lack of school uniforms or due to illness of their parents. However, after the families began receiving social transfers, their children no longer missed school for whatever reason. The children were thus able to stay in school and complete their studies as their parents recovered physically and were able to provide their nutritional and other additional needs (Adato and Bassett, 2009; Miller and Tsoka, 2012). It is therefore clear from both the present study and literature that inability to provide for the needs of their children are key challenges confronting PLHIV. Of these needs, the most critical one is that of providing them with good education through which the children may be equipped with the knowledge, attitudes and skills for success in an increasingly competitive world.

6.8.5 Health Concerns

In somewhat surprising findings, difficulties related to health were mentioned by only three participants and therefore does not seem to be a serious concern. There are possible explanations for these results. They could be due to the therapeutic benefits of ARVs and the changes the PLHIV have implemented in their lives. These, among other reasons, could provide partial explanations as to why in comparison to the period during or immediately after diagnosis, many of them do not mention health as a big problem currently. As was presented in the section on coping strategies, the PLHIV had implemented a lot of changes, adopted new healthy practices and abandoned old health-risk behaviours. Additionally, they strictly adhered to the prescriptions and other instructions given by their health care providers, especially with regard to taking their medication at the times indicated and as far as eating well-balanced diets is concerned.

Other studies have documented ill-health as one of the challenges to living adaptively with HIV. Health problems affecting the PLHIV primarily, but also those affecting other family members, such as a sick child, have the potential of undermining household economic and livelihood security. In addition, in cases where the health problems are serious, PLHIV may lose the capacity to perform their daily activities independently. The loss of capacity for self-reliance may undermine their ability to provide for themselves and their families and limit their coping options. Such a scenario would necessitate dependence upon others even for the most basic tasks, such as preparing food, taking medications, performing normal hygiene and cleaning tasks and the care of young children (Nyamathi *et al.*, 2011; Russell *et al.*, 2007). Besides, through loss of capacity to work, physical ill-health may lead to an elevated sense of uncertainty for the future, result in loss of sense of control and consequently diminish the sense of self of PLHIV (Carel, 2008; Conrad and Bury, 1997; Freund and McGuire, 1999; Nyamathi *et al.*, 2011; Russell *et al.*, 2007).

Additionally, the irrevocable reality that they were living with HIV, a chronic, though incurable condition, and the associated uncertainty attached to it, may continue to be a constant source of worry to the PLHIV leading to a host of emotional and psychological disturbances. As PLHIV, they may continually experience changes in their lives occasioned by their HIV positive status. For instance, they are vulnerable to OIs such as malaria, typhoid, TB, and other conditions. They are also faced with the prospect of being on medication for life and sometimes experience treatment failures necessitating being put on a different course of treatment. Coupled with the responsibility lying upon them for their children’s immediate and future well-being as well as for their own daily well-being, they may be plagued with negative thoughts. Moreover, the perpetual notion of imminent death that being HIV positive may mean to some PLHIV could be a constant source of fear and worry (Freund and McGuire, 1999; Medley *et al.*, 2009; Russell and Seeley, 2010).

6.9 Chapter Summary

The chapter began by discussing the methodological considerations including quality and trustworthiness and strengths and limitations of the study. Quality and trustworthiness have been assured through the four main criteria of credibility, transferability, dependability and confirmability. It can be stated that the study meets the standards for ensuring quality and trustworthiness. The way these have been ensured and how they can be ascertained have been outlined. Therefore, in spite of its limitations, the study generally met its research objectives and obtained the answers to the research questions that were posed. Consequently, the findings, discussions, conclusions and recommendations of this study are the product of a rigorous research process. The PI can thus provide the assurance that the study succeeded in providing a hermeneutical phenomenological account of the meanings that PLHIV in Kisumu County, Kenya, attach to their experiences of living with HIV and how they cope with and adapt to life with an HIV-positive status

Diagnosis was often in the context of emergencies requiring hospitalization and when the participants had already suffered unexplainable, recurring illnesses. Decisions for testing were often made by the participants themselves, although in some cases, health personnel, spouses, siblings, relatives and friends also influenced such decisions.

The chapter next discussed the effects of being HIV positive on the lives of PLHIV. The main effects on social relationships included stigma and discrimination, restored and enhanced social relationships and restructured social relationships. Diminished capacity, retained capacity and regained capacity were the main effects on capacity to fulfil social obligations. However, a number of participants did not experience any effects. A disrupted, a stable and a restored or enhanced sense of self were the main effects on the perceived sense of self. Finally, the chapter discussed the coping strategies adopted by PLHIV and the difficulties they experienced in coping with and adapting to life with HIV. The main coping strategies were psychosocial and emotional which comprised of acceptance of status, access to counselling, and disclosure of status. Social coping strategies adopted included joining support groups and restructuring of social relationships. Other strategies were adherence to medication, livelihood enhancement strategies—such as carrying on with the normal activities of life, producing own food and ensuring good nutrition—adopting safe sexual behaviours and abstinence from or minimization of the use of alcohol and drugs.

The next chapter presents the conclusions and recommendations for policy and programming and for further research.

7 CONCLUSIONS AND RECOMMENDATIONS

7.1 Chapter Overview

This chapter addresses the conclusions and recommendations that have been derived from the findings of the study. The chapter begins with conclusions on methodology. Conclusions on circumstances and contexts of being diagnosed HIV positive are then presented. The chapter then gives conclusions on the effects of HIV on the lives of PLHIV. The next series of conclusions deal with the coping strategies PLHIV adopted and the difficulties they faced in adapting to life with HIV. Finally, a number of policy, programmatic and research recommendations are given to help find ways of making PLHIV and their families achieve more adaptable life outcomes.

7.2 Conclusions on Methodology

The present study was designed to provide a descriptive account of the experiences of PLHIV in Kisumu County, Kenya. The study set out to achieve a number of objectives. First, it sought to establish the circumstances and contexts within which PLHIV in Kisumu were diagnosed HIV positive. Second, it aimed at describing how PLHIV made sense of the diagnosis in terms of their initial reactions and how they reconciled themselves to a positive HIV status. Third, it examined how being diagnosed HIV positive affected their social relationships, their capacity to fulfil social obligations and their perceived sense of self. Fourth, the study examined the coping strategies PLHIV adopted in order to adapt to a life with HIV including the changes they instituted in their lives. Fifth, the research inquired into the difficulties that PLHIV faced in coping with and adapting to a positive HIV status.

Based on the methodology employed, which involved a triangulation of data collection methods (in-depth interviews, FGDs, and KIIs), sources (male and female participants and different age-groups) and settings (St. Joseph’s Nyabondo and JOOTRH), the PI is of the conviction that the objectives of the study have been achieved and the research questions have been answered. Triangulation helped produce mutually reinforcing participant accounts, corroborated by key informants, thus providing a more reliable basis for making inferences, interpretations and for drawing conclusions and recommendations. Through this process, the PI was able to generate a generalized account of what living with HIV meant for the participants. Cooperation with the health facility personnel and the extensive preparation prior to fieldwork made it possible for the whole research process to flow smoothly.

The validity of the findings can be demonstrated through the similar patterns identified during the coding and analysis process, irrespective of method, source or setting of data collection. The research methodology can be said to be valid and the findings trustworthy as they have been shown to resonate with the existing body of both theoretical and empirical literature. The findings substantiate and are also substantiated by the findings of other studies in this field. The theoretical frameworks adopted—symbolic interactionism and chronic illness trajectory model—as well as the unique concepts within the sub-field of sociology of health and illness with specific reference to living with chronic illness are also corroborated by this study.

The PI enhanced the quality and trustworthiness of the study by rigorous adherence to criteria accepted for evaluating qualitative research. These criteria included credibility, transferability, dependability and confirmability. These quality assurance efforts have yielded a number of strengths. One of the strengths included reliance on triangulation of methods, sources and settings already described above. The other was the preparatory field visit prior to field research that helped the PI to familiarize himself with the setting, create rapport with the gatekeepers, and identify potential pitfalls that could jeopardize quality and trustworthiness.

Nonetheless, some limitations were noted as well. The study was based on the accounts of the PLHIV and their health providers, and did not get opinions from members of the communities in which these people lived. There was also little opportunity to realize some of the recommended mechanisms for ensuring quality and trustworthiness such as member checking. However, other quality measures, including those already described above, were relied upon to overcome the limitations. Additionally, the PI gave a justification for every decision made pertaining to the research methodology and design. Moreover, the PI located the findings within the context of both the theoretical and empirical literature. As such, the study is not only an outcome of a rigorous methodological process but also resonates with and builds on the scientific literature on the experiences of living with HIV.

7.3 Being diagnosed HIV Positive

The study has demonstrated that PLHIV are diagnosed under a variety of circumstances and conditions but which can be mostly described as critical or emergency situations. It has also been shown that people are not accessing voluntary counselling and testing (VCT) in considerable numbers and as has been corroborated by KAIS, 2012, more than one-half of people infected with HIV are not aware of their HIV status. This also shows that people are not taking proactive steps to get to know their HIV status. This may call for strengthening, scaling up and intensifying of the strategies and best practices geared towards getting more people to know their HIV status.

Some of the strategies that need to be scaled-up include voluntary counselling and testing (VCT), prevention of mother-to-child transmission counselling and testing (PMTCT), provider-initiated testing and counselling (PITC) and home-based testing and counselling (HBTC). The main reasons or circumstances under which people get tested are related to personal illness, illness or death of a closely related family member such as spouse or child, in the event of pregnancy during antenatal visits, and also due to voluntary counselling. Even though the decision to be tested should be made by the competent individual himself, and that whereas this is mainly the case, there is evidence that the lay-referral system is equally influential in prompting such HIV testing decisions.

The advent of ARVs has brought with it a new perspective as far as the future for PLHIV is concerned. With increasing knowledge of how one can take care of him or herself coupled with the therapeutic benefits of good and well-balanced nutrition, physical exercises and psychosocial support from family, friends and relatives, one can live a long satisfactory life in spite of being HIV positive. The hope derived from the remedy made possible by ARVs has made the future look less frightening and more predictable even though the reality of death still cannot be ignored.

People diagnosed with HIV reacted differently to the information that they had tested HIV positive. Being diagnosed HIV positive is an example of a traumatic experience with the potential of disrupting the taken-for-granted assumptions of everyday life. As such, the kind of reactions PLHIV exhibited were consistent with reactions to other traumatic events. In the present study, the main reactions were acceptance of HIV test results, notions of immediate and imminent death, concerns about source of infection, shock, worry, fear, shame, painful feelings and suicidal thoughts. The fears about the future and worries about personal health and the well-being of dependent children were some of the key concerns of people diagnosed HIV positive.

Whereas a majority of the individuals accepted the diagnosis, a number went into denial and initially rejected the test results. Those who rejected the test results visited other health facilities for confirmatory tests believing that the equipment where they were initially tested might have been faulty. Some newly HIV diagnosed subjects did not experience any negative emotion such as shock and fear but received the information calmly and without shock. Such people were invariably content that there was something that could be done for their illness condition. In sum, the study suggested possible links between the circumstances under which a person is tested and their reactions to test results and subsequent reconciliation to a positive HIV status.

The participants viewed acceptance as the most crucial turning point in coping with and adapting to a life with HIV. The path to acceptance was different for different participants, but the majority immediately accepted their status when informed of the HIV positive test results. This was after they were counselled and informed about the availability of care and treatment, a pointer to the relative robustness of the health and counselling programs. Besides psychosocial counselling and emotional support from the PSCs, an accommodative atmosphere within the home and the community equally made acceptance and enrolment into treatment and care a pragmatic option.

Normalization mentalities, whereby the participants viewed HIV as no unique condition and realized they were not the only ones infected, also aided reconciliation. The perception that HIV was a more widespread human tragedy and the concern for the present and future well-being of their children were other critical considerations influencing the PLHIV to reconcile to their status. PLHIV were motivated to live as long as possible in order to help equip their children for the future.

Additionally, the state of one's physical health was a critical consideration in realizing adaptable health outcomes. Studies have found a link between health status and perception of self. This study suggests that a state of good health made it possible for PLHIV to continue with or to resume a normal and routine way of life. The study argues further that one who is physically healthy is less dependent on others for their basic needs and that self-reliance enhanced the sense of self-control over one's life—a critical consideration for a positive self-image. Availability, accessibility and affordability of ARVs as well as other drugs to counter opportunistic infections were therefore critical components of adaptive coping as they enabled PLHIV to participate actively in social life.

7.4 Effects of HIV on the Lives of PLHIV

It can be concluded that HIV has a number of effects on the lives of PLHIV arising from their HIV status. These effects relate to their social relationships, their capacity to fulfil their social obligations and their perceived sense of self. Three main effects on social relationships were identified. First, a number of relationships remained stable and did not realize any disruptions. The PLHIV reported observing no remarkable differences in their present interrelations with others compared to their pre-diagnostic status. Secondly, some experienced worsened social relationships marked by stigma and discrimination that seemed to affect widows more than the other categories of participants. Stigma and discrimination took the form of desertion, rejection and abandonment. They were also insulted and ridiculed by their family members and acquaintances.

Thirdly, some PLHIV restructured their social relationships and interaction patterns in adjusting to the effects of the stigmatization and discrimination they experienced. This involved creating new relationships, mostly with other PLHIV, and reducing the significance of other relationships and associations, especially those they no longer found beneficial. Some PLHIV ended up isolating themselves from social interaction altogether, in spite of the potential negative impacts of isolation on coping. Fourthly, other participants noted improvements in their relationships, observing that family members, relatives and friends became closer, showed them more love and interacted with them more intensely.

PLHIVs capacity to fulfil their social obligations was also affected, either positively or negatively. The first group of participants involved those whose capacity to fulfil social obligations remained intact and were therefore largely unaffected by illness. These participants were either those who had not suffered from the debilitating effects of HIV or those who had recovered from such effects through enrolment into treatment. The second group comprised those who had regained their capacity to fulfil social obligations. This category included those who had been bedridden and so severely affected by the illness. However, after knowing their status and being enrolled into treatment, they regained a state of normal functioning and could perform their daily activities effectively. Despite being enrolled on medication and responding well to treatment, the third group experienced diminished capacity to perform their duties effectively compared to the past.

Regarding perceived sense of self, most participants experienced being HIV positive as a new and delicate phase of existence that required care and caution concerning their lives. The first main effect was the perceived retention of a stable sense of self. These participants considered themselves to be okay, normal, healthy and mentioned not seeing any change in their lives. The second main effect included the experience of a disrupted sense of self, mostly related to perception of altered bodily conditions. This group comprised those who mentioned being unable to gain weight, having insufficient physical strength to perform their duties as before and feeling socially insecure.

The final main effect comprised the experience of a restored or enhanced sense of self. These participants had realized remarkable improvements in their health after suffering from minor to severe episodes of on-and-off illness and were invariably those who had regained the strength to fulfil their social obligations, and their physical form such as the shape of the body, and physical vitality. The recovery of the body enabled some participants to regain capacity to be engaged in social activities and interactions. As such, they were able to reintegrate into the life of the community. Enhanced perception of self arose from observed elevated social standing and usefulness of such participants to the community, especially whenever they could be consulted by families with members suffering from HIV-like symptoms. They also provided health education to individuals, families and the entire community, encouraging them to get tested and to assume responsibility for their own health.

7.5 Coping Strategies adopted by PLHIV

The participants adopted six main coping strategies. First, they employed psychosocial and emotional strategies. These included disclosure or non-disclosure of their HIV status to significant others. Disclosure could help create a conducive atmosphere for adherence, free from stigmatization and discrimination. They also learnt to avoid stress and to be contented with life as stress could lead to deterioration of their health status. PLHIV also benefited from counseling, which constituted an important element in coping for through counseling, they received information on how to live with and successfully respond to the challenges of HIV.

Second, some participants experienced an increased salience in their religious identity. They exercised faith and trust in God, and believed that he (God) would heal them, give them strength to face their struggles, protect and guide them, grant them length of life, and help them prosper in their endeavours. They also participated in religious activities such as joining church-related clubs (e.g. the choir).

Third, joining and participating in patient support groups was one of the key social coping strategies adopted by the participants. Through support groups, PLHIV had access to information on HIV/AIDS, ARV adherence, nutrition, and received psychosocial support and counseling. Social support groups also provided a forum for them to remain socially active as through these groups, the PLHIV created awareness about the disease and encouraged members of the wider community to get to know their status through testing.

Fourth, PLHIV also practiced adherence to medication and clinical appointments and reduced their consumption of alcohol and drugs. They took their medication as prescribed by the health personnel and attended their clinical appointments as scheduled. The participants have been educated and counseled and are aware of the benefits of these regimen-related practices especially in so far as suppressing the viral load and ensuring optimal clinical and medical outcomes are concerned. The participants understood the link between well-balanced diets and efficacy of the medications they were using. Consequently, PLHIV strictly adhered to ART and clinical appointments. The participants abstained from or reduced the use of alcohol and other substances of abuse. Due to the dangers associated with such behaviour—e.g. promotion of risk-taking behaviour—the PLHIV realized that for them to live well with HIV, they had to give up such habits.

Fifth, they adopted strategies aimed at enhancing their livelihoods. For them to live successfully with HIV, realize the goal of viral suppression and have an enhanced quality of life, PLHIV undertook steps to ensure self-sufficiency in providing for their daily needs. These measures included carrying on with normal daily activities such as continuing in employment, and working in their farms or in other enterprises such as business. A number of PLHIV also reported producing their own food, especially those that had access to arable land. Production of their own food enhanced food and nutritional security for both themselves and their households. PLHIV also engaged in income-generating activities (IGAs) including agribusiness, bricklaying, and welding. IGAs were considered a surer source of livelihood support by those who engaged in such activities.

Sixth, the participants recognized the risk of reinfection with other strains of HIV, which could trigger drug resistance, and consequently adopted safe sexual behaviours that encompassed protected sexual intercourse, abstinence, reduction in number of sexual partners and marital fidelity.

Concerning the difficulties faced in coping with a positive HIV status, it can be concluded that because chronic illness has the potential of undermining a person's sense of self and of challenging the taken-for-granted conceptions of social reality, PLHIV are confronted with an enormous struggle to regain a sense of normal functioning. Coping therefore represents an endless struggle to present a positive and normal image of both the body and of the self to the society. Coping could be made lighter if an accepting and accommodating atmosphere was provided by the family, friends, relatives and the wider community. Such an atmosphere would give the PLHIV a sense of belonging, dignity and worth and the perception of being seen as normal as everyone else. Although participants perceived that stigma and discrimination were declining and that substantial numbers of community members demonstrated greater sensitivity, still some PLHIV experienced stigma and discrimination within the community.

Among the key challenges facing PLHIV was the lack of reliable incomes and proper means of livelihood. Evidently, due to their illness and the associated contingencies, PLHIV and their families were often not in a position to provide for themselves the basic necessities of life. PLHIV lacked sufficient income for meeting expenses, such as paying school fees for their children and paying transportation costs to collect medications or to attend clinical appointments. Lack of incomes and proper means of livelihood was often linked either to widespread poverty, lack of access to productive resources, difficult economic times or to adverse climatic conditions. The PLHIV therefore need support in the form of food supplements, social cash transfers, food tickets or vouchers and food for work programmes to enable them access basic needs.

7.6 Recommendations for Public Health Policy and Programming

For a person diagnosed with HIV to adapt effectively and live positively with HIV, certain conditions need to obtain within the society. However, society is not always ideally structured to the needs of people diagnosed with HIV. Consequently, a life with HIV is a continuous struggle to survive in an uncertain and threatening environment. Deliberate efforts can be made by key players in society such as the government, civil society organizations and PLHIV to help ensure that the conditions that hinder adaptive coping are minimized.

As the findings of this study have shown, and as has been corroborated by both empirical and theoretical literature, people with chronic illness need the support of others in their social world to help them adapt to and cope with the disruptions, emotional consequences, effects and difficulties arising from their status. The health care and other social systems are often not well equipped to respond to the unique needs of the PLHIV. On a brighter note, literature shows that a lot is currently being done at the international and local levels to address the problems associated with HIV and AIDS and to relieve the suffering, especially of PLHIV. The recommendations proposed suggest ways of addressing some of the difficulties faced by PLHIV and how response to HIV can be made more robust.

7.6.1 Social Support and Social Capital

To ensure a good quality of life for PLHIV, there is need for members of society to confront some of the attitudinal and social barriers that may hinder this task. The barriers that need to be confronted include the social definitions of what it means to be healthy. Often, it is taken for granted that the normal condition is that people always ought to be in an excellent state of health and to retain the capacity to be productive, to be engaged in work as well as to be able to live a normal life. This definition tends to exclude those who are not in an optimal state of health thereby making them vulnerable to stigma and discrimination.

The other barrier is that the society is apathetic and lacks sensitivity and sympathy to the needs and difficulties chronically ill people. Mobilization of social capital is important as a way of responding to the physiological and mundane needs as well as other material and non-material resources required to help PLHIV address their needs. In this regard, helping PLHIV realize a healthy outcome would call for mobilization and education of the entire society, including health care providers and other professionals so that they become more knowledgeable about and responsive to the needs of PLHIV. To achieve this, there is need for community education and enhanced participation and inclusion of all key actors including support groups and social networks of PLHIV.

As such, measures should be taken to create HIV/AIDS-related awareness and to sensitize and mobilize the general population to help scale-up the continuum of care. The HIV continuum of care includes prevention, treatment, care and support, reduction of stigma and discrimination, provision of critical life skills and community empowerment. The goal of these efforts should be to help all members of society realize positive health outcomes irrespective of HIV status.

7.6.2 Community Information and Education

The fact that HIV is communicable makes it a serious public health issue. Success in dealing with HIV requires addressing the dynamics of the social interactions that foster its transmission. There is therefore the need for education of the entire community to make them aware of the objective facts about HIV. The key issues about HIV and AIDS to be addressed should include the modes of transmission, the means of prevention, and care, support and treatment. Such awareness creation should equip the communities with knowledge, skills and attitudes to help them adopt health protecting behaviours and thereby avoid or reduce infection and reinfection for those already infected.

It is recommended that programs targeting community members with awareness and information of HIV should also emphasize details about benefits of early testing and enrolment into ART. This is informed by the fact that if detected early, people diagnosed HIV positive can be able to control the course of the disease, delay onset of full-blown AIDS and retain normal functioning. In this regard, efforts and programmes should be in place to encourage the lay-referral system to take an active part in encouraging community members suffering from recurrent and inexplicable illness conditions to get tested. Linkages should also be made to alternative health care providers such as herbalists and private facilities in order to foster HIV test-seeking behaviour.

PLHIV are facing a tremendous struggle to maintain a certain sense of control and self-worth. They are struggling against enormous odds to project and portray a sense of being the same like the rest of society. A great effort at training the community, health care providers and professionals, communities and the PLHIV so as to help enhance systemic capacities to deal with HIV is therefore necessary. In this regard, innovative programmatic ideas appropriate for resource poor settings should be crafted. This could include enhancing home-based care for PLHIV which is a way of helping relieve the burden on health systems and reducing costs to communities and families (Kaplun-Le Meitour 1992).

The need for continuous education also calls for regular and participatory reviews of HIV and AIDS information, education and communication (IEC) materials and curricula. The reviews of IEC materials and curricula should take into account the dynamic nature of the definitions of HIV both within the community and society. Development and review of IEC materials and curricula may mean targeting particular segments of the population, or regions of the country to take into account the contextual variations that may not be addressed by generalized approaches. The IEC materials and curricula should be so packaged that they are sensitive to the circumstances of PLHIV and limit potential to further alienate PLHIV. With effective ongoing community education on the facts and meanings of life with HIV, the levels of stigma and discrimination are likely to go down considerably.

7.6.3 Participation and Inclusion

PLHIV indicated having various needs and difficulties that cannot be met by the solitary efforts of discrete institutions. Addressing the needs of PLHIV require the concerted involvement of families, networks and support groups of PLHIV, networks of religious leaders, and religious organizations, the health system and other public and private sector organizations. The involvement of the aforementioned social institutions is essential in supporting development of IEC materials and curriculum and in implementing programs to help create enduring partnerships, strengthen community resources and community capacities and support members affected and infected with HIV.

Active and participatory involvement of educational institutions, education managers, teachers, and learners in the entire continuum of care and management of HIV is also essential if schools and other learning institutions are to be transformed into friendly and safe environments. In this sense, life with HIV is a public health issue that calls for far-reaching partnerships to create a conducive social atmosphere for adapting to and coping with HIV. Effective partnerships require active engagement between the various actors in HIV on the one hand and the communities to which the PLHIV are members on the other.

7.6.4 Livelihood and Economic Empowerment

Helping PLHIV stay healthy longer could have both public health and social benefits. For instance, helping parents with HIV live longer may help alleviate the burden of orphans as their children would continue to have a secure livelihood as long as these parents are alive. Therefore in the long-term, the national and county governments, in collaboration with CBOs, FBOs and other civil society organizations, should work to ensure PLHIV have sustainable livelihoods. This goal could be achieved through deliberate efforts aimed at empowering CBOs, for example, through seed funding to enable them engage in IGAs. There should also be deliberate efforts to economically empower PLHIV to enable them have sustainable access to adequate nutrition and to acceptable standards of living.

Consequently, capacity assessment of CBOs and support groups dealing with matters of PLHIV should be conducted, so as to ascertain their gaps and needs and to help fill in the gaps identified. PLHIV recognize that they still have a role to play to support themselves and their families and as such, successful efforts would be those targeted at making them self-reliant. Efforts to make PLHIV self-reliant would enhance their perception of self thereby boosting the control they can exercise over their life circumstances.

Because the resources of PLHIV could have been overstretched either due to the struggle to secure treatment for themselves or for their loved ones, or due to loss of productive capacity as a result of illness, the government should in the short-term support families of PLHIV in concrete terms. One way is by ensuring that the children of PLHIV are supported through school. In this sense, the government can put in place targeted programmes to support PLHIV educate their children through social cash transfers, fee waivers, and school bursaries and through provision of school materials such as books, uniforms and other necessary school supplies. The national and county governments could also provide employment quotas for PLHIV or some sort of work programs to engage PLHIV so that they have an opportunity to earn a livelihood.

One of the coping strategies adopted by PLHIV was engagement in livelihood enhancement strategies, such as producing their own food. As such, efforts aimed at empowering PLHIV and their families to produce food to meet their household nutritional needs could be another short- and medium-term intervention in supporting them with their coping strategies. Such support to PLHIV would go a long way in helping them respond better to medication and thus enhance adherence and ensure desirable clinical and health outcomes. Moreover, research has shown that supporting PLHIV in resource poor settings like Kenya with agricultural resources—such as farm inputs, seeds, fertilizers and dairy animals—can be pivotal in helping them to reconstruct their lives and rejuvenate their means of material well-being (Medley et al. 2009; Anderson et al. 2009; Russell, Seeley 2010; Liamputtong et al. 2012).

7.6.5 Education and Attitude change for Health Care Workers

Because HIV is a multi-faceted and potentially stigmatizing illness, there is need for a review of medical school curriculum to bring HIV care, treatment and management to the mainstream of medicine. The goal of medical curriculum review efforts should be the full integration of HIV into the core of medical care provision as opposed to the current status where it is considered in isolation and granted a different status. Given that HIV has been transformed from an acute condition and become a generalized chronic epidemic in Kenya, it should no longer be granted a separate status. The continued isolation of HIV to special clinics (PSCs) seems no longer valid and therefore may be unjustified. For the drive towards integration to succeed, it should begin by revising medical school curricula to ‘normalize’ HIV and treat it like the other medical conditions such as malaria and tuberculosis.

There is also the need to empower and sensitize healthcare workers through regular refresher trainings with a view to enhancing continuous attitudinal change among them towards PLHIV. The emphasis should be on the fact that PLHIV are in greatest need of the sympathies and support of fellow human beings. PLHIV have great hope in the efficacy of ART and high regard for the health care system and believe that the health system can provide a solution to their condition. This high regard and trust in the capacity of health care personnel to provide unrivalled clinical and nursing care is evidenced in PLHIV's commitment to adhere to the instructions and prescriptions of the medical workers. For instance, PLHIV take their medications on time, adhere to the prescriptions and honor clinical appointments. Health care workers can thus help by being considerate, compassionate and sympathetic and by appreciating the traumatic nature of being diagnosed HIV positive. Such an attitude can only be acquired through regular refresher training and sensitization workshops.

7.6.6 Improving the Health Care Services and Infrastructure

There is need for the government to increase the numbers of health care workers, especially given the fact that HIV is still increasing and the fact that PLHIV are living longer. There is bound to be more demand for treatment and care services. The revision of the WHO guidelines concerning when PLHIV should be enrolled into ARVs (a CD4 count of ≥ 350) means there will be more people requiring prolonged treatment and care (World Health Organization, 2013). Therefore, there is need for a trained corpus of medical workers, versatile in HIV matters. Besides improving the curriculum to 'normalize' HIV, there is need for training of more health workers of different cadres (e.g. nurses, surgeons, physicians, pediatricians, and gynecologists) who are fully equipped to address HIV-related health matters.

7.6.7 Ensuring Sustainability of Anti-retroviral Treatment

The study demonstrated the effectiveness of ART in helping the PLHIV recover from severe illness episodes even enabling some who had been bedridden to resume normal functioning. Those who reported on-and-off illness also recovered substantially. It is therefore the recommendation of this study that mechanisms be devised to ensure the sustainability of treatment. Deliberate efforts also need to be made to establish the role of alternative treatment options, especially herbal-based ones, as a way of ensuring sustainability. Alternative, plant-based remedies could have potential benefits due to the possibility that they could have less side effects compared to HAART. Moreover, such therapies could be locally produced in Kenya. Because local production could help reduce the expenditure on procurement, manufacturing and transportation of ARVs—which consume most of the funds allocated to HIV programmes—it provides a good platform for enhancing sustainability.

On a budgetary and practical level, sustainability of HIV care and treatment needs to be fully taken up by both the national and county governments. Presently, the treatment of PLHIV is largely dependent on international initiatives such as those supported under the auspices of the Global Fund, United States Agency for International Development (USAID), and private foundations such as the Bill and Melinda Gates Foundation and the Clinton Foundation. Even if HAART is still to be sourced through these foundations, the counties and the national government ought to still look into how HIV management can be made more sustainable.

7.7 Recommendations for Further Research

From the findings and the discussion of the study, a number of recommendations are made with regard to further research. First, a comparative study is needed between counties with varying HIV prevalence. The findings from such a study would provide information to enable low-prevalence counties initiate proactive measures to promote a healthy HIV test-seeking behaviour and address the realities of living with HIV among their residents. The present qualitative study could act as a springboard for generation of hypotheses for a wider mixed-method approach to document experiences of PLHIV across the spectrum of age, gender, socio-economic status, and place of residence.

Second, an in-depth study is needed to look into the health-seeking behaviour of PLHIV—especially the circumstances surrounding HIV diagnosis and enrolment into care. Such a study could inquire into the barriers and facilitating factors to access and motivations for continued use of ART services. This in-depth study could also look into the role of the lay-referral systems and other actors in the health sector—such as support groups of PLHIV, CBOs, FBOs and NGOs—in facilitating access to testing and counseling services.

Third, a nationwide, cross-sectional study is needed to inquire into community attitudes towards life with HIV and towards stigma and discrimination. Such a study would help gauge the knowledge of the community members pertaining to the basic facts of HIV and their definitions of health and well-being. The findings of such a study would provide useful baselines for development of programmes and initiatives to provide care for PLHIV and for development and review of HIV training curriculums and IEC materials.

Finally, a cohort study that follows PLHIV through their illness course would be essential to help document the transitions through the illness trajectory. Such a study would be vital in helping detail the various needs of PLHIV and their families and thereby, the disruptions and effects of HIV in the lives of PLHIV and the difficulties that PLHIV face. Such a study would also provide the necessary knowledge to health care providers on the kind of preparations necessary to address the needs of PLHIV through the illness course.

7.8 Chapter Summary

This seventh and final chapter of the study dealt with the conclusions and recommendations arising from the research findings. PLHIV were diagnosed under four main conditions of personal illness, illness or death of spouse or child, antenatal care and public health campaigns. The participants reacted differently to diagnosis with the main reactions being acceptance, shock, fear, notions of immediate and imminent death and suicidal thoughts. The participants of the study were prompted to reconcile to their status by receiving counseling and psychosocial support, having an undying quest for health and longevity, and being concerned about the present and future well-being of their children.

The main coping strategies adopted were psychosocial and emotional, relying on faith and religious beliefs, maintaining active social engagement including joining support groups, adopting health strategies, enhancing their livelihoods including producing their own food, and adopting safe sexual behaviours. The PLHIV reported facing a number of barriers to coping that included lack of proper means of livelihood, lack of access to adequate food and nutrition, stigma and discrimination and difficulty in providing an education for their children.

For PLHIV to successfully cope with and adapt to a positive HIV status, certain conditions in the society as well as in the lives of PLHIV are necessary. These include a good state of health, presence of strong social support networks, an accepting and accommodating social environment, the presence of children and hope for the future. A desirable social environment is one in which there is less stigma and discrimination and in which social, spiritual, emotional and mental needs of the PLHIV are met. Such an environment can make it possible for PLHIV to resume their normal lives, accomplish their life dreams and have their basic needs of everyday life guaranteed. This may require the contribution of various stakeholders in the society to help supplement the resources that the affected families may have. A conducive environment would also enhance the willingness of the general community to know their HIV status and thereby effectively take control of their own lives and plan for their futures.

Arising from all this, the study has recommended that a number of policy and programmatic options be considered by the various stakeholders. These recommendations include providing psychosocial and emotional support to PLHIV and their families, increasing social support and social capital, scaling up community information and education, ensuring wide-ranging participation and inclusion of all stakeholders including PLHIV in policy and programmatic interventions, enhancing livelihood and economic empowerment for PLHIV and their families, reviewing the training and enhancing attitude change among health workers and health care providers, improvement of the health care services and infrastructure and ensuring sustainability of ART.

Further research is recommended to generate comparative data between counties with disparate HIV prevalence rates so as to document any significant differences in the experiences of living with HIV. Studies are also needed that document the health seeking behaviour of PLHIV, and that inquire into and document the health definitions and attitudes of communities with regard to life with HIV. Finally, cohort studies are needed that generate information on living with HIV through the illness trajectory.

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APPENDICES

Appendix I: PLHIV Qualitative Interview Consent Forms.

My name is George Evans Odero Owino, a doctoral student from the University of Bielefeld, Germany. I am doing a research on a study entitled "***Illness Experiences and Self-Identity of People Living with HIV in Kisumu County, Kenya***." The purpose of the study is to find out the implications and the meanings of being infected with HIV for PLHIV in Kisumu County. The study also seeks to find out the effects of a life with HIV on the daily lives and routines of PLHIV, how they cope and the challenges they face in coping with HIV. This study is scientifically guided by the university and ethically approved by the Kenyatta University Ethical Review Board. For any question, I can be contacted at the following address:

George Evans Odero Owino, Department of Public Health Medicine, School of Public Health,
University of Bielefeld, P.O. Box 100131 D-33501 Bielefeld, Germany.
E-mail:jauriri2007@gmail.com, gowino@uni-bielefeld.de, owino.george@ku.ac.ke.

Supervisors Contacts:
Dr. med. Dr. PH Reinhard Bornemann: Email: bornemann@uni-bielefeld.de.
Dr. Anne Kamau: E-mail: avwairimu@yahoo.com.

Kenyatta University-Ethical Review Committee - **Email:** kuerc.chairman@ku.ac.ke ,
kuerc.secretary@ku.ac.ke

Statement of study benefits: The findings of the study may be useful in helping generate knowledge on the experiences of PLHIV and provide useful information to the government and civil society organizations such as NGOs in designing programmes and providing services to PLHIV. There is no physical harm associated with the discussions. However, there may be emotional and psychological distresses as we discuss these issues together.

Assurance of Confidentiality: Further, I will undertake to ensure that the discussions will be kept strictly confidential and will be available only to members of the research team. I request that you grant me permission to audio-record the discussions for ease of transcriptions and accuracy in analysis and report-writing. After transcriptions, I undertake to erase all the audio-versions of this interview. Quotations from interview/individual results may be part of the final research report, but under no circumstances will your name or identifying characteristics be included in the report which will be submitted to the University for Examination or in any further publications thereafter.

Please sign this form to show that I have read the contents to you.

(Signature or thumb print)______________________Name:___________________Date:__________

Researcher's Signature____________________________Date:_____________________________

Right to Self Determination and rewards: Thank you for agreeing to take part in the project. Before we start, I would like to emphasize that: Your participation is entirely voluntary. You are free to refuse to answer any question; You are free to withdraw at any time and you will not be penalized, and denied any services or rewards for such withdrawal. You shall receive an appreciation for your time and to cover any costs such as travel amounting to Kshs. 300. There shall also be a snack after the session.

Appendix II: Consent Form for Key Informants

My name is George Evans Odero Owino, a doctoral student from the University of Bielefeld, Germany. I am doing a research on a study entitled "***Illness Experiences and Self-Identity of People Living with HIV in Kisumu County, Kenya***." The purpose of the study is to find out the implications and the meanings of being infected with HIV for PLHIV in Kisumu County. The study also seeks to find out the effects of a life with HIV on the daily lives and routines of PLHIV, how they cope and the challenges they face in coping with HIV. This study is scientifically guided by the university and ethically approved by the Kenyatta University Ethical Review Board. For any question, I can be contacted at the following address:

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Kenyatta University-Ethical Review Committee- **Email:** kuerc.chairman@ku.ac.ke,
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Statement of Study Benefits: The findings of the study may be useful in helping generate knowledge on the experiences of PLHIV and provide useful information to the government and civil society organizations such as NGOs in designing programmes and providing services to PLHIV. There is no physical harm associated with the discussions. However, there may be emotional and psychological distresses as we discuss these issues together.

Assurance of Confidentiality: Further, I will undertake to ensure that the discussions will be kept strictly confidential and will be available only to members of the research team. I request that you grant me permission to audio-record the discussions for ease of transcriptions and accuracy in analysis and report-writing. After transcriptions, I undertake to erase all the audio-versions of this discussion. Quotations from this interview results may be part of the final research report, but under no circumstances will your name or any identifying features be included in the report which will be submitted to the University for Examination or in any further publications thereafter.

Please give an oral consent to show that I have read the contents to you and that you agree that we continue with the discussion.

Signature (participants' representative):____________________Date:__________________

Researcher's signature: __________________________________Date:__________________

Right to Self Determination and rewards: Thank you for agreeing to take part in the project. Before we start, I would like to emphasize that: Your participation is entirely voluntary; You are free to refuse to answer any question.

Appendix III: Consent Form for Focus Groups

My name is George Evans Odero Owino, a doctoral student from the University of Bielefeld, Germany. I am doing a research on a study entitled "***Illness Experiences and Self-Identity of People Living with HIV in Kisumu County, Kenya***." The purpose of the study is to find out the implications and the meanings of being infected with HIV for PLHIV in Kisumu County. The study also seeks to find out the effects of a life with HIV on the daily lives and routines of PLHIV, how they cope and the challenges they face in coping with HIV. This study is scientifically guided by the university and ethically approved by the Kenyatta University Ethical Review Board. For any question, I can be contacted at the following address:

George Evans Odero Owino, Department of Public Health Medicine, School of Public Health,
University of Bielefeld, P.O. Box 100131 D-33501 Bielefeld, Germany.
E-mail:jauriri2007@gmail.com, gowino@uni-bielefeld.de, owino.george@ku.ac.ke.

Supervisors Contacts:
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Dr. Anne Kamau: E-mail: avwairimu@yahoo.com.

Kenyatta University-Ethical Review Committee- **Email:** kuerc.chairman@ku.ac.ke,
kuerc.secretary@ku.ac.ke

Statement of Study Benefits: The findings of the study may be useful in helping generate knowledge on the experiences of PLHIV and provide useful information to the government and civil society organizations such as NGOs in designing programmes and providing services to PLHIV. There is no physical harm associated with the discussions. However, there may be emotional and psychological distresses as we discuss these issues together.

Assurance of Confidentiality: Further, I will undertake to ensure that the discussions will be kept strictly confidential and will be available only to members of the research team. I request that you grant me and my team permission to audio-record the discussions for ease of transcriptions and accuracy in analysis and report-writing. After transcriptions, I undertake to erase all the audio-versions of this discussion. Quotations from this group discussion results may be part of the final research report, but under no circumstances will any names or identifying characteristics of this group or any of its members be included in the report which will be submitted to the University for Examination or in any further publication thereafter.

Please give an oral consent to show that I have read the contents to you and that you agree that we continue with the discussion.

Signature (participants' representative):____________________Date:__________________

Researcher's signature: __________________________________Date:__________________

Right to Self Determination and rewards: Thank you for agreeing to take part in the project. Before we start, I would like to emphasize that: Your participation is entirely voluntary; You are free to refuse to answer any question; You are free to withdraw at any time and you will not be penalized, and denied any services or rewards for such withdrawal. You shall receive an appreciation for your time and to cover any costs such as travel amounting to Kshs. 300. There shall also be a snack after the session.

Appendix IV: PLHIV Qualitative Interview Guide

1. How did you get to know about your HIV status? (**Probe:** for length of time, circumstances under which they got to know and place-facility where they got information).
2. How did you initially react when you got to know of your status? (**Probe:** thoughts, actions, feelings).
3. How did you reconcile/relate to the idea that you were HIV positive?
4. Which people, if any, know or have you disclosed your status to? (**Probe:** reasons for the disclosure, process of disclosure, outcomes of disclosure)
5. What changes, if any, have you observed in your relationships with others due to being HIV positive? (**Probe:** for relations with siblings, parents, spouse, children, and friends).
6. What effects or changes, if any, have occurred in your ability to fulfill your social obligations? (**Probe:** daily routines of life; productive activities or occupational roles; social roles-parent (mother/father).
7. What effects, if any, has being diagnosed with HIV brought to bear on your sense of self (**Probe:** for future in terms of life dreams/plans; their past; beliefs/thoughts about self (who she/he believes she/he is; self-worth).
8. What, if any, do you consider as significant losses as a result of being HIV positive?
9. What are some of the ways through which you cope/manage to live an HIV positive status? (**Probe:** adjustments, activities engaged in, activities avoided, precautions taken, kinds of health services utilized, people confided in; things found meaningful, things found meaningless).
10. What challenges do you face in your attempt to live a normal life? (**Probe:** most significant challenges; How the challenges are overcome)
11. What are some of your ideas on how life could be made easier for PLHIV? (**Probe**: roles of community, role of PLHIV themselves, roles of affected family, role of the government, role of the church, CBOs, NGOs).

Appendix V: Focus Group Discussion Guide

1. Under what circumstances do people normally get to know about their HIV status? (**Probe:** for length of time, circumstances under which they got to know and place-facility where they got information).
2. What are some of the initial reactions when one gets to know of their HIV status? (**Probe:** thoughts, actions, feelings).
3. How do people reconcile to or live with the idea that they are HIV positive?
4. Which people, if any, get to know or do people diagnosed with HIV disclose their status to? (**Probe:** reasons for the disclosure, the process of disclosure, outcomes of disclosure)
5. What changes, if any, occur or are observed in a person's social relationships due to being HIV positive? (**Probe:** for relations with siblings, parents, spouse, children, and friends).
6. What changes, if any, occur in a person's ability to fulfill his/her social obligations? (**Probe:** daily routines of life; daily routines of life; social roles-parent (mother/father).
7. What effects, if any, does being diagnosed with HIV have on a person's sense of self (**Probe:** for future in terms of life dreams/plans; their past; beliefs/thoughts about self (who she/he believes she/he is; self-worth).
8. What are the common ways through which a person diagnosed with HIV cope or manage to live with an HIV positive diagnosis? (**Probe:** activities engaged in, activities avoided, precautions taken, kinds of health services utilized, people confided in; things found meaningful, things found meaningless).
9. What challenges does a PLHIV face in the attempt to live a normal life? (**Probe:** most significant challenges; How the challenges are overcome)
10. What are some of your ideas on how life could be made easier for PLHIV? (**Probe:** roles of community, role of PLHIV themselves, roles of affected family, role of the government, role of the church, CBOs, NGOs).

Appendix VI: Key Informant Interview Guide

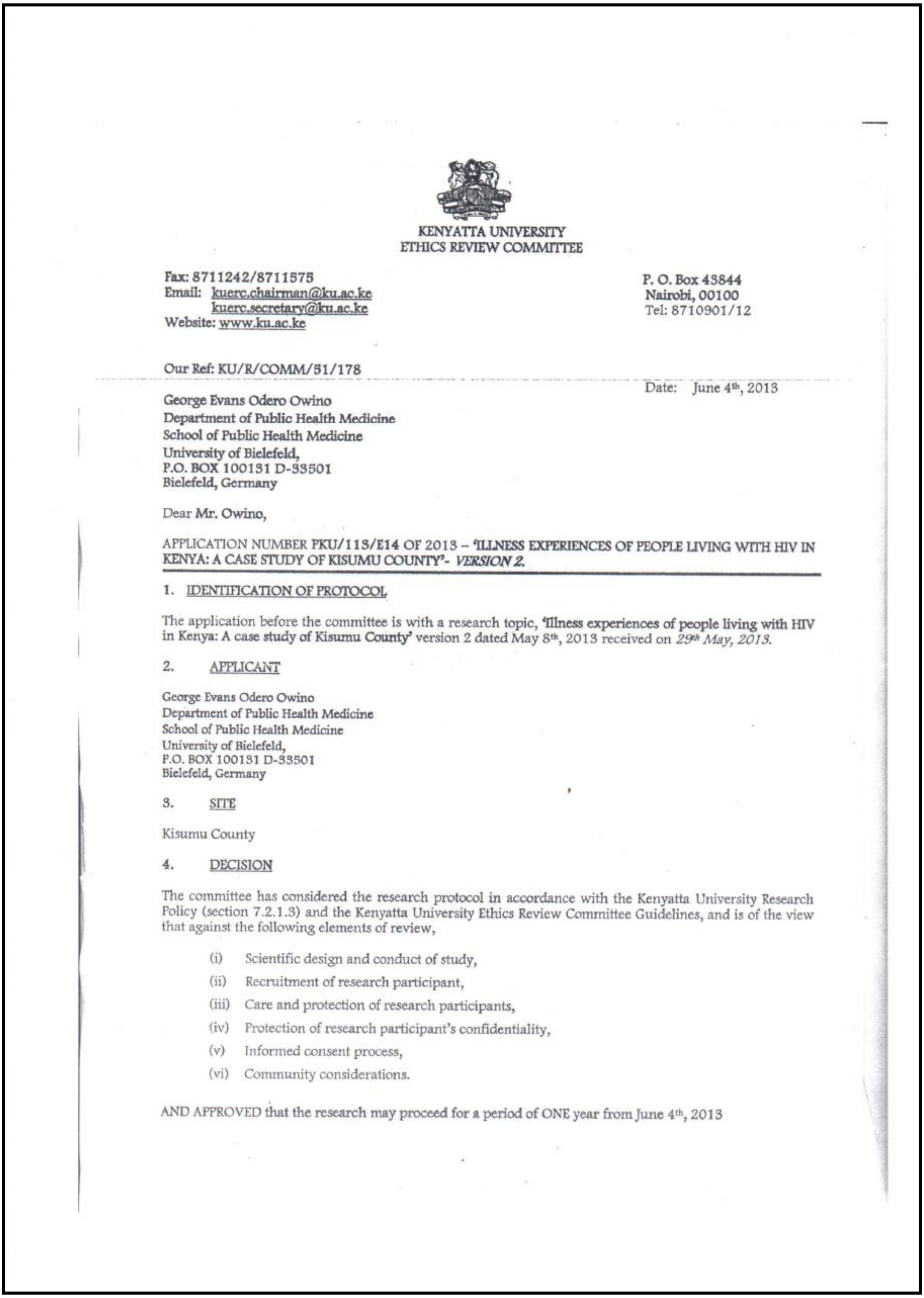
1. Under what circumstances do people normally get to know about their HIV status? (**Probe:** for length of time, circumstances under which they got to know and place-facility where they got information).
2. What are some of the initial reactions when one gets to know of their HIV status? (**Probe:** thoughts, actions, feelings).
3. How do people reconcile to or live with the idea that they are HIV positive?
4. Which people, if any, get to know or do people diagnosed with HIV disclose their status to? (**Probe:** reasons for the disclosure, the process of disclosure, outcomes of disclosure)
5. What changes, if any, occur or are observed in a person's social relationships due to being HIV positive? (**Probe:** for relations with siblings, parents, spouse, children, and friends).
6. What changes, if any, occur in a person's ability to fulfill his/her social obligations? (**Probe:** daily routines of life; daily routines of life; social roles-parent (mother/father).
7. What effects, if any, does being diagnosed with HIV have on a person's sense of self (**Probe:** for future in terms of life dreams/plans; their past; beliefs/thoughts about self (who she/he believes she/he is; self-worth).
8. What are the common ways through which a person diagnosed with HIV cope or manage to live with an HIV positive diagnosis? (**Probe:** activities engaged in, activities avoided, precautions taken, kinds of health services utilized, people confided in; things found meaningful, things found meaningless).
9. What challenges does a PLHIV face in the attempt to live a normal life? (**Probe:** most significant challenges; How the challenges are overcome)
10. What are some of your ideas on how life could be made easier for PLHIV? (**Probe:** roles of community, role of PLHIV themselves, roles of affected family, role of the government, role of the church, CBOs, NGOs).

Appendix VII: Basic Data Demographic Sheet for PLHIV

This is to be filled for before the interview questions begin addressed as a way of creating rapport. (**Tick** the option that best applies)

1) Gender
    a) Male [ ]
    b) Female [ ]
2) Age in years
    a) 18-25 [ ]
    b) 26-35 [ ]
    c) 36-45 [ ]
    d) 46-and above [ ]
3) Education
    a) Primary and below [ ]
    b) Up to Secondary [ ]
    c) College and above [ ]
4) Monthly Income (in Kshs)
    a) 0-5,000 [ ]
    b) 5,001-10,000 [ ]
    c) 10,001-and above [ ]
5) Marital Status
    a) Single [ ]
    b) Married/constant partnership [ ]
    c) Divorced/living separated [ ]
    d) Widowed [ ]

Appendix VIII: Ethical Approval (Kenyatta University)



KENYATTA UNIVERSITY
ETHICS REVIEW COMMITTEE

Fax: 8711242/8711575
Email: kuerc.chairman@ku.ac.ke
kuerc.secretary@ku.ac.ke
Website: www.ku.ac.ke

P. O. Box 43844
Nairobi, 00100
Tel: 8710901/12

Our Ref: KU/R/COMM/51/178

Date: June 4th, 2013

George Evans Odero Owino
Department of Public Health Medicine
School of Public Health Medicine
University of Bielefeld,
P.O. BOX 100131 D-33501
Bielefeld, Germany

Dear Mr. Owino,

APPLICATION NUMBER PKU/113/E14 OF 2013 – **'ILLNESS EXPERIENCES OF PEOPLE LIVING WITH HIV IN KENYA: A CASE STUDY OF KISUMU COUNTY'- *VERSION 2.***

1. IDENTIFICATION OF PROTOCOL

The application before the committee is with a research topic, **'Illness experiences of people living with HIV in Kenya: A case study of Kisumu County'** version 2 dated May 8th, 2013 received on *29th May, 2013.*

2. APPLICANT

George Evans Odero Owino
Department of Public Health Medicine
School of Public Health Medicine
University of Bielefeld,
P.O. BOX 100131 D-33501
Bielefeld, Germany

3. SITE

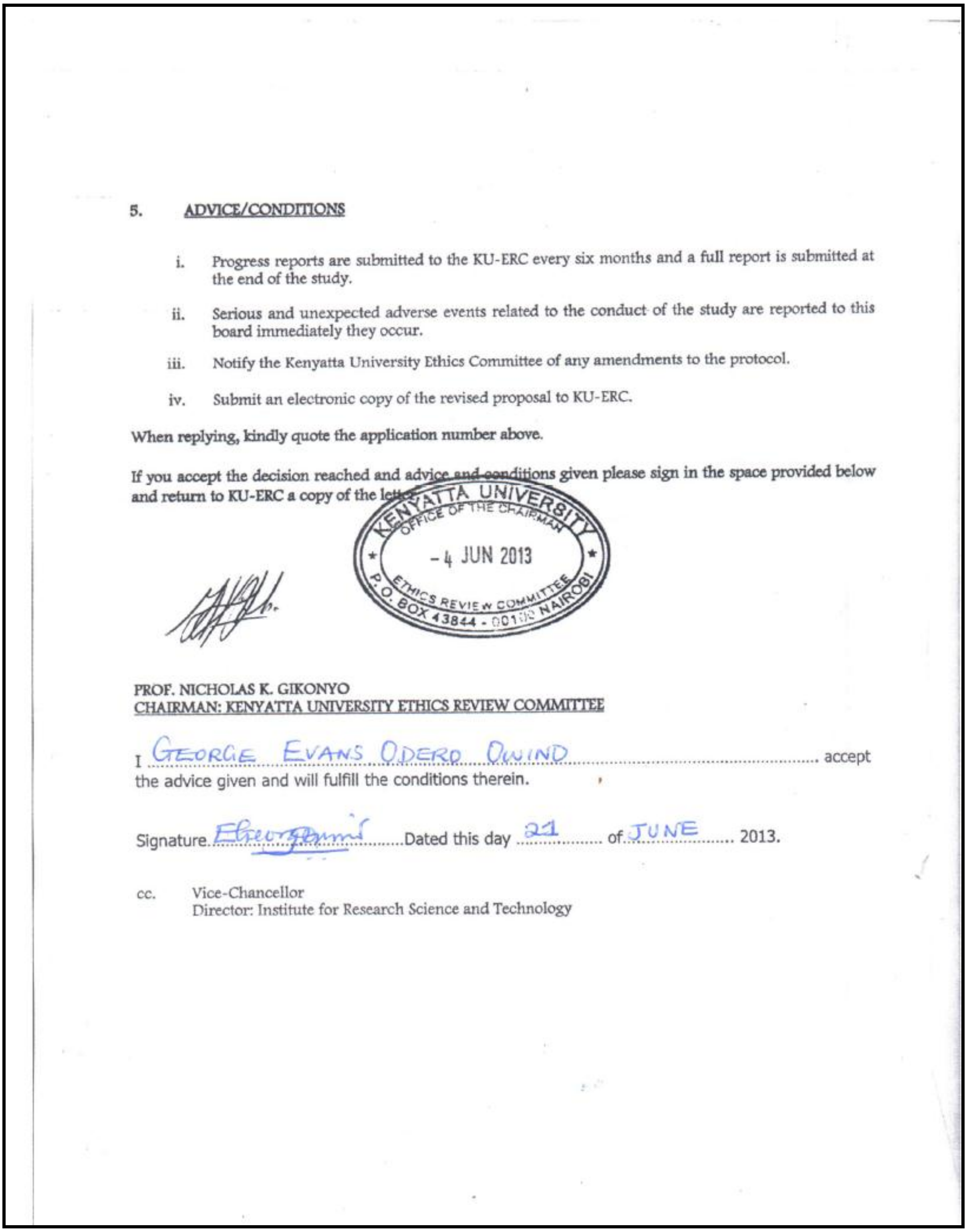
Kisumu County

4. DECISION

The committee has considered the research protocol in accordance with the Kenyatta University Research Policy (section 7.2.1.3) and the Kenyatta University Ethics Review Committee Guidelines, and is of the view that against the following elements of review,

(i) Scientific design and conduct of study,
(ii) Recruitment of research participant,
(iii) Care and protection of research participants,
(iv) Protection of research participant's confidentiality,
(v) Informed consent process,
(vi) Community considerations.

AND APPROVED that the research may proceed for a period of ONE year from June 4th, 2013



5. **ADVICE/CONDITIONS**

i. Progress reports are submitted to the KU-ERC every six months and a full report is submitted at the end of the study.

ii. Serious and unexpected adverse events related to the conduct of the study are reported to this board immediately they occur.

iii. Notify the Kenyatta University Ethics Committee of any amendments to the protocol.

iv. Submit an electronic copy of the revised proposal to KU-ERC.

When replying, kindly quote the application number above.

If you accept the decision reached and advice and conditions given please sign in the space provided below and return to KU-ERC a copy of the letter.

- 4 JUN 2013

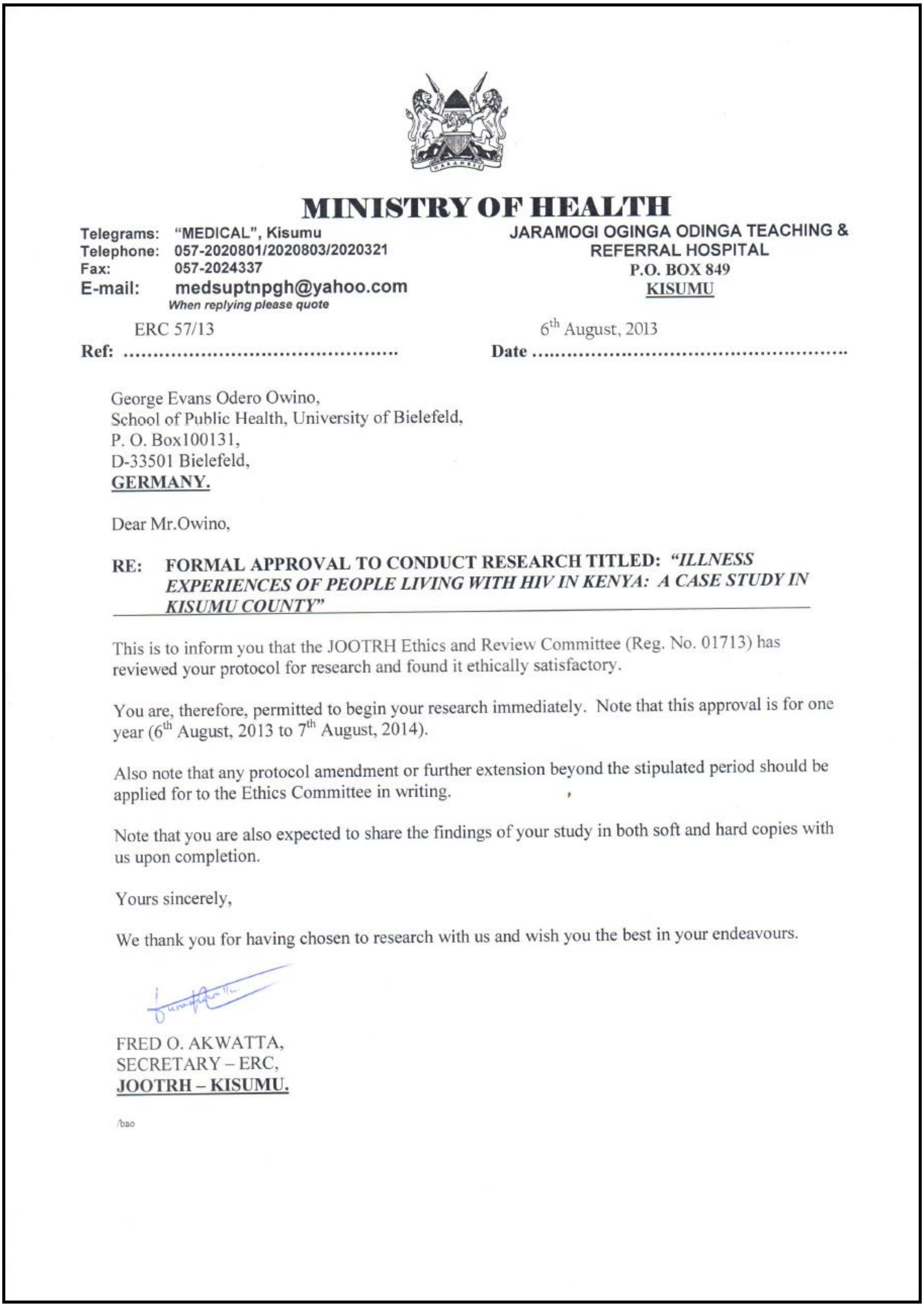
PROF. NICHOLAS K. GIKONYO
CHAIRMAN: KENYATTA UNIVERSITY ETHICS REVIEW COMMITTEE

I GEORGE EVANS ODERO OWINO accept the advice given and will fulfill the conditions therein.

Signature..................Dated this day 21 of JUNE 2013.

cc. Vice-Chancellor
Director: Institute for Research Science and Technology

Appendix IX: Ethical Approval (JOOTRH))



MINISTRY OF HEALTH

Telegrams: "MEDICAL", Kisumu
Telephone: 057-2020801/2020803/2020321
Fax: 057-2024337
E-mail: medsuptnpgh@yahoo.com
When replying please quote

JARAMOGI OGINGA ODINGA TEACHING &
REFERRAL HOSPITAL
P.O. BOX 849
KISUMU

Ref: ERC 57/13

Date 6th August, 2013

George Evans Odero Owino,
School of Public Health, University of Bielefeld,
P. O. Box100131,
D-33501 Bielefeld,
GERMANY.

Dear Mr.Owino,

RE: FORMAL APPROVAL TO CONDUCT RESEARCH TITLED: *"ILLNESS EXPERIENCES OF PEOPLE LIVING WITH HIV IN KENYA: A CASE STUDY IN KISUMU COUNTY"*

This is to inform you that the JOOTRH Ethics and Review Committee (Reg. No. 01713) has reviewed your protocol for research and found it ethically satisfactory.

You are, therefore, permitted to begin your research immediately. Note that this approval is for one year (6th August, 2013 to 7th August, 2014).

Also note that any protocol amendment or further extension beyond the stipulated period should be applied for to the Ethics Committee in writing.

Note that you are also expected to share the findings of your study in both soft and hard copies with us upon completion.

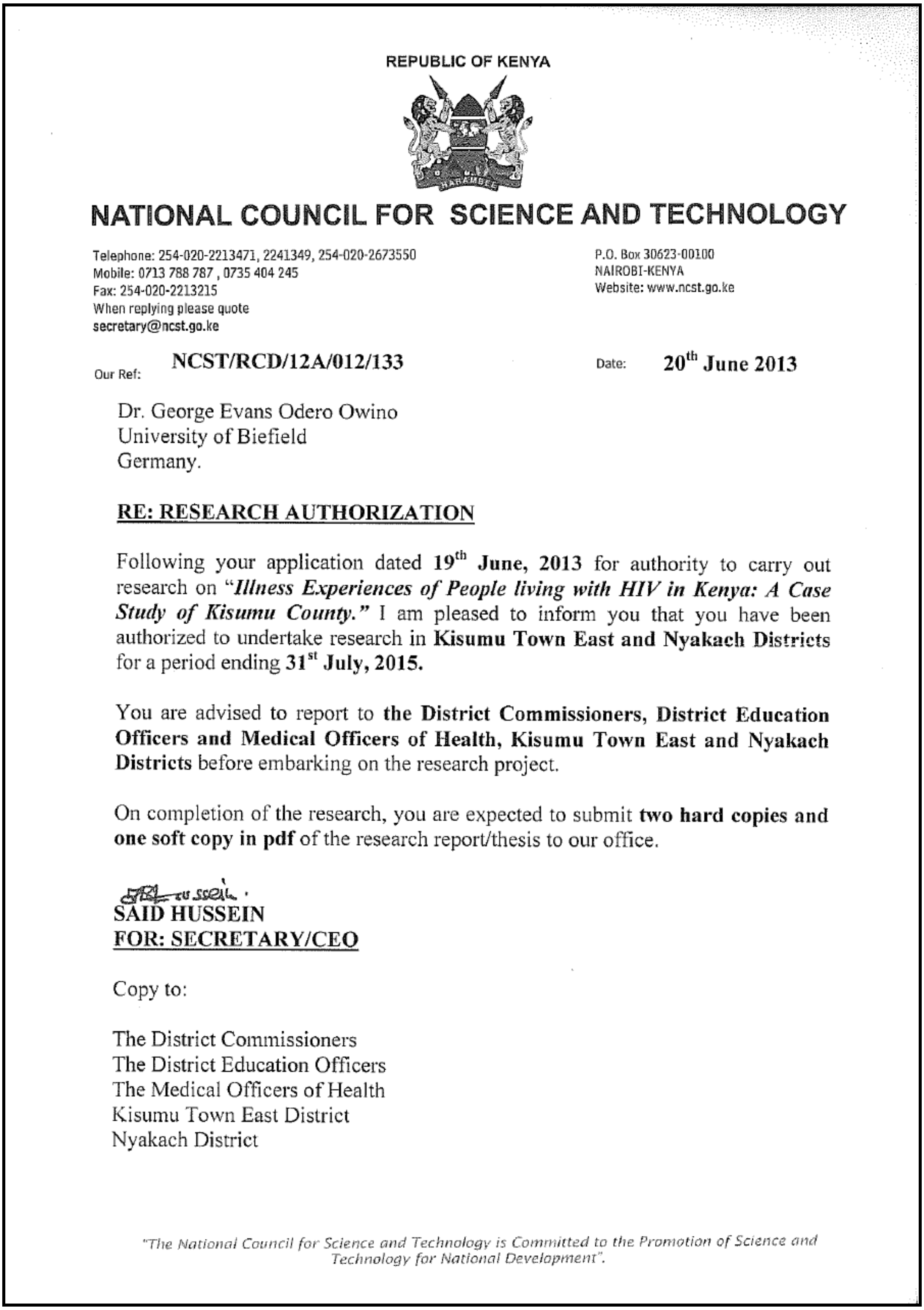
Yours sincerely,

We thank you for having chosen to research with us and wish you the best in your endeavours.

FRED O. AKWATTA,
SECRETARY – ERC,
JOOTRH – KISUMU.

/bao

Appendix X: Research Authorization



REPUBLIC OF KENYA

NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telephone: 254-020-2213471, 2241349, 254-020-2673550
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Fax: 254-020-2213215
When replying please quote
secretary@ncst.go.ke

P.O. Box 30623-00100
NAIROBI-KENYA
Website: www.ncst.go.ke

Our Ref: **NCST/RCD/12A/012/133**

Date: **20th June 2013**

Dr. George Evans Odero Owino
University of Biefield
Germany.

RE: RESEARCH AUTHORIZATION

Following your application dated **19th June, 2013** for authority to carry out research on "***Illness Experiences of People living with HIV in Kenya: A Case Study of Kisumu County.***" I am pleased to inform you that you have been authorized to undertake research in **Kisumu Town East and Nyakach Districts** for a period ending **31st July, 2015.**

You are advised to report to **the District Commissioners, District Education Officers and Medical Officers of Health, Kisumu Town East and Nyakach Districts** before embarking on the research project.

On completion of the research, you are expected to submit **two hard copies and one soft copy in pdf** of the research report/thesis to our office.

SAID HUSSEIN
FOR: SECRETARY/CEO

Copy to:

The District Commissioners
The District Education Officers
The Medical Officers of Health
Kisumu Town East District
Nyakach District

"The National Council for Science and Technology is Committed to the Promotion of Science and Technology for National Development".

Appendix XI: Time Schedule and Workplan

Session *	**Activities**	**2012**				**2013**				**2014**				**2015**			
		1	**2**	**3**	**4**	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**
	Finalized Dissertation Topic		▨														
Block 1	Attended Block on State of the Research			▨													
Block 2	Attended Block on Theoretical Framework			▨													
	Phase I of Field Work in Kenya- Reconnaissance & Rapport			▨													
Block 3	Presented ** Exposé				▨												
Block 4	Submitted QP on Research Methodology				▨												
Block 5	Submitted QP on Public Health Relevance				▨												
Block 6	Submitted QP on Research Deficits & Present Research Questions					▨	▨										
	Submitted QP on State of Research in Field of Study						▨										
	Submitted QP on Theoretical Framework						▨										
	Phase II of Field Work in Kenya-Data Collection							▨	▨								
	Transcribed and Analysed Data								▨	▨							
Block 7	Submitted QP on Research Process								▨								
Block 8	Submitted QP on Data collection and Analysis									▨							
Block 9	Submitted QP Findings Part I-Being Diagnosed HIV Positive										▨						
Block 10	Submitted QP on Findings Part II-Initial Reactions & Reconciliation										▨						
Block 11	Submitted QP on Findings Part III-Coping Strategies											▨					
Block 12	Submitted QP on Conclusions & Recommendations												▨				
	Submitted Dissertation Draft to Supervisors (in Dec.2014)												▨				