Beyond statistics: the cumulative effect of vulnerability in management of HIV

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Abstract

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Background: Health outcomes of antiretroviral therapy (ART) are well studied, while the psychosocial processes of seeking clinical care and adhering to lifelong medications to achieve viral suppression are understudied. This study explores how vulnerability to HIV and in the context of HIV affect individuals' decisions as they start self-management of HIV.

Methods: This study utilized mixed methods to obtain information from persons newly diagnosed with HIV at an urban high-patient load facility in Lilongwe, Malawi. First, a one-time survey of 151 persons newly diagnosed with HIV was used to generate information on individual- and social-level factors of intent to start and follow antiretroviral treatment. As a follow-up, in-depth interviews were conducted with 26 of the survey participants to explore how cumulative vulnerability affected their intent and actual follow-up of clinical care during the

initial 6-month period. Linear regression analysis was used to assess the effect of vulnerability on intent to follow clinical care, while multinomial regression analysis was used to assess effect of vulnerability on actual 6-month follow-up status. A grounded theory approach was used to organize and analyze qualitative data and prepare them to a synthesized narrative.

Results: By the time HIV-related services were sought, newly diagnosed persons reported experiencing persistent sickness, disrupted relationships and behavior guided by societal gender norms. Given the demonstrated outcomes of initiating ART early, participants welcomed initiation of ART but were unsure how they could manage stigma. They feared experiencing changes in appearance, being labelled as someone who has had reckless sexual experience, having limited fertility options, including partner choices, and needing more than usual resources to care for their compromised health. Intent to follow clinical care was not associated with age and gender. It was, however, independently associated with education level, recent physical health conditions, reason for current HIV testing and anticipation of sustained support from core social network after disclosure. Whether individuals reported having current social support did not affect their intent to follow care. However, those who anticipated sustained social support were highly likely to intend to follow care. In the initial months of self-management of HIV, the need to attend to additional health conditions resulted in added pill burden and clinic visits. Once good health was regained, it enabled dignity and resumed social activities. Emotional, physical and financial support were sought and obtained from current marital and non-marital partners, kin (siblings, parents and children), and close friends. Facility- and community-based social groups provided financial and emotional support, while religious framework provided emotional support.

Conclusions: Newly diagnosed individuals had existing vulnerabilities that led to their HIV infection and acquired new vulnerabilities once diagnosed with HIV. Consideration of continuing to take ART needed constant weighing of stigma. Anticipation of sustained social support facilitated clinical care follow-up. Those who have sustained social support demonstrated resilience, despite being vulnerable. Public health approaches should consider complementing clinical services with facilitation of social support for newly diagnosed individuals, in order to achieve positive health outcomes.

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Dedication

To Eyu and Matu

May you thrive, reflect and write

Chapter 1

The cumulative effect of vulnerability in management of HIV

The concept of vulnerability to HIV infection appears throughout the literature on self-management of health. Earlier studies have differentiated between the concepts of 'risk' and 'vulnerability' on the basis of whether the danger to health arises from factors within the individual or from the environment. When conceptualizing risk as 'potentially stressful factors or hazards in the environment' (Rose & Killien, 1983), the potential hazards or stressful factors come from the immediate (such as temperature, light, noise, and pollution) and broader (such as family, community, and society) environment. Vulnerability, on the other hand, is not viewed solely as a characteristic of either the individual or the environment but as an attribute of a system of which both are a part (Phillips, 1992).

Describing vulnerability

In common language, vulnerability is used to describe susceptibility to health problems, harm, neglect or other negative life experiences at an individual-level. However, vulnerability is a dynamic continuum that changes over time, especially in times of change and development, such as adolescence, pregnancy, and diseased state. Vulnerability has been described as the "exposure to contingences and stress, and difficulty in coping with them" (Chambers, 1989), demonstrating two sides to vulnerability: (1) external factors that an individual is exposed to, and (2) internal factors that affect a person's coping ability. Using similar framing, it was further described as the process of accounting for why some individuals or groups are more likely to experience negative life events (Bohle, Downing, & Watts, 1994). In later years, the concept of vulnerability was more

articulated as ‘experiences that create stress and anxiety and affect the physiological, psychological, and social functioning’ of an individual (J. De Santis, 2008).

Literature to date describe vulnerability with various areas of focus. *Environmental* vulnerability was defined as “an aggregate measure of human welfare that integrates environmental, social, economic and political exposure to a range of potential harmful perturbations” (Bohle et al., 1994). This conceptualization emphasizes that coping with a given change must be rooted in a full understanding of the complex structures and causes of the present vulnerability, and how that can evolve in the future. This includes consideration of three dimensions for risks to negative life events: exposure, capacity and potentiality. Similar conceptualization can be used to describe vulnerability associated with various types of illnesses. Although the three dimensions (exposure, capacity and potentiality) remain the same, the causal relationships that connect the dimensions vary based on the context of vulnerability that is being studied. Descriptions of *disease* vulnerability used these concepts to demonstrate that an individual’s vulnerability to exposure needs to take into consideration a community’s capacity to cope with illnesses and also the potentiality of the society and resources around the individual (Gould, 2005). These include the social and environmental factors that affect the society’s potential to intervene and alleviate a given events potentially devastating effects.

Vulnerability has also been defined as a combination of past, present and future risk that can be perceived or real (Dorsen, 2010). Such framing of vulnerability demonstrates the role of accumulated history of vulnerabilities in related areas in how individuals cope with negative life events. Human experiences of vulnerability to any negative outcomes increase with negative environmental inputs such as vulnerable periods, unfavorable situations, and increased risk.

Specific to health, environmental inputs such as poverty and inadequate diet play a role in how an individual incurs and copes with illness (Gould, 2005).

Vulnerability 'to' versus 'in the context of' HIV infection

In a number of literatures, the theoretical framing of vulnerability is constructed by describing the relationship between *vulnerability* itself, *environmental support systems*, and *personal resources* (Rogers, 1997). Vulnerability is found to be inversely proportional to environmental support systems and personal resources. It increases when environmental support and personal resources erode. Whether a person has an acquired infection or not, an experience of vulnerability creates stress and anxiety which will in turn affect an individuals' physiological, psychological and social functioning (Rogers, 1997). The various levels of vulnerability affect how a person utilizes and is utilized by personal and environmental resources such as the family unit, the community, and other environmental support systems - including the health care delivery system. As the number of vulnerable individuals (e.g. prevalence of HIV) increase in a given community, the burden on community resources increases and contributions made to these resources decreases.

It is important to note that many groups may be vulnerable to contracting HIV, which is different from the experience of 'vulnerability in the context of HIV infection' (J. De Santis, 2008). The latter refers to stress and anxiety that results from living with HIV infection and continues to accrue over time. A theory that describes vulnerability in the context of HIV frames the process of vulnerability occurs using four categories: (1) confronting mortality and illness, (2) struggling with change, (3) encountering a lack of psychosocial support, and (4) experiencing vulnerability – with some of the categories overlapping and contributing to the intensity of one another (J. P. De Santis & Barroso, 2011).

In the absence of appropriate self-management of HIV, different aspects of vulnerability, such as material, relational, and psychological vulnerabilities, have been observed to lead to behavior that is likely to lead to negative health outcomes, specifically having unprotected sex and non-adherence to treatment (Peretti-Watel et al., 2006). This differentiated between ability versus willingness to adhere to clinical recommendations, which is one of the main predictors of improved health outcomes. Poverty and instability affect an individual's ability to adhere to clinical recommendations while side-effects of treatment on the other hand affect an individual's willingness to adhere to treatment. Thus, it should be stressed that non-adherence can result from implicit or explicit appraisals of costs and benefits of choosing to follow biomedical instructions, rather than just constraints due to vulnerability.

Material, relational, and psychological vulnerabilities interact and affect adherence to ART differently depending on the attributes of the person (Peretti-Watel et al., 2006). Material vulnerability, for example, contributed to non-adherence via unfavorable daily circumstances, which includes learned powerlessness. This can demonstrate itself as an inability to negotiate sex, substance abuse and intravenous drug use. Relational and psychological vulnerabilities, on the other hand, work against improvements in health outcomes via different mechanisms. These mechanisms are affected by how individuals conceptualize their body, trust scientific knowledge, and perceive their vulnerability. Depending on these mechanisms, individuals can minimize the dangers of some of their behavior or engage in lifestyle that poses risk to their health.

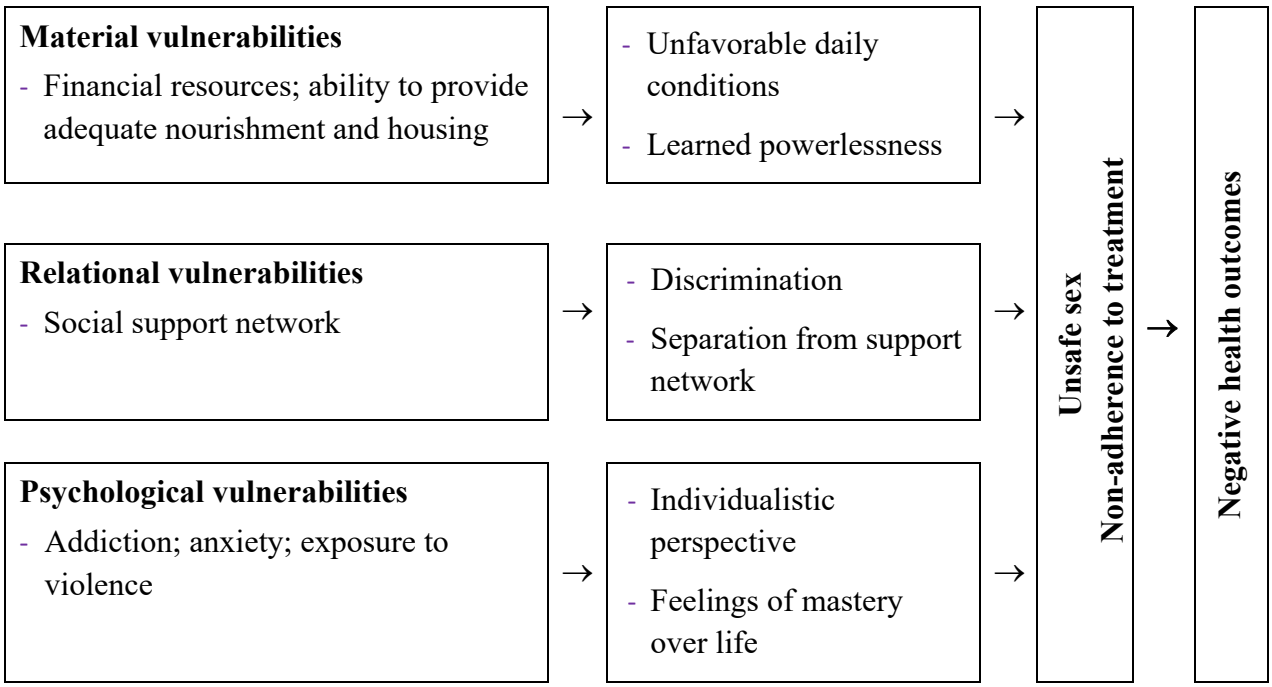

Table 1. Summary discussion by Peretti-Watel et al. (2006) on how material, relational, and psychological vulnerabilities affect HIV related health outcomes

When compared to previous discussions of vulnerability (Bohle et al., 1994; Chambers, 1989; Rogers, 1997), the relational and material aspects of vulnerability in later studies can be compared to the environmental support and personal resource aspects of vulnerability. When constructing vulnerability, the psychological aspects of it are discussed as one aspect of vulnerability in some studies (Ayres et al., 2006; Peretti-Watel et al., 2006) while other researchers discuss psychological functioning, along with physiological and social functioning, as *consequences* of vulnerability (J. De Santis, 2008).

Measuring vulnerability

Studies that focused on vulnerabilities of people living with HIV (PLHIV) to date measured environmental characteristics that lead to vulnerability, characteristics of vulnerable groups of individuals, and the interaction of the two aspects. Aspects of vulnerability in the context of HIV

studied to date include examined psychosocial factors such as perceived quality of life and barriers to care (Huba et al., 2000), socioeconomic status including income, education, and employment status (van Servellen, Chang, & Lombardi, 2002), the physical, mental, and behavioral factors that led to negative health (Ayres et al., 2006), and the interaction of economic, social, and personal components, specifically financial status, food privation and housing condition (Peretti-Watel et al., 2006). Most of these characteristics were associated with placing an individual with HIV at higher risk for other negative health conditions.

Some studies that focused on vulnerability of PLHIV have used a construct known as Health Related Quality of Life (HRQOL) to measure predictors of vulnerability (Huba et al., 2000; van Servellen et al., 2002). However, vulnerability did not mediate the relationship between health status and HRQOL (van Servellen et al., 2002). Instead, vulnerability was predicted by social attributes of the individual or group of individuals such as income, education, and employment status. Another analysis of vulnerability aimed to identify "the physical, mental, or behavioral factors that may expose an individual to a disorder through risk assessments and other approaches" (Ayres et al., 2006). After interviewing HIV-positive adolescents and their caregivers, the qualitative analysis focused on the implications of an HIV diagnosis for health care needs and categorized vulnerability into three broad dimensions: the **individual** dimension (physical and psychosocial components), **social** dimension (socioeconomic and political components) and **programmatic** dimension (institutional, governmental, and public health policy components) of HIV infection.

Resilient while vulnerable

Despite the opposing aspects of these terms, individuals with HIV infection have been described as both vulnerable and resilient in the research community. Resilience has been defined as a group of phenomena that result in positive outcomes when an individual is confronted with negative life events that may threaten adaptation or development (Masten, 2001). Resilience, specifically to the context of HIV infection, has been described in a number of ways: as an adaptation and readjustment that occurs despite multiple personal and social losses (Rabkin, Remien, Williams, & Katoff, 1993), coping with a diagnosis of HIV infection despite an initial sense of hopelessness and suicide ideation (Siegel & Meyer, 1999), a combination of commitment to life, a sense of control of one's life course, and acceptance of challenge as part of life (Farber, Schwartz, Schaper, Moonen, & McDaniel, 2000), a protection from a variety of risks that contributes to survival from extreme circumstances without debilitating disabilities (Pivnick & Villegas, 2000), strengthening and empowerment in the face of adversity (Cadell, Karabanow, & Sanchez, 2001), a period of uncertainty in which the individual adapts to living with HIV infection as a chronic illness (Thompson, 2003), the process whereby an individual is confronted with adversity and yet is able to move forward with life (Dyer, Patsdaughter, McGuinness, O'Connor, & De Santis, 2004) and the successes in life despite the challenges of living with HIV infection (Bletzer, 2007).

Lessons learned and next steps

Vulnerability in the context of HIV is a concept that continues to accumulate overtime. While cumulative vulnerability is known to predict negative health outcomes (with or without HIV infection), a combination of coping mechanisms can allow for resilience to be achieved by vulnerable individuals. This process of adaptation can be measured using individual, social and

environmental characteristics that are contributors of the potential negative or positive health outcomes. To explore how vulnerabilities can be managed and their effects overcome (or not), we will first summarize the current state of self-management of HIV in resource limited settings (Chapter 1) and then utilize mixed methods to explore sociobehavioral determinants and predictors of vulnerabilities in persons newly diagnosed with HIV. This sub-group of the population is selected as they have been vulnerable to HIV and now transitioning to manage the added and experienced vulnerabilities of being a PLHIV - i.e. - vulnerability in the context of HIV. The predictors that lead individuals to be a PLHIV and their adjustment processes are explored in Chapters 3-5. This is done through prospective follow-up of newly diagnosed individuals starting from the day they were diagnosed with HIV and by following them through the initial 6 months of living with an HIV diagnosis.

Chapter 2

Clinical management of HIV in resource-limited settings

Since the 1980s, HIV infection has progressed from being handled as an acute emergency to being managed as a chronic cause of illness. Given that HIV infection is a chronic infection, its management heavily relies on uninterrupted access to clinical care, and continuous self-management of behavior in regard to treatment follow-up and engagement in behaviors that will further compromise health status. An individual's behavior is heavily affected by continual re-strategizing processes made on a daily basis and can affect an individual's will to continue to follow a lifelong treatment (M. P. Fox, Brennan, Maskew, MacPhail, & Sanne, 2010). Interrupting or dropping out of HIV care compromises the benefits obtained from biomedical care both at individual and population levels. Predictors of attrition from biomedical treatment programs can be categorized into *clinical* (both lower and higher CD4 count, poor adherence to ART, and TB coinfection), *demographic* (male gender, younger age, pregnancy in women, lower level of education, financial constraints, and migration), *structural* (greater distance from tarred road, year of ART program implementation, and increased time on ART), *psychosocial* (dissatisfaction with care, shame about returning to care after missed visits, social stigma of using biomedical treatment, and seeking care from alternative options including religious healing methods) and other *unintentional* reasons (competing demands) (Evangeli, Newell, Richter, & McGrath, 2014; Roura et al., 2010). Studies to date have clearly established the clinical, demographic and structural determinants of loss to follow up while psychosocial determinants are understudied.

Framework for self-management of HIV as a chronic illness

Self-management of chronic illnesses has been described in an integrative framework using 14 elements that can be categorized into three broad categories: physical health, psychological functioning, and social relationships (Swendeman, Ingram, & Rotheram-Borus, 2009). Table 2 summarizes the elements discussed and categorized into these three broad categories.

Physical health	Psychological functioning	Social relationships
1. Understanding illness and wellness 2. Health promoting behaviors 3. Adherence to treatment 4. Self-monitoring of physical health 5. Access to treatment and services 6. Prevention of transmission	1. Self-efficacy and empowerment 2. Cognitive skills 3. Reduction of negative emotional states 4. Managing identity shifts	1. Relationships with healthcare providers 2. Self-disclosure and stigma management 3. Positive social and family relationships 4. Social support

Table 2. The 14 elements of integrative framework for self-management of chronic diseases described by Swendeman et al. (2009)

This general framework of self-management of chronic diseases is instrumental in designing and delivering HIV prevention, treatment, care, and support services that integrate other types of health care needs. In most resource-limited settings, HIV programs mainly focus on the physical health aspects of the self-management framework. At clinics, where contact between patient and health care provider happens, greater emphasis is given to assisting the patient to adhere to treatment and have continued access to treatment and services. Few programs focus on raising awareness about illness and wellness, health promoting behaviors, self-monitoring of physical health, and prevention of transmission. In relatively well-resourced clinics in resource limited settings, these aspects are covered in a group session of health education in waiting areas of clinics. Generally speaking, psychological functioning and social relationships are usually not included as part of the

biomedical care provision, leaving individuals to devise ways on how to manage them. In few and relatively well-resourced facilities located in a generally resource limited setting, referrals are made to potential community-level services that provide support though such services are de-linked from biomedical services.

Theoretical framing for understanding illness and wellness

In cultural evolution theories, decision-making forces include guided variation as well as forces that incorporate biases such as imitating others' preexisting traits instead of attempting to make new innovations (Richerson, Mulder, & Vila, 1996). Similar concepts are at play when it comes to behavioral changes that are triggered by unexpected life events. Behavior is guided in response to the changes in the environment and may use predefined constructs to minimize the cost of making new innovations. The predefined paradigms that shape individuals perceptions of disease, prevention and healing in many settings can be categorized into (1) **scientific,** (2) **religious,** and (3) **traditional** (Benn, 2002). These frameworks provide means of interpretation of illness by the individual and his/her social network. They also specify the limitation and availability of options an individual perceives to have.

Belief systems are one of the ways in which individuals transmit socially acquired information such as beliefs, values and ideas to others directly or indirectly. Similar to genetic inheritance, cultural transmission of information is prone to producing errors with maladaptive effects. Compared to genetic transmission of information or a trait, cultural transmission allows individuals to respond quickly to environmental changes by lowering the cost of information transmission (Henrich & McElreath, 2003). This aspect of cultural transmission makes it favorable for

responding to a quickly changing environment although it comes with a cost of producing errors at a higher rate.

Early anthropologists have demonstrated that religious acts arise and function in situations where individuals are exposed to emotional stress (Malinowski & Redfield, 1948). Recent studies have also demonstrated that religious practices reduced stress, anxiety, and depression by giving individuals a sense of control (Koenig, McCullough, & Larson, 2001). When examining these protective behaviors, individuals who have experienced emotional stress were likely to exhibit religious behavior (Sosis, 2007). However, these coping mechanisms of religion were found to be effective only when individuals were in unpredictable situations. Religion was ineffective when individuals are only faced with more mundane and controllable conditions (Sosis & Handwerker, 2011). Religious frameworks provide an individual a sense of control under uncertain conditions. A study that examined the cultural etiology of HIV noted that individual narratives were constructed mainly with a "moral framework, which viewed HIV acquisition as a consequence of moral failing and living an un-Christian life" (Kelly-Hanku, Aggleton, & Shih, 2014). Such moral framework made individuals responsible for "reform and re-establishing a relationship with God" in order to "effect healing on the material body infected with HIV".

While this aspect of religious response may be considered good for survival, it is important to note that these behaviors are correlated with reduced short- and long-term precautionary behaviors, which may make them maladaptive (Sosis, 2007, 2008). In resource limited settings where HIV infection presents a high level of uncertainty and loss of control, religious explanations and frameworks are documented to have given individuals a sense of hope and meaning in their daily lives (Katz et al., 2015) or provided social support (Olds, Kiwanuka, Ware, Tsai, & Haberer, 2015). On the other hand, religious frameworks have also been used as negative coping mechanisms when

HIV is considered as sin or when religious healing is taken as a substitute of ART (Roura et al., 2010; Seeling, Mavhunga, Thomas, Adelberger, & Ulrichs, 2014; Tweya et al., 2014). In the case of treatment choices for HIV infection, both religious and clinical treatments come with costs and benefits that can be avoided or gained when choosing one type of treatment exclusively. Individuals weigh these pros and cons before making decisions on solutions to explore for the problem they have at hand.

Decisions related to health outcomes of an individual depend not just on that person's actions but the collective social network around an individual. An individual's social network plays key role in informing the individual for the decision pertaining to their life history management (Smith & Christakis, 2008). For example, influences of fertility decisions may be driven by the goal of increasing inclusive fitness. After controlling for socioeconomic factors, individuals with social networks that are dense with kin were more likely to make decisions that are pronatalist while those who have less contact with kin are likely to make less pronatalist decisions (Newson et al., 2007). Similar influences might be affecting individual-level decision making once incurring new infection and made aware of a compromised immune status.

Based on how an individual processed the new information, type of framework used to understand the infection, and the support they anticipate getting from their social network, individuals make various decisions that affect their day-to-day lives. For example, studies have demonstrated that adjustments to fertility intentions are made differently based on whether an individual's test result matched the self-predicted infection likelihood measured before administration of an HIV test (S. Yeatman, 2009; S. E. Yeatman, 2009). Adjustments in fertility intentions were steep for respondents who learned they were HIV positive despite their lower perceived risk. Confirmatory or suspected news of HIV diagnosis did not affect fertility intentions (S. E. Yeatman, 2009).

Although studies to date have not focused on it, similar mechanisms may be at play when processing the news of HIV infection and making subsequent decisions that affect their self-management of health.

Governmental response for biomedical services

After noting that the HIV epidemic is fueled by transmission that occurs before initiation of clinical treatment, laws and policies in various countries have been encouraging initiation of integrated HIV care for all persons diagnosed with HIV. In the United States, the National HIV/AIDS Strategy did set a national target of increasing the proportion of newly diagnosed patients linked to HIV care within 3 months of HIV diagnosis to 85% by 2015. Individual State laws aligned with this target by requiring health care providers to refer persons newly diagnosed with HIV to follow HIV care. In New York State, this approach was taken by passing it as the HIV Testing Law in 2010. This approach resulted in increased proportion of newly diagnosed persons entering HIV care within 90 days (Gordon, Bian, Anderson, & Smith, 2015).

HIV, the most prevalent chronic infection in sub-Saharan Africa, has caused layered problems in resource limited countries, causing them to struggle in managing old problems (related to famines, wars, infectious diseases, malnutrition, and maternity complications) along with new problems (related to degenerative diseases, stress and other man-made diseases) (Omran, 1971, 1998). To start with, significant proportion of HIV infected persons do not access health care for the purpose of HIV testing and counseling, a key step in diagnosis of HIV infection. This is especially true for men, migrants, persons older than 35 or younger than 20 years of age, and individuals that live in high HIV prevalence settings (Kranzer et al., 2011). Upon diagnosis, individuals are made aware of an infection within their body – a knowledge that is likely to prompt them to weigh options on

how to manage their health. Based on a population-based survey conducted from November 2015 to August 2016 in Malawi, HIV infected individuals who self-reported no prior diagnosis were immunosuppressed (68%) and with low viral suppression (28%), when compared to those who were previously diagnosed and on ART – 52% and 91% respectively (Malawi Ministry of Health, 2018).

Up to 2016, the biomedical HIV care continuum in many resource-limited settings recommended individuals who were diagnosed with HIV to be referred, linked and then enrolled in care. Upon enrollment for HIV care, PLHIV were assessed for initiation of clinical treatment, receive results of the assessment, and initiated clinical treatment, if eligible. Those initiated on antiretroviral therapy (ART) were expected to continue to adhere to prescribed medications for the remainder of their life in order to achieve suppressed levels of HIV. This intended outcome of viral suppression was to improve the health outcomes of the person and minimize or stop new transmissions of the virus in their community. However, with this approach of public health, the majority of loss from the care continuum happened among patients who were aware of their status but not yet assessed for their eligibility for clinical treatment (Rosen & Fox, 2011), especially in pregnant women (Pati et al., 2013). Based on this observation and demonstrated clinical benefits of early initiation of ART, WHO has recently encouraged health systems to start clinical treatment for individuals who are ready to start, on the same day (or as soon as possible) after testing and diagnosing them with HIV (World Health Organization, 2017). Despite these clinical recommendations, individuals who are counseled to start a lifelong treatment may not see HIV infection as an immediate health concern. Biomedical evidence, on the other hand, shows that late presentation for HIV treatment increases the likelihood of negative health outcomes once on ART (Eholie et al., 2016; Meintjes et al., 2015; Temprano ANRS Study Group et al., 2015).

In many resource limited settings, a number of countries have been progressively expanding HIV care and treatment services to be accessible to all persons that need it. In Malawi, the national HIV management guidelines have expanded access to treatment services to PLHIV: first by using clinical criteria (CD4 count and WHO stages) prioritizing persons who are more sick, and then making HIV treatment available to sub-groups of the population that are considered high impact or priority: all pregnant and lactating women since 2011 (also known as an 'Option B+' strategy), to children younger than 2 years and 5 years since 2011 and 2014, respectively, and finally to all PLHIV since 2016 (Malawi Ministry of Health, 2011, 2014, 2016). While this phased approach has been working towards significant reduction in new transmissions of HIV, retention in care that allows for viral suppression has been a challenge, especially in young adults (ages 15-34) and women who were pregnant and/or breastfeeding and started on ART with the 'Option B+' strategy (Alhaj et al., 2019; Ayieko et al., 2019; Tweya et al., 2014). As guidelines were updated, retention in HIV care generally improved in later years of implementation of updated ART initiation guidelines (Tenthani et al., 2014). The magnitude of loss from care was observed to improve in later years with introduction of differentiated models of care that were tailored to closely follow and encourage women (S. Phiri, Tweya, et al., 2017) and adolescents (MacKenzie et al., 2017) to stay in care.

Lessons learned from starting pregnant and lactating women on ART on the same day as diagnosis have demonstrated the complexity of decisions that have to be made to start and stay in lifelong treatment (Stinson & Myer, 2012). Individuals that have considered themselves as healthy have found their good health to be both a motivator and a barrier to initiating lifelong treatment recommended by clinical health care providers (Magaco et al., 2019). As a result, the process of

accepting or denying a new HIV diagnosis is identified as a key influencer of initiating care (Horter et al., 2017).

Justification for the proposed study

Overall, most biomedical interventions that aim to resolve health problems in resource-poor settings advocate for counseling in order to enable individuals to avoid risk and seek treatment, with the assumption that they will do as advised. However, the daily lives of many individuals do not happen in a logical pathway. Humans are described as reproductive strategists who "constantly make decisions about the best possible allocation of their limited investment possibilities" all along their life span (Voland, 1998). While most of the energy allocation decisions made at the gene level are relatively fixed, decisions made at the behavior level are plastic and continuously changing throughout one's lifespan. Given that clinical recommendations focus on specific components of an individual's physical health, this project aims to investigate the socio-behavioral influences that affect individual-level decision making after knowing about a new HIV diagnosis.

A number of countries in resource-limited settings have already adopted early or same day initiation of HIV treatment for those who are newly diagnosed with HIV. Malawi's recent strategic decision to start with initiation of antiretroviral treatment on the same day of HIV diagnoses, also known as universal test-and-treat (UTT), starting April 2016 is based on programmatic targets set by the Joint United Nations Programme on HIV/AIDS (UNAIDS). This strategy aims to enable 90% of the persons living with HIV to know about their HIV status, for 90% of those that know their status to be initiated on sustained antiretroviral treatment, and for 90% of those on treatment to be virally suppressed by the year 2020 (UNAIDS, 2014). This ambitious plan is a logical approach that is supported with mathematical models especially in high prevalence settings

(Granich, Gilks, Dye, De Cock, & Williams, 2009). However, the implementation of UTT programs will need to take into consideration the 'dynamic, non-linear and time-dependent process' of start, loss and return to HIV care (Kranzer, Govindasamy, Ford, Johnston, & Lawn, 2012). This complex process is highly influenced by daily health-related decisions individuals make. Although the clinical outcomes that are the results of these decisions are well studied, the psychosocial processes of testing for HIV, enrolling for HIV care, starting ART and adhering to medications to achieve viral suppression are understudied.

The need to understand factors and processes that lead towards uptake and retention in HIV care and viral suppression is of great importance in high HIV prevalence settings. In this setting, attempts for self-management of HIV as a chronic infection face many challenges. As public health programs scale up to initiate all people living with HIV on treatment in an attempt to control the HIV epidemic, the proposed project intends to address the knowledge gap in understanding of vulnerabilities in the context of HIV in a resource limited setting. By doing so, the project intends to generate information about the essential socio-behavioral considerations biomedical programs need to make while aiming to start and retain individuals on a lifelong clinical treatment.

This project utilized mixed methods and was implemented in two phases. **Phase I** utilized a one-time survey of persons newly diagnosed with HIV to generate information on individual- and social-level factors and intent to start and follow antiretroviral treatment. Findings of this survey are discussed in Chapter 3 with focus on *what* determined intent to start and actually follow clinical care. A subset of the survey participants was recruited for further follow-up. In **Phase II**, in-depth interviews were conducted with the selected individuals to explore how cumulative vulnerability affects the intent and actual follow-up of HIV care during the initial 6-month period after a new HIV diagnosis is made. Findings from this follow-up period are summarized in Chapters 4 and 5,

with focus on *how* vulnerability determined individual decisions to start and continue to follow clinical care. Overall, the project aimed to describe the socio-behavioral considerations made by persons newly diagnosed with HIV infection in a resource-limited setting. Specifically, it aimed to explore the role of cumulative vulnerability on individual-level decisions regarding initiation and continued follow-up of HIV care once diagnosed with HIV.

Chapter 3

The role of vulnerability on individual-level decisions to start a lifelong clinical treatment

Abstract

Background: In the context of HIV, material, relational, and psychological vulnerabilities can continue to accumulate even after an HIV infection is acquired and subsequently results in negative health outcomes. Initiation of HIV care, on the other hand, improves health outcomes. However, health outcomes depend on an individual's acceptance of the clinical diagnosis and adherence to lifelong treatment. This study sought to describe individual- and social-level determinants of intent to initiate and follow clinical care upon HIV diagnosis in the universal test-and-treat (UTT) era.

Methods: A cross-sectional survey was administered during 2016-2017 for adults who were newly diagnosed with HIV at an urban high-patient load health facility in Lilongwe, Malawi. Data on their treatment initiation and follow-up of care six months later were abstracted from HIV Testing Services (HTS) registers and treatment cards. Univariate and multivariate regression analysis were used to assess the effect of vulnerability proxies on intent to initiate clinical care.

Results: Most of the 151 participants had high school level (54%) or less (40%) formal education attainment; and only 39% reported having a steady source of income. Two-thirds of the participants reported previous HIV testing experience, 61% of whom were tested for HIV within the last 3 years. Intent to follow HIV care was independently associated with higher formal education level [OR 2.09, 95% confidence interval (CI) 1.32-3.32], fewer number of children (OR

0.71, CI 0.54-0.92), more frequent days with poor physical health in the last 30 days (OR 1.07, CI 1.01-1.12), and reason for current HIV testing (OR 0.72, CI 0.59-0.89). Lack of supportive relationships (33%) wasn't associated with intent to follow care for more than 2 visits. However, intent to follow care was associated with anticipation of sustained support if the new diagnosis were disclosed to core social network (OR 5.30, CI 1.17-23.99).

Conclusions: For newly diagnosed individuals in this setting, intention to follow HIV care was associated with higher level of formal education, poor physical health in the recent past, and anticipation of sustained social support after disclosure. Persons who self-report previous negative tests tested again within 3-years based on their self-assessment of their own and partners' behavior. Individuals weigh current health status along with anticipated support before initiating care. For vulnerable individuals, linkage with social support systems and promotion of improved health as an incentive may influence their decision to start antiretroviral therapy.

Introduction

Vulnerability has been described as the "exposure to contingences and stress, and difficulty in coping with them" (Chambers, 1989). In the context of HIV, vulnerability continues to accrue as an individual who is exposed to HIV is infected with HIV, diagnosed with the infection, and attempts to self-manage the subsequent health needs. Material, relational, and psychological vulnerabilities are associated with negative health outcomes (Peretti-Watel et al., 2006). On the other hand, early initiation of antiretroviral therapy (ART) in people who are diagnosed with HIV has been associated with increased likelihood of positive health outcomes (Eholie et al., 2016; Meintjes et al., 2015; Temprano ANRS Study Group et al., 2015). Based on this evidence, WHO has recommended health systems to start clinical treatment as soon as readiness to start clinical

care is established (World Health Organization, 2017). In Malawi, similar to other countries in sub-Saharan Africa, ART was previously initiated using clinical criteria (CD4 count and WHO stages) for the purpose of prioritizing persons who are sicker. This prioritization was later expanded to population sub-groups that were considered high impact or priority: all pregnant and lactating women since 2011, children younger than 2 years and 5 years since 2011 and 2014, respectively, and finally to all PLHIV since June 2016 (Malawi Ministry of Health, 2011, 2014, 2016). Initial comparisons of retention in care between those initiated before and during the first year of universal test-and-treat (UTT) era in Malawi demonstrate a slight improvement in 12-month retention rates (Alhaj et al., 2019).

During routine delivery of clinical health services, UTT requires health care providers to convince persons who view themselves as healthy, despite their vulnerabilities, to start on lifelong treatment with significant opportunity cost. Initiation of healthy PLHIV on lifelong treatment poses good health both as a motivator and a barrier to initiating clinical care when recommended by a health care provider (Magaco et al., 2019). Exposure to HIV and the decision to initiate clinical treatment depends on how an individual is managing their vulnerabilities to date and whether they accept or deny a new identity as PLHIV as something they can add on their lifestyle and manage (Horter et al., 2017; Mufune, 2014). Determinants of initiating care after an HIV diagnosis have been studied in controlled settings for sub-groups of the population. However, the topic is yet to be studied in routine public health service delivery settings. This study sought to establish individual and social level determinants of two key care outcomes among individuals newly diagnosed with HIV in a clinic setting in urban Malawi in the early years of the UTT era: initial intent to start and follow clinical care and actual follow-up status during the initial 6-month period after a new HIV diagnosis.

Methods

Study design and population: From October 2016 to September 2017, a cross-sectional survey was administered for 151 newly diagnosed HIV-infected adults at Lighthouse Clinic in Kamuzu Central Hospital (KCH), a high-patient load HIV clinic in Lilongwe, Malawi. The survey was administered on the date of the new diagnosis. Participants were adults (18 years and older) who came to Lighthouse Clinic for HIV testing and counseling services voluntarily or after being referred to the service by health care providers, family members or friends – and were subsequently diagnosed with HIV for the first time. Persons who self-reported a previous HIV positive test result and children under 18 years of age were excluded.

Setting: According to a recent population-based report, Malawi has an adult HIV incidence of 0.37% per person-year and adult HIV prevalence of 10.6%, with approximately one in every five households affected by HIV (Malawi Ministry of Health, 2018). Lighthouse Trust works in close coordination with Malawi's Ministry of Health (MOH) to operate three clinics that provide integrated HIV testing, treatment and care services in Lilongwe and Blantyre cities. All medications needed for HIV-related symptoms are provided to individuals free of charge to clients. However, individuals still incur the cost of transportation, displaced time, and lost income when following clinic-based care (Sande et al., 2018). This project was conducted at one of the high patient load HIV clinics located in KCH in Lilongwe. Compared to other public health facilities in Malawi, both KCH and its Lighthouse Clinic are relatively well known for their availability of expert-level health care providers. Lighthouse Clinic is known for providing specialized HIV prevention, testing and treatment services. The detail setup of Lighthouse Trust is described elsewhere (S. Phiri, Neuhann, et al., 2017; Sam Phiri, Weigel, Housseinipour, Boxshall, & Neuhann, 2004).

Recruiting and data handling: After routine post-test counseling, all eligible persons were provided with a description of the study along with benefits and possible adverse effects, after which informed consent was solicited by a trained counselor. Eligible persons who self-reported the HIV-positive diagnosis as a new diagnosis to the counselor were referred to a survey administrator. The survey administrator read survey questionnaires to participants and entered self-reported information using an electronic Open Data Kit (ODK) tool loaded on tablet. Key variables obtained include sociodemographic information, health-related quality of life, ability and willingness to self-monitor physical health, profile of psychological functioning, anticipated HIV result before testing, perceived stigma surrounding HIV, profile of social support systems, and anticipated social and economic support after self-disclosure.

As part of the routine HIV testing, referral and linkage services provided at Lighthouse, survey participants were escorted to the reception area of the clinic and prioritized for registration to HIV care services, if Lighthouse Clinic was their choice for follow-up of care. If participants opted to follow care at another facility, the facility of their choice was noted in the HTS register. The treatment initiation and status of linkage were later abstracted from the HTS registers and HIV treatment cards, and categorized as (1) in care at the same facility six months post-initiation of care, (2) initiated ART at the same facility but officially transferred care to another facility after one or more visit(s), (3) initiated ART at the same facility but defaulted from care after one or more visits, (4) opted to initiate care at another facility when offered at the clinic diagnosis was made, or (5) failed initiation (initiated care after being escorted on the day of new HIV diagnosis, but did not come back to follow care from the same facility).

Statistical analysis: Descriptive statistics were used to summarize the individuals' sociodemographic and behavioral information, along with individual and social information

obtained on the date of a new HIV diagnosis. The first set of analyses considered a single binary outcome on intent to follow care at the same facility at diagnosis. Those categorized as having such intent to follow care included respondents who initiated care at the same facility and followed for two or more visits, regardless of whether they subsequently remained in care, transferred care, or defaulted within 6 months of diagnosis. Those categorized as *not* having such intent included persons who registered for care on the day of diagnosis but never returned to follow care, and those who stated a desire to follow care at a different facility. These latter two groups were included as no intent in this initial analysis, since the impressions of clinic staff were that both represented strategies widely used by patients who did not intend to start treatment at all, but wished to avoid expressions of disagreement to a health care provider with outright refusal of care. Using STATA version 15.1, logistic regression was used to calculate odds ratios (OR) of intent to follow treatment for proxy variables of vulnerability. For risks identified, further multiple regression analysis was done by controlling for related sociodemographic (age, gender, marital status, and source of income) and behavioral variables (partner's HIV status, anticipation about result, ability to monitor health, and plans to disclose status) and their interactions.

To assess effect of vulnerability on 6-month follow up status, multinomial regression analysis was used to calculate relative risk ratios (RRR) of four actual 6-month follow-up statuses (initiated but transferred care, initiated but defaulted later, opted to initiate care at another facility, and failed initiation) when compared to remaining in care at the same facility for 6 months. RRR for continuing to follow care at the same facility was calculated for proxies of related vulnerabilities. Further investigation was made for identified associations, by controlling for related variables and their interactions.

Ethics approval for this project was obtained from the University of Washington in the United States and the National Health Science Research Committee in Malawi. Participants were not compensated to participate in the survey.

Results

A total of 151 newly diagnosed persons were surveyed. Table 3 summarizes their sociodemographic characteristics. The median age was 33, and 60% of the respondents were female. A majority of the participants had high school level (54%) or less (40%) formal education attainment. A majority of the participants (83%) had children. Although 39% of the participants reported steady employment, others reported dependence on piecemeal jobs (47%) or other individuals (14%).

Out of those who were currently married or in a relationship (n=104), 63% reported knowing if their partner had tested for HIV before, with 32% being aware of a positive HIV result, 28% aware of a negative HIV result, and 4% not being aware of the test result. Thirty (91%) of the 33 HIV positive partners were reported to be on ART.

Sociodemographic information		**N**	**% or IQR**
Gender	Female	91	60.3
	Male	60	39.7
Age	Median	33	IQR (21, 55)
	18 – 25	28	18.5
	26 – 35	59	39.1
	36 – 45	33	21.9
	45 – 70	30	19.9
	Missing	1	0.7
Education level	No formal education	7	4.6
	Adult literacy	2	1.3
	Primary school	52	34.3
	High school	81	53.6
	Beyond high school	9	6.0
Source of income, own	Steady employment	59	39.1
	Unstable jobs	71	47.0
	Wholly dependent on others	21	13.9
Religion	Yes, following religion	151	100.0
	Christianity	137	90.7
	Muslim	13	8.6
	Other	1	0.7
Marital Status	Single	8	5.3
	In relationship, unmarried	29	19.2
	Married	75	49.7
	Separated	1	0.7
	Divorced	28	18.5
	Widowed	10	6.6
HIV status of partner	Didn't know if tested	39	25.8
	Yes tested	65	43.1
	Not applicable: no current partner	47	31.1
	Know tested; not result	4	6.2
	Know tested: result negative	28	43.1
	Know tested: result positive	33	50.8
	Know tested; positive; on ART	30	90.9
Children	Yes, have them	125	82.8
	Median	3	IQR (1,6)

Table 3. Sociodemographic characteristics of 151 persons newly diagnosed with HIV at Lighthouse Clinic from October 2016 to September 2017

Testing experience

Unlike their current self-reported new positive result, 66% of the participants had a previous HIV testing experience that yielded a negative test result. Approximately one fourth of the individuals were accompanied by someone when they came to be tested: 28% of previous testers and 24% of new testers. Of those that had previously tested (n=100), 61% reported being tested previously within the last 3 years. Reasons for previous tests were mainly curiosity (24%) and pregnancy (23%). Reason for current testing in the 151 participants was dominated by sickness (55%).

HIV testing experience		**N**	**%**
Came with someone for present test	Yes	40	26.5
	No	111	73.5
Reason for current test	Sickness	83	55.0
	Pregnancy	1	0.7
	Suspected behavior	25	16.6
	Encouraged by others	24	15.9
	For planning future	1	0.7
	Curiosity	17	11.3
Tested for HIV before	Yes	100	66.2
	No	51	33.8
Time since last test, for repeat testers	Within the last 3 years	61	61.0
	Over 3 years ago	32	32.0
	Don't remember	7	7.0
Reason for previous test, for repeat tested	Sickness	17	17.0
	Pregnancy	23	23.0
	Suspected behavior	14	14.0
	Encouraged by others	15	15.0
	For planning future	7	7.0
	Curiosity	24	24.0

Table 4. Reasons and HIV testing experiences of persons newly diagnosed with HIV at Lighthouse Clinic from October 2016 to September 2017

Intent to follow HIV care at the facility of diagnosis

Overall, 71% of the participants demonstrated an intention to follow care at the same facility where they were newly diagnosed. The subsequent care trajectories of this group included remaining in care for a minimum of 6 months post initiation of care (62%), transferring care to another facility on a later date (3%) and defaulting from care within the 6 months of initiating care (7%).

The remaining 29% of the participants did not demonstrate intent to follow care at the facility of their new HIV diagnosis. This included those who reported an intention to follow care at another facility (17%) and those who were escorted to reception, registered, and prescribed the initial dose of medication but never returned to receive continued care at the same facility (12%). None of the survey participants indicated intention to delay or outright refusal of clinical care to counselors.

Intent to follow care	**Linkage status**	**N (151)**	**%**
Yes		107	70.9
	On ART at same facility	93	61.6
	Transferred initiated care later to another facility	4	2.7
	Defaulted after 2 or more visits	10	6.6
No		44	29.1
	Opted for initiation at another facility	26	17.2
	Failed initiation (only 1 visit; on day of testing)	18	11.9

Table 5. HIV treatment and care initiation and 6-month follow-up status of persons newly diagnosed with HIV at Lighthouse Clinic from October 2016 to September 2017

Determinants of intent to follow care once newly diagnosed with HIV

Intent to follow HIV care was not associated with age and gender. It was, however, independently associated with education level [OR 2.09, 95% confidence interval (CI) 1.32-3.32], physical health (specifically, being frequently affected by sickness in the past 30 days; OR 1.07, CI 1.01-1.12),

current testing reason being not related to sickness (OR 0.72, CI 0.59-0.89) and anticipation of sustained support from the person most relied after disclosure (OR 0.19, CI 0.04-0.85). These associations persisted when controlling for related sociobehavioral variables such as age, gender, marital status, source of income, partner's HIV status, anticipation about result, ability to monitor health, and plans to disclose status.

Not having children (17%) was not associated with intent to follow HIV care in both univariate analysis and when adjusting for related variables in a multiple regression analysis. For those with children, however, having more children was associated with reduced intent to follow care (OR 0.71, CI 0.54-0.92, p=0.010). This association persisted when controlling for age, gender, source of income, marital status, and HIV status of a partner; however, the association was lost when controlling for educational status.

	OR (95%CI)	**p-value**
Age	0.97 (0.94-1.01)	0.145
Gender	1.81 (0.85-3.84)	0.124
Educational level	2.09 (1.32-3.32)	0.002
Number of children	0.71 (0.54-0.92)	0.010
Poor physical health	1.07 (1.01-1.12)	0.012
Having general health concerns	1.42 (0.53-3.82)	0.490
Reason for current testing	0.72 (0.59-0.89)	0.002
Anticipated social support	5.30 (1.17-23.99)	0.030

Table 6. Odds ratios of sociobehavioral proxies of vulnerability and their effect on intent to follow care at the same facility once newly diagnosed with HIV

Determinants of HIV care follow-up in the initial 6 months

Compared to those with a high school level education, those with less formal education were less likely to follow care. This association was observed in both categories that didn't express outright refusal of care but did not demonstrate intent to follow by not returning to follow care (RRR 0.52, CI 0.28-0.94) or opting to start care at another facility when offered to initiate care (RRR 0.51, CI 0.30, 0.87). However, when controlling for knowledge of HIV testing history and HIV status of the participants' partner, the association was lost for both follow-up statuses.

When compared to those who stayed in care at the same facility for 6 months, those who stated a preference to seek care from another facility were more likely to have more children (OR 1.48, CI 1.08-2.04), and a fewer number of days with affected physical health (RRR 0.93, CI 0.87-1.00), and less likely to have anticipated support from the person they relied on the most (RRR 9.09 CI 1.89-43.63). These associations were independent of other sociobehavioral characteristics assessed. Those who defaulted within 6 months of initiating care were likely to have reported having general health concerns on the day of their diagnosis (RRR 6.15, CI 1.56-24.25).

	Opted for another	**Failed initiation**	**Defaulted**	**Transferred**
Age	1.03 (0.98-1.07)	1.01 (0.95-1.06)	0.92 (0.84-1.01)	0.92 (0.80-1.05)
Gender	0.54 (0.21-1.36)	0.51 (0.17-1.55)	0.81 (0.21- 3.06)	0.40 (0.04-4.04)
Educational level	**0.51 (0.30, 0.87)**	**0.52 (0.28-0.94)**	0.85 (0.36-2.02)	1.17 (0.26-4.92)
Number of children	**1.48 (1.08, 2.04)**	1.26 (0.87-1.82)	0.97 (0.57-1.64)	0.29 (0.05-1.81)
Poor physical health	**0.93 (0.87-1.00)**	0.95 (0.89-1.02)	1.04 (0.98-1.09)	0.99 (0.88-1.11)
Having general health concerns	0.80 (0.21-3.06)	1.32 (0.33-5.23)	**6.15 (1.56-24.25)**	6.15 (0.80-47.60)
Reason for current testing	**1.59 (1.24-2.04)**	1.15 (0.85-1.56)	0.90 (0.58-1.42)	0.84 (0.39-1.77)
Anticipated social support	**0.11 (0.23-0.53)**	*	*	*

*All patients in this category anticipated support when they disclose their status.

Table 7. RRR (95%CI) when compared to staying in care at the same facility for 6 months post diagnosis

Reasons for previous testing were not associated with intent to follow care and 6th month follow-up status. However, current reasons for testing were associated with opting for another facility when being offered to follow care at the same facility. This was specifically true for participants who came to be tested for HIV because of other individuals' (health care provider, friends, or family) encouragement (RRR 4.38, CI 1.31-14.68, p=0.017) and those who reported testing out of curiosity (RRR 9.31, CI 2.58-33.57, p=0.001).

Availability of social support

Overall, 33% of the participants stated having no relationship they relied on for physical, emotional and financial well-being, while 37%, 15%, 11%, and 4% of the individuals surveyed reported 1, 2, 3, and 4 relationships, respectively. None of the participants reported having five relationships whom they relied on for support. Whether individuals reported having a relationship they relied on for their well-being did not affect their intent to follow care. However, for those who had at least one relationship they relied on, persons who anticipated support from the person they relied the most after a planned disclosure were highly likely to intend to follow care at the same facility after a new diagnosis (OR 9.09, CI 1.12-22.89, p=0.035). These association persisted even when controlling for other related physical and social characteristics assessed.

Discussion

This study provides lessons from a routine health service delivery setting in the early years of implementing UTT in sub-Saharan Africa and identified individual- and social-level determinants of demonstrated intent to follow clinical care once newly diagnosed with HIV and actual follow-

up of care. Intent to follow care was associated with higher formal education, poor physical health in the recent past, having fewer children, and anticipated social support from a core social network.

Proxies of socioeconomic vulnerability

Sociodemographic characteristics of survey participants were comparable to other studies in sub-Saharan Africa (M. P. Fox & Rosen, 2010; Magaco et al., 2019; Rosen & Fox, 2011; Rosen, Fox, & Gill, 2007). A majority (94%) of the participants had high school level or less formal education; 60% did not have a steady source of income. These characteristics indicate socioeconomic and material vulnerabilities that have been previously established as predictors of entering risky sexual behavior (Ngugi, Benoit, Hallgrimsdottir, Jansson, & Roth, 2012). This study demonstrates that once newly diagnosed with HIV, persons who have low formal education were less likely to follow HIV care while persons with high school level education were likely to follow HIV care. This relationship with intent to initiate clinical care was however affected by the HIV status of sexual partners. Those with relatively higher education were more likely to be in a partnership with an HIV negative partner while those with lower education level reported either not knowing the HIV status of their partner or the partner being HIV positive. In addition to indicating their increased exposure to HIV, this association may also be related to their learned powerlessness in communicating and negotiating sensitive issues despite their potential drastic effect on their health.

In addition to the individual-level factors, the findings from this study suggest that it may be important to focus on who is delivering the news of a new diagnosis and how. In Malawi, counselors that conduct HIV testing are adults (18 years of age and above) with high school level education (two years or more years completed) and ability to be a certified counselor after passing an intensive 3-week long HIV testing and counseling training. In addition to complementing their

training with a 1-week long practical session, counselors are also expected to be re-certified every year following a formal assessment and with biannual participation in proficiency testing and scoring 100%. While the rigorous certification process assures the counselors continue to have up-to-date HTS knowledge and skill, their education level is typically higher than approximately half of persons to whom they routinely provide services to. The re-certification process may be an opportunity to re-focus counselor's attention on how to deliver the news of HIV diagnosis to persons with lower formal education. Many countries have used information, education and communication (IEC) tools to disclose or deliver major health news. In Malawi, the contribution of education level in determining intent to follow care and actual follow-up status at 6-month may indicate the need to use such IEC tools in delivering news that has traumatic effects. Such low-cost tools have been used in similar settings to disclose HIV status to pediatric patients (O'Malley et al., 2015).

Having no children was not associated with intent to initiate treatment. However, for those with children, having more children was associated with declining initiation of care at the facility of diagnosis citing the need to seek care at another facility. If taken literally, this may indicate a need or burden of arranging for childcare before choosing a facility. However, opting for another facility is widely believed in the local setting as a polite or strategic decline of services without confrontation. Before the UTT era (when eligibility criteria were used to initiate ART), having children had been associated with discontinuation from HIV care before and after initiation of ART (Evangeli, Newell, & McGrath, 2016; Evangeli et al., 2014). This effect seems to be sustained in the test-and-treat era where individuals may be aware of their HIV status but have to weigh child care and its assurance with the opportunity cost of following clinical care.

Testing experience

After bending the HIV epidemic in the last decade, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has an updated '95-95-95 target' which aim to diagnose 95% of those living with HIV, initiate 95% of those that are diagnosed on clinical treatment, and achieve viral suppression for 95% of those that are on ART by 2030 (UNAIDS, 2014). When prioritizing HTS delivery, national HIV programs are currently using or preparing to create and use categories of people who may be most at risk of being infected with HIV. In this study, persons who are newly diagnosed with HIV at an urban clinic that is based within a central hospital were sicker and likely to have sought HTS but had a negative result in the past 3 years. Although this may not be generalized for repeat testers in other (non-HIV) health service outlets and community based-HIV campaigns, repeated tests that actively sought care from specialized HIV clinics had legitimate concerns based on their own and their social network's assessment. Prioritization criteria needs to consider the socioeconomic vulnerabilities of individuals, such as low formal education attainment and lack of sustained income, which may be associated with having relationships that are not well negotiated and prone to exposure to HIV. As such, a more frequent testing strategy may be necessary in vulnerable populations. Cost-effectiveness of frequency of testing has been studied for populations that are considered high risk in well-resourced settings (Hutchinson, Farnham, Sansom, Yaylali, & Mermin, 2016). Similar studies may inform the cost-effective frequency of HIV testing for vulnerable populations in resource limited settings.

The role of health status

Good health has been demonstrated as having a dual role in decisions around initiation of HIV care and its continued utilization (Magaco et al., 2019). In the group we surveyed, we mostly found

that the need to have or maintain good health to be a motivator of intent to follow care at the same facility where the new diagnosis was made. Those that chose to be tested because of a compromised health status were more likely to intend to follow care at the same facility. This may be because they were more purposeful in the HTS they sought and prepared for the consequences of the results. This is demonstrated in the comparison made with those who tested for HIV because someone else made the recommendation or out of general curiosity. These groups were likely to decline care at the same facility citing that they will start at another facility. Given that these groups were not perceiving themselves to be sick to begin with, their perceived good health may have been a barrier for initiation of care on the same day of diagnosis.

The role of social support

The study highlights that people who anticipate having sustained social support are likely to stay in care, while those who anticipate losing support are likely not to demonstrate intent to follow care at the same place of diagnosis. Given the misconceptions that exist about what it means to be HIV infected, PLHIV are still stigmatized and disclosure of their HIV status can significantly affect their social capital. In many cases where disclosure was anticipated as a loss of social support from one's core social circle, individuals opted not to seek care at the location of HIV diagnosis. This may be because they travelled to a location away from their facility to be tested to begin with or preferred to decline the counselor's recommendations without justifying their choice.

One's understanding of illness and wellness is informed by personal experiences and those within the social network (Brown, 1995). Until 2016, being on HIV treatment has been recommended only for those with significantly compromised health status or those who were symptomatic with AIDS. This recommendation has been used to categorize HIV infection fatalistically, despite the

demonstrated improved health outcomes once a person initiates ART (Conroy, Yeatman, & Dovel, 2013). In UTT era, there is a need to demystify this myth at a societal level and establish knowledge of HIV as chronic infection. Such up-to-date messaging should not be limited to those who are at risk of HIV but also individuals that construct the general society. In this study, although individuals were provided with post-test counseling on management of HIV, their anticipation of maintaining social support affected their decisions on whether they followed the recommendations of the counselor. Once individuals leave a clinic setting, the potential of loss of support and lowered social capital within their social network (e.g. friends, partners, employers, etc.) may be too high a cost to tradeoff for many.

Sub-optimal reporting of supportive relationships in this study may be actual or not disclosed to a surveyor purposefully. If actual, the lack of support system may translate to relational vulnerabilities (related to support from their social network) that play a major role in an individual's ability to commit to lifelong clinical treatment. Having supportive relationships by itself did not determine intent to follow care at the same facility. However, persons who had a support system but anticipated its loss if they disclose their status were highly unlikely to intent to follow care at the facility where they were diagnosed. This may be a result of purposeful weighing of risks to a means for physical, emotional or financial sustenance for the sake of clinical treatment which they have not yet been accepted as an immediate need. Provided that core social support is hard to replace, its retention is a major area considered by persons newly diagnosed with HIV. Linking vulnerable individuals to support groups may provide a safety network that can make them feel secure in their decision making for self-management of their health.

Limitations

All of the data collected from the survey was self-reported and may have limitations caused by recall and interviewer bias. Further interpretations of this study should be made with this in mind. Additionally, information collected was from persons who sought care from a specialized HIV clinic located in a central hospital of a capital city. Given the reputation of the facility and its accessibility, summaries made from this study may not apply to facilities that are smaller, not easily accessible, or specialized to provide other types of health care (maternity, tuberculosis, or other outpatient services).

The study focuses on intent to initiate clinical care and not actual start of treatment right after new HIV diagnosis. Follow-up status was obtained only from individuals that followed care. The lack of outright refusal can be understood as stated literally or as a strategic refusal of recommendations made by an expert. However, individuals who opted to initiate care at another facility may have actually started care as communicated, and those that initiated but did not return to follow care may have 'silently' transferred care (without formal documentation and communication with the first facility). Future studies that capture contact information of persons with new diagnosis, despite the sensitivity of recruitment at this time, and continue to assess individuals over time may generate more reliable information than what is interpreted in this study.

Conclusions

Newly diagnosed individuals in this setting had material and relational vulnerabilities, that may have been a result of low formal education attainment, affected physical health, and sub-optimal social support systems whose members may not appreciate the new reality of HIV as a manageable chronic illness. The recommendations made by clinical health care providers are weighed against

their perception of current health status, opportunity cost of following care, and anticipated support. For individuals with demonstrated vulnerabilities, linkage with social support systems and promotion of improved health as an incentive may influence their decision to start a lifelong clinical treatment. This can be further facilitated by constructing societies that are aware of the benefits of ART in otherwise healthy individuals.

Chapter 4

Initial considerations made by vulnerable individuals newly diagnosed with HIV during a universal test-and-treat era

Abstract

Background: Vulnerability in a setting of poverty mediates exposure to HIV. Persons newly diagnosed with HIV will need to start managing continuing vulnerabilities that led them to being infected with HIV, and also new vulnerabilities in the context of their HIV infection. We explored this transitional process by analyzing how newly diagnosed PLHIV receive, interpret and conceptualize a new chronic diagnosis and the experiences that led to it.

Methods: From October 2016 to November 2017, 93 in-depth interviews were conducted with 13 male and 13 female newly diagnosed persons in Lilongwe, Malawi. Their narration of experiences that led them to HIV infection and the concepts of receiving and interpreting a new diagnosis were analyzed using a grounded theory approach. ATLAS.ti was used to analyze and compare raw data, emerging themes, and conceptual categories, which were further updated by organizing principles and prepared into a synthesized narrative.

Results: Individuals reported persistent sickness, disrupted relationships and behavior guided by gender norms before coming to be tested for HIV. Clinical and non-clinical solutions were sought for the sickness without finding resolutions. Family, friends and health care providers then advised individuals to test for HIV. Recent past sexual relations were reported as fluid and were used as a means of proving gender roles, preserving relationships and securing physical or financial care.

Given the demonstrated improved health outcomes of initiating ART early, participants welcomed initiation of clinical treatment but feared stigma: including changes in appearance, being labelled as someone who has had reckless sexual experience, limited fertility options (including partner choices) and needing resources more than usual to care for their compromised health.

Conclusions: Given the demonstrated positive health outcomes of ART, clinical treatment was welcomed by newly diagnosed persons. However, initiating ART came at a cost of revealing them to be identified with societal labels of what it means to be a PLHIV. Acceptance of individuals diagnosed with HIV in the collective society will require demystification of HIV as a chronic infection, revelation of implications of current gender roles and norms. Doing so will remove the powerlessness and calculated risk taken by many vulnerable sub-groups of the population increasing their vulnerability to HIV and how society views those who acquire the infection.

Introduction

Poverty contributes to compromised health conditions that result in a temporarily or permanently compromised immune system. The health of individuals living in poverty is also affected when they are vulnerable and exposed to HIV/AIDS (Mufune, 2014). Solicited and unsolicited reproductive behaviors in their social network exposes them to initial or repeated sexually transmitted infections. In addition to the direct physical implications, poverty comes with several indirect social implications. When hard-hitting events happen in an individual's life, social ties are affected either positively (strengthened) or negatively (become disturbed and fragile). Even without experiencing poverty at the individual-level, those who live in areas where sexually transmitted infections are highly prevalent and those with a mobile lifestyle (including travelling businessmen, mobile farmers, and fishermen and women) have increased likelihood of being

infected with HIV (Deane, Ngalya, Boniface, Bulugu, & Urassa, 2018; Macpherson et al., 2015; Ombere, Nyambedha, & Bukachi, 2015; Pinho, Sampaio, Monteiro, Murray, & Bastos, 2016).

Vulnerability to HIV in a setting of poverty poses a high risk for HIV infection. Individuals who are infected and diagnosed with HIV as a result of this will have to continue to manage a combination of continuing and new sets of vulnerabilities in the context of their HIV infection. In Malawi and other sub-Saharan African countries, following care for ART requires frequent visits to a health facility in the first months after initiation of treatment and at a more spread apart frequency (every 3 months) once the person stabilizes and responds well to biomedical treatment. This regular clinic-based monitoring requires the individual to dedicate resources, such as time and money, for the purpose of following care as prescribed by health care providers. Additional considerations in areas of privacy, management of stigma, and other socio-behavioral issues are expected to be made by the individuals and persons in their social network. In this chapter, the lived experiences of HIV-positive people are explored by analyzing how a sample of such persons in urban Malawi receive, interpret and conceptualize a new chronic diagnosis and the experiences that led to it during the initial 6 months after the new diagnosis is made.

Methods

Study design: A grounded theory approach (Glaser & Strauss, 1967) was utilized to explore the lived experiences of newly diagnosed HIV positive people in urban Malawi. Data that informed these concepts were obtained during in-depth interview (IDI) of 26 individuals who were newly diagnosed with HIV at 1, 2, 4, and 6 months after the date of their new diagnosis. Theoretical constructs were generated and revealed at various points of data collection and used to add specific probing questions progressively while capturing individual's narrations. A trained evaluator used

an interview guide (Appendix I) to ask universal questions using the framework for "Translating the News" (H. Perazzo, Veloso, Grinsztejn, Hyde, & Castro, 2015) which uses five distinct stages that follow a new HIV diagnosis: (a) receiving the news, (b) interpreting the news, (c) incorporating the news, (d) acting on the news, and (e) moving beyond the news.

Study population: Participants were adults (18 years and older) who came to Lighthouse Clinic for HIV testing and counseling services voluntarily or after being referred to the service by health care providers, family members or friends – and were subsequently diagnosed with HIV for the first time. Persons who self-reported a previous HIV positive test result and children under 18 years of age were excluded.

Recruitment and data handling: From October 2016 to November 2017, a total of 104 interviews were attempted with 13 male and 13 female participants. Based on participants' preference and availability, a total of 93 (89%) interviews were conducted in participants' homes, community and clinic settings. Participants were recruited after routine post-test counseling was conducted for an HIV test that was self-reported to be a first new diagnosis. All adults (18 years and older) were offered a description of the study along with benefits and possible adverse effects, after which informed consent was solicited by a trained counselor to participate in a survey (discussed in Chapter 3). After the survey was conducted, the survey administrator solicited consent for follow-up interviews from 13 males and 13 women (total 26 persons). After consent was obtained, the qualitative data collector scheduled follow-up interviews for 1, 2, 4, and 6 months after the date of consent. As patients followed routine health services according to their individual decisions, a series of four in-depth interviews were attempted for each participant, at a place and time preferred by the participant.

Section A and B of Appendix I were used to guide the initial in-depth interview at 1-month post HIV diagnosis. Sections B through E of Appendix I were used to guide discussions in the following three consecutive sessions at 2, 4, and 6-month after the new HIV diagnosis was made. Interviews were conducted in Chichewa, English or a mix of the two based on the participant's preference, and then audiotaped, transcribed verbatim and translated to English. The investigator reviewed interview transcripts, and jointly identified strategies to strengthen data collection and interview techniques with the qualitative data collector. The interview guide was edited further to probe more on specific concepts and used in follow-up interviews.

Names of participants and other personal identifying information was not captured on the consent or transcripts of interviews. Data logs were used to record time, date, place, interviewer, and other basic record-keeping components at the end of each day after research activities have been undertaken. Qualitative analysis, including coding and thematic analysis was done by the investigator using ATLAS.ti version 8.4.2, and modified continually. Using study objectives and problem analysis, the raw data, themes, and conceptual categories were systematically analyzed and compared. Updated themes and conceptual organizing principles were used in a second round of analysis and prepared into a synthesized narrative. In this chapter, we focused on concepts related to how participants received and interpreted the news during the initial 6 months after diagnosis. We also explored how they interpreted the experiences that they believed to be causes of their HIV infection.

Results

Sociodemographic and interview summary of the 93 IDIs conducted with 26 individuals who self-reported a new HIV diagnosis are shown in Table 8. An equal number (13) of male and female participants were interviewed; their ages ranged from 19 to 52 years old.

#	Age	Gender	Marital Status	# of kids	Month of new HIV diagnosis	# of follow-up interviews conducted	Year of most recent previous HIV test
1	24	Female	Married	2	Oct-16	3	2011
2	33	Female	Married	4	Oct-16	4	2015
3	28	Female	Married	1	Oct-16	1	2015
4	26	Female	Divorced	1	Oct-16	4	2016
5	21	Female	Single	0	Oct-16	2	2014
6	40	Male	Married	4	Oct-16	4	2000
7	39	Female	Separated	3	Nov-16	4	2016
8	52	Male	Divorced	2	Nov-16	4	Never
9	24	Female	Single	0	Nov-16	4	Never
10	32	Male	Separated	3	Dec-16	4	2016
11	25	Female	Married	1	Dec-16	3	2014
12	21	Male	Partner	0	Dec-16	4	2016
13	28	Female	Married	1	Dec-16	3	Never
14	48	Female	Widowed	4	Dec-16	4	Never
15	52	Male	Married	4	Jan-17	4	2012
16	36	Male	Partner	1	Jan-17	3	2010
17	34	Male	Married	2	Feb-17	4	2013
18	42	Male	Married	3	Feb-17	4	2002
19	31	Male	Divorced	1	Feb-17	4	2014
20	28	Male	Married	2	Mar-17	4	2014
21	19	Female	Single	0	Mar-17	4	Never
22	42	Male	Divorced	1	Mar-17	4	Never
23	21	Female	Married	1	Mar-17	2	2016
24	40	Female	married	3	Mar-17	4	2013
25	48	Male	Married	5	Mar-17	4	2015
26	33	Male	Married	0	May-17	4	2015

Table 8. Sociodemographic and interview profiles of in-depth interview participants from October 2016 to November 2017

Although four interviews were attempted for all participants, only 12 (92%) of the 13 male and 7 (54%) of the 13 female participants were available for all 4 interviews. Reasons for fewer than 4 interviews per participant include travel away from home (for school and to visit or stay with relatives), and not being able to be reached to arrange a follow-up interview as agreed. When available, participants were interviewed even if the earlier months' follow-up interviews were missed.

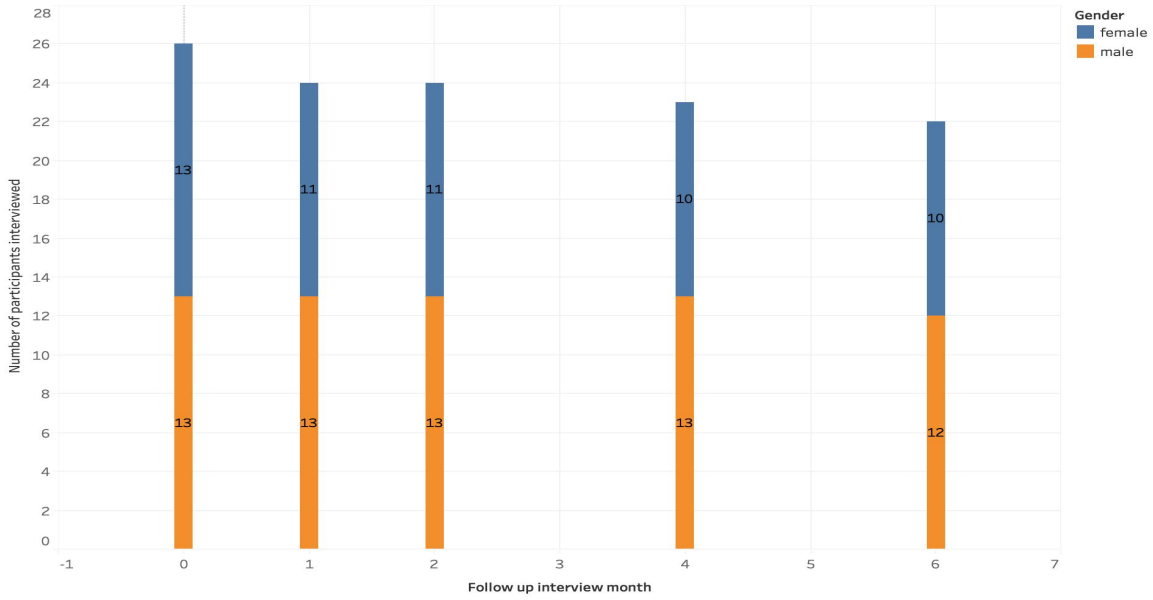

Figure 1. Distribution of follow-up in-depth interviews conducted for 26 participants during October 2016 to November 2017

Health condition leading to HIV testing

Most participants reported having been sick for months before coming to be tested for HIV. The types of sicknesses cited include malaria, lowered appetite and opportunistic infections such as diarrhea, anal and mouth herpes, lowered appetite, stomachache, cough, and general body weakness. However, for some participants these sicknesses were not associated with HIV infection right away.

"I should just say that I had problems with appetite. I had been drinking beer and smoking for a long time and it was difficult for me to concentrate on food and I attributed that to the beer. At one point I noted that my digestive system was not normal. It might be that my liver was affected due to taking beer and smoking. There have been certain things that have changed since the first treatment I was given, as I was not aware where these things were emanating from. I also observed that I felt pain on my gum and was not able to chew." - *52-year-old male at 1-month follow-up*

"I would experience dizziness and will feel weak in the joints. I wondered if it was because of lack of food or caused by a disease. That is why I reported to the clinic, so that they can find out what the main cause is. I experienced [the sickness] for 5 months. I would get better for a month and then it will restart." – *48-year-old male at 1-month follow-up*

As a result, many participants sought clinical and non-clinical solutions from various sources, including traditional medicine and use of prescription and non-prescription medicines. When seeking clinical care, there were some instances where symptoms were treated without the person being tested for HIV.

"Sometimes [the traditional doctor] will tell me that it was in relation to magic. That some people were making me work during the night and that was the reason I felt weak in the joints. It didn't assist. That is why I was certain to follow what the hospital will say." – *48-year-old male at 1-month follow-up*

"I was not feeling well and that is what made me report to the clinic. I was suffering from stomach pains and coughs most of the times, when I realized that the stomach pains were getting worse, I decided to report to the clinic so that I should know the truth. It is not good to report to the clinic when one is very sick. I reported to [another] clinic where I told them that

I am having stomach problems and they gave me some drugs. There was no improvement when I took the drugs. I then decided to come here. – *25-year-old female at 1-month follow-up*

"I felt general body pains whenever I have been working continuously. I would take/swallow [a pain killer]. I just made the decision depending on how I have been feeling and also that I lost my husband. I thought he might have died due to the same disease (referring to HIV)." – *48-year-old female at 1-month follow-up*

When sickness persisted, most individuals sought care from a specialized HIV clinic suspecting an HIV infection. This was sometimes initiated by health care providers when seeking care for other reasons. In social circles, such encouragement came from co-workers and other PLHIV who knew the risks for and symptoms of HIV. Such advices were taken by most participants as loving care expressed by someone who felt close to them.

"I was suffering from Malaria and was referred here from Kamuzu Central Hospital. There was also a certain problem. I had developed some sores at the anal area. I think that is what made [the health care provider] send me here. The wounds were there [for almost 6 months] but I reported to the hospital because of Malaria. It was like blisters that look like the ones that develop when one has been burned by hot water. It will heal after some time. I explained to them about it and the doctor said no to Lighthouse (a specialized HIV clinic). I was given some drugs and they healed." - *42-year-old male at 1-month follow-up*

"[The friend] said "you have reached a point where you need to report to the clinic and get tested. You don't know the disease that resulted in your husband's death. There is need for you to go and get tested so that you should know your status". – *48-year-old female at 1-month follow-up*

Some participants had realized that they may be at risk of HIV and had considered to get tested for HIV themselves or asked their partners to be tested. However, this approach was abandoned because their partner refused to get tested for HIV.

> "We thought about [getting tested] one time but he refused. I brought it up because of how he was behaving." – *48-year-old female at 1-month follow-up*

When female partners asked male partners, refusal reasons cited by male partners were being too busy, being afraid of an HIV diagnosis, or lack of trust indicated by their partner's asking to get tested.

> "He saw me and asked me out. I accepted. Where I stay, there are no relatives of his who I could have asked about his history, how he lives and what he does. I just accepted and got into the relationship. He wanted us to have sex, but I told him that 'I cannot take off my clothes for you. These days are dangerous as there is a disease. There is need for us to get tested.' He then said "I am busy. It is possible (for you) to take my health passport and the health personnel will be able to check the (identification) number in the system. It is possible since I tested at [a clinic]". I didn't believe him and asked, 'Why are you refusing to get tested?' He said 'You should get my health passport. When they check my number, they will know that I am fine. I can't find time to get tested.'" – *21-year-old female at 4-month follow-up*

> "At first it was difficult for him to accept but after giving it some thought he agreed. I don't know what happened for him to agree because he refused at first saying I don't trust him. I told him that I do trust him, but he does not know my status. He then agreed." - *19-year-old female at 1-month follow-up*

"I know my status and I don't know his status. It is not good that the virus that he has should be combined with the virus that is in my body. He refused which shows that maybe he is not serious. That is why we decided that the relationship should be over." – *24-year-old female at 6-month follow-up*

"I got separated with my (previous) husband and he refused to get tested when he visited. When I met with this one (*the current partner*), he was also reluctant to get tested and we did not have the test. There were some family issues. Whilst I was here, he married another woman and that is why I called him so that he should get tested, but he refused to have the test." - *39-year-old female at 1-month follow-up*

Fluid sexual relationships

When describing their sexual partners before being diagnoses with HIV, most individuals described recently disrupted marital relationships. Some participants had found out that persons whom they had sexual relationships with or considered for potential life partnership were now suspected of being diagnosed with HIV or have passed away.

"I talked to her about marriage. I didn't know about her status at the time. I had a chance to find out her history and also heard that she passed away last year." – *52-year-old male at 4-month follow-up*

Most of the relationships described were fluid and terminated, as needed, after starting sexual relationships. Multiple men described being separated from their wives and living in separate locations when they were not able to support them financially or due to other personal conflicts.

"I left her there and I went to my home. It took 6 months. Her family members then realized that they made a mistake after they had discussed. They came and told me that "Sorry things

were not right. Here is your wife. We have brought her." I didn't refuse because I knew that I had no problems with her. It was the other people who brought issues. I was living alone with the children." – *48-year-old male at 2-month follow-up*

"The houses are close, but we do not live in the same house. We prepare food together. We farm together. I don't have a child for him. She (referring to the first wife) has also not bore a child for him. When we started a relationship we didn't get tested, so each one of us may be suspecting the other. I can say that it was him, and he can say that it is me. It could have been good if we had gotten tested at the beginning of the relationship. Everyone would have known. From my own perspective I think he is the one who contracted the disease. I think the woman whom he separated with is also on treatment. He gets one woman and then dumps her. I didn't know his behavior, but I still stayed because of the condition that he found this one (referring to her child from a previous relationship). My child was not breastfed, and he was the one who was buying milk for her. He has left so many wives. I may be the 10th one." - *21-year-old female at 4-month follow-up*

"We have never had adultery issues since we got married. Of course, we have had disagreements. For instance, about children. The children may have bad behavior and one of us would get angry upon being corrected, may be up to a point of living separate lives for three months." – *48-year-old male at 4-month follow-up*

One 19-year-old female described being from a family of 11 children from 7 mothers. She lived with her father who travels frequently, a stepmother whom she considers 'talkative' and siblings who are close in age to her and care for her. She suspects her stepmother is taking ART but there was no clear communication about it. She doesn't know the HIV status of her father because she

has not seen him taking his antiretroviral drugs (ARVs[1]). Her biological mother lives in a different town and is on ART. She describes having had four non-concurrent boyfriends, so far. Regarding the many stepmothers she has had, she describes: "One of them just considered me as her sister, not a step daughter. I used to share a lot of things with her. She is not around since she broke up with my father. My parents got divorced when I was 10 or 11-year-old." Her father travels frequently and her stepmother follows him frequently. Regarding her biological mother who lives in a different city, she states "I can't say that we communicate because I do not talk to her. Her phone was damaged."

Power dynamics in sexual relationships

Older women assumed that condom use could be negotiated once condoms are secured from clinics. However, this was not a reality for the younger women participants. They described not being able to negotiate use of protection in sexual relationships. Their partner's fertility intentions and pleasure trumped their preferences for self-management of their health. Clinical services were able to, however, give women control regarding fertility intentions but not regarding use of protection during sexual encounters. This left them prone to sexually transmitted and other illnesses that negatively affected their health status.

> "We don't agree properly. We stopped using condoms a long time ago. I am anxious because we are doing something different from what we were told. I don't know exactly why he refuses to use [condoms]. He just says that he is used to doing it plain and that he can't manage. I plead with him. He doesn't give me a definite answer. He wants a child. His main wish is that he wants a child and that is why he does it plain. I did get an injection for family planning and

[1] ARV which is an acronym for antiretrovirals is also a commonly used term when speaking in the local language (Chichewa) to refer to the antiretroviral drugs.

he does not know that. He thinks that I stopped doing that. I don't want a child as of now. I want this (3-year-old) child to turn five. That is when I will give birth." – *21-year-old female at 4-month follow-up*

"We were using condoms but sometimes he will refuse. He would not agree. He would ask me if I wanted him to have sex outside our marriage. If I let him use condoms, it was like eating a sweet while it is in its wrapper. I would just accept as house wife. The owner of the house has decided." – *24-year-old female at 2-month follow-up*

"He wouldn't just let me be. As his partner, he would want to feel that he is my partner. Each of us had not tested to know our status, whether we had it or not. None of us knew. We were protecting ourselves but in the midst of protecting ourselves we wouldn't know if what he had used was fine. It's not that we were not using protection. We were using it. We were using condoms when we wanted to have sex. Maybe the condom had a mistake somewhere." – *21-year-old female at 2-month follow-up*

Cause of infection according to self-assessment

Individuals formed theories about how they acquired an HIV infection. The majority of their theories are influenced by general knowledge that originated from or were influenced by clinical explanations. Some participants preferred to attribute the cause of their infection to non-sexual reasons, such as stabbing, blood transfusion, and shared household items when caring for relatives that were sick and known or unknown to be infected with HIV.

Most described having been in relationships that were not exclusively monogamous and suspected their own and their partner's behavior as the cause of their infection.

"I may not trust the wife and she may also not trust me. I was thinking that either one of us misbehaved at some point and that resulted in contracting the virus. It could be that sometimes I have not given my wife some money and she may be disappointed as to why I have done that. I may also be disappointed by my wife and think of leaving her and finding another partner. Those are some of the things that may make us have different ideas. I don't know what happened." – *48-year-old male at 1-month follow-up*

"Before I met him, I had another partner and we got tested at the beginning of that relationship. I did not get tested when I started the relationship with him (current husband) and we started having unprotected sex which resulted in pregnancy. I got tested when I was pregnant and even at the time that I was with my ex, the results were fine (negative). It all happened after I got into relationship with him (current husband). I have never been with any other man since I got into relationship with him." - *25-year-old female at t 2-month follow-up*

A number of men admitted socializing with women outside their steady relationships routinely. A good amount of the men interviewed travelled for work. Among businessmen who travel for work, having casual sexual relations after a night of drinking was considered a norm.

"I used to travel a lot as I was visiting markets and it wouldn't be possible that I should not meet someone. It was impossible for me not to sleep with a woman whenever I go to the field. You know when you are immature, you tend to be involved in social activities such as drinking beer. When we are in the field, we used to communicate and meet up as we were all business people." – *34-year-old male, 1-month follow-up*

Some attributed their infection to a casual sexual encounter they had with a specific person.

"It was during the time that I went [away from home] I stayed there for 9 months. There was a certain lady who was sleeping near the same area. I used to chat very well with the woman, and I had a crush on her. I asked her and she accepted. I rushed into sleeping with her as she may think like I am not a real man. I had to sleep with her so that she should know that I am a man. After I did that, some of my friends told me that the woman that I am sleeping with sleeps around. That is when I realized." – *33-year-old male at 1-month follow-up*

"I misbehaved at one point. Actually, there was one lady. She came from [another city] and came into my house as my wife. She was a prostitute and eventually she left me. She just moved into my house. I can't say that I married her as there were no marriage arrangements. I believe it was her, because she passed away in 2014." - *42-year-old male at 1-month follow-up*

Women who thought their risk came from their husband's behaviors stayed in the marriage because they felt other options were not sustainable. Leaving a current relationship would have resulted in having to rely on kin as a safety network, or with a need to establish a support system anew.

"I contracted it from the man who passed away (referring to her husband). His business involved a lot of travelling. He was selling fish. I suspected because most business people have a certain kind of behavior. He liked having other partners. I have been married to him for 25 years but most of the times he had other partners. He was my husband. What else could I have done? I thought it will be difficult for me to get tested on my own, yet we were sleeping together." – *48-year-old female at 1-month follow-up*

"He likes women. Sometimes we would not communicate well. We had disagreements which resulted in him sleeping out. It would happen that today he will sleep out, then return the

following day and go back the next day. At the time he hated that I was doing business. He wanted me to stay home and he was also just staying home. The vehicle was not good (he is a minibus driver). I thought it was not a wise thing for both of us to just be staying home (not earning money). We live in a rented house." - *28-year-old female at 1-month follow-up*

"I went to his home village and that is where I heard more about him. The women were not from the village. They were from the town. He mostly spends much time in town. [At that point] it was difficult for me to leave. How will I leave with this burden that I received (referring to the HIV diagnosis)? I can leave but I will have to start leading my own life and it will be difficult to find a man who is also taking the drugs. That is why I just stayed because it had already happened, but I have the desire to leave." - *21-year-old female at 4-month follow-up*

General knowledge about management of HIV

Previously, HIV infection was blamed on other causes such as witchcraft.

"In the past people tended to forget what they had been doing. They would blame it mostly on witchcraft. Our parents and forefathers were tortured just because of witchcraft. For instance, if a child gets sick some will say 'This one is bewitching my child'. It was due to ignorance in the past. If it still happens, it might be because people don't want to accept. People know the kind of life they lead. When that time comes, they would not want to accept and report to the clinic, as some as scared." – *52-year-old male at 4-month follow-up*

However, in recent times, even before being diagnosed with HIV themselves, participants were aware of HIV, its mode of transmissions, and effects of ART. A good number of participants mentioned having co-workers, friends or immediate and extended family members that were

infected with HIV and taking ART. Their own or others' diagnosis, even if it was positive, was well received by a number of participants because it equipped them with the knowledge that prompted them to seek further guidance and modify behavior, as needed.

> I thought it was good for them because their life could have been going on well unlike us, who are not aware of our status." - *48-year-old male at 6-month follow-up*

Based on observations of other PLHIV, being on ART was generally considered as a game changer. A good number of participants highlighted that starting ART while healthy resulted in better health outcomes, when compared to starting it after being severely ill. However, there were also fears expressed about ART's effectiveness wearing off with time.

> "They set an example to me as some of them will say that 'I have been taking the drugs for this long'. I was telling myself that they said that they have been taking the drugs for that long, but their health is good. If I can be taking the drugs that means I can also stay for a long time." – *48-year-old male at 1-month follow-up*

> "They looked fine and their health had improved. They are happy, unlike how they were at the beginning." – *25-year-old female at 1-month follow-up*

> "For most of them, they were improving but I observed that it is difficult for someone's health to get back to normal when they had started taking the drugs at the time when they were sick. Unlike nowadays with the new program where one needs to start taking the drugs once diagnosed. Those who had started taking the drugs after waiting for time can be noticed, unlike those who start taking the drugs right away after the diagnosis." - *52-year-old male at 1-month follow-up*

"Some may have diarrhea. Some just die. In my case, I don't know how I will be at the end, when the drugs run out because people say that when you take the drugs for 6 years, they tend to be useless (ineffective). If you have been taking the drugs for 6 years, the immunity declines and the drugs becomes useless. Even if you will be taking them, they do not function. That is what I hear from those who are not doctors." – *21-year-old female at 4-month follow-up*

Implications of living with HIV

Most people were also acutely sensitive about an HIV diagnosis being associated with having too many sexual partners.

"They say that those who were diagnosed (with HIV) are those who were indulging in a lot of sexual activity. That is what they think yet maybe it is not like that. It is because they hear that HIV is contracted through sexual intercourse. Sometimes it is contracted through sharing of razor blades or needles, or blood transfusion." - *48-year-old male at 6-month follow-up*

Changes in in appearance were noted by onlookers as effects of being on ART. However, not all changes in appearance were wanted. Some described weight (re-)gain as an improvement while other described it as disproportionate. Developing rashes was also a feared change in appearance that was believed to have resulted from taking ART. Since most PLHIV did not openly discuss their own status, such changes were used to infer that someone is on ART or suspected to be infected with HIV.

Someone said that a person may swell once they start taking the drugs and that was holding me back." – *34-year-old male, 1-month follow-up*

*"*Some people will start taking the drugs and develop skin rashes. Yet they don't stop. Some will look good once they start taking the drugs. I have seen people who have developed black

spots once they started taking the drugs but people tend to accept as it has happened." – *21-year-old male at 1-month follow-up*

"My twin sister looked healthy. She was gaining weight. And someone like me, who was fine was just losing weight. The one who was taking the drugs looked healthy." - *24-year-old female at 1-month follow-up*

"I lost weight when I got separated with my husband but since I started taking the drugs I have changed. People say that it is because I am eating well. If I tell someone today that I am taking the drugs, the person may think that I am lying just because of my appearance. There is one woman near where I live. I actually know that she is infected even though she lies to people about her skin rash. Her appearance shows that she is infected. For instance, you can't say that you have developed skin rash just because of a cold. What kind of a cold? The woman actually refuses to report to the clinic, but her husband spends much of his time drinking and comes home in the night. She says that she can't go to the clinic because she is fine. No one has ever talked about me, but they gossip about her that she is failing to accept. If I had been irresponsible, I could have reached a point where people could have been talking about it. But I didn't." – *26-year-old female at 6-month follow-up*

Because of preconceived notions about how HIV is acquired, people who perceived themselves to be young or inexperienced considered HIV as an infection of older people who are assumed to have had have extensive life experiences that can resulted in an infection.

"I used to think that it is for those who are older. There are things that I was considering, for example maybe they have done a lot in life, especially on going around. Maybe sharing of items, it could be that they were lending each other razors for cutting. Sometimes one may be

involved in an accident. I thought that I am still young, I have not reached an age where I am supposed to be infected with the virus." – *33-year-old male at 1-month follow-up*

A number of participants were aware of health care providers advising PLHIV not to have unprotected sex. This common knowledge was frequently equated with the understanding that a person who is infected with HIV won't have a child.

"I heard some were saying that if you have the disease you don't have a child because you are told at the clinic not to have unprotected sex. I also heard that a person gets disfigured, the body develops somethings and whenever I think like that eeeh." – *33-year-old male at 1-month follow-up*

Being infected with HIV was associated with having a need for being well resourced, especially when it comes to food.

"Considering what I have observed, I think that one needs the right resources. When I think of people who live in the village and do not have anything, it is very sad. When I say right resources, I am referring to good food, one shouldn't lack food. Good food can be any kind of food, but one requires to eat at a proper time, and it is dangerous not to do so. You get weak when you have taken the drugs without food. Sometimes you can't even work, and one needs to work." - *42-year-old male at 1-month follow-up*

Overall, the vulnerabilities described by participants and considerations made about initiation of ART are summarized in Table 9.

Self-described vulnerabilities	Actions taken by individuals and their social network	Considerations made before starting ART
Persistent sickness	Took prescription pills, traditional medicine, sought clinical care for symptoms	Benefit: - known to have improved health outcomes, if started early Fears: - change in physical appearance - being insulted by others - labelled as someone with reckless sexual experience - affected fertility intentions; limited choice of partners - need for resources to self-manage health
	Advice from family, friends and health care providers to be tested for HIV	
Suspected partner may have extramarital relations	- Asked partner to be tested - Discontinued relationship; sought new relationship	
Expected gender norms: of 'real man', need to preserve relationship, need for physical or financial care provider	Started or remained in relationships with known risks	

Table 9. Concepts of vulnerability, actions, and considerations described by persons newly diagnosed with HIV in Lilongwe, Malawi

Discussion

Poverty has been linked to higher risk of HIV in both developed and developing nations. However, when deciphering the types of poverty, the relatively poor maybe at a higher risk of HIV infection when compared to the absolute poor (A. M. Fox, 2010). Absolute poverty has been defined as lacking basic needs such as food, water and sanitation, while relative poverty is defined as having basic needs met but having relatively fewer resources. Recent research has identified that material deprivation, vulnerability and marginality mediate the association between poverty and exposure to HIV (Mufune, 2014). The findings in this chapter demonstrate how vulnerability accumulates and plays a role in vulnerability to HIV infection and in the context of HIV infection. The layered vulnerabilities result in unfavorable daily lives, learned powerlessness, separation from support systems, and lowered feeling of mastery over life (Peretti-Watel et al., 2006). Subsequently, these vulnerabilities resulted in living a life with known risks but without feasible way out of their

current situations. A person with such vulnerabilities in a poverty setting has a high risk of being infected with HIV. These sets of vulnerabilities continue to affect their lives as a PLHIV and play a role in how they manage vulnerability in the context of HIV.

Individuals were aware of the negative health outcomes posed by their cumulative vulnerability, and also the potential future of having positive health outcomes if found HIV positive and initiating ART early. However, these dynamics were complicated by the social implications of what it means to be HIV positive. A previous study has found that a number of individuals in a similar setting worried about others, predominantly their partners', behavior rather than their own behaviors when assessing their risk of contracting HIV (Roth, Ngugi, & Fujita, 2009). Similarly, participants in this study also discussed their partner's behavior as their reason for testing or cause of infection. This was especially pronounced with female participants. Other explanations given were sharing of household items when caring for sick relatives. This may be actual, or an internal process taken before accepting the diagnosis and making further lifestyle adjustments. Once infected and before being clinically diagnosed, most participant's physical health was already compromised, and possible options were explored, and known to not be working. Given the widely demonstrated positive health outcomes of ART, most individuals actively sought HIV testing and welcomed being on treatment with the anticipation of improved health outcomes.

Our study participants were well aware of ART's positive outcomes on health status. This is not a surprising finding since participants were selected from a specialized HIV clinic, and more likely to be health care seeking groups that have already exhausted other clinical and non-clinical options. However, minimal disclosure practices and hearsay about effects of ART have resulted in individuals having to extrapolate about the meaning of concepts introduced by health care providers during counseling sessions. Changes in physical appearances were the common ways

used for suspecting an HIV infection or being on clinical treatment to manage HIV. The suspected diagnosis, its treatment, or counseling for self-management of health was usually interpreted by participants as having a causal association with the symptoms they observe in their daily lives. For example, weight loss and rashes were associated with HIV infection, weight gain and rashes were associated with being on ART, and advice for practicing safe sex were translated as resulting in a childless future.

Individuals came from disrupted or fluid relationships that were not secured with trust or mutual expectations of monogamy[2]. However, their current situation was taken as the better option of other available alternatives. Sexual relationships were described as a means to financial security, obtaining physical care, or proving social gender norms. Some individuals incurred the risk of a chronic infection knowingly. Most women describe being in relationships that were known to have a risk of sexually transmitted infections but were not in a position to leave the relationship or negotiate protected sex.

The dimensions of vulnerability have previously been categorized at individual, social and programmatic levels, with governmental laws being categorized under the latter dimension (Ayres et al., 2006). The Government of Malawi has laws that aim to protect individuals that may consider themselves to be victims of disrupted relationships. Malawi's Marriage, Divorce and Family Relations Act of 2015 recognized marriages of various types: civil marriage, customary marriage, religious marriage, and marriage by reputation or permanent cohabitation. Polygamy is punishable by law with five years of imprisonment. In non-marital relationships, the responsibility for a single

[2] Marital relationships did not come with expectations of exclusive monogamy. There was uncommunicated understanding that one of the partners can choose to have sexual relations outside their marriage. Extramarital relationships were not clearly communicated, but only suspected until proven by hearsay. Other sexual relationships usually happened during times of conflict between couples.

pregnant woman's support during her pregnancy and delivery lays with the father of the child. However, the Marriage Act leaves open the responsibility of child care. It simply states enforcement of order for what the single pregnant woman may apply for. In some cases of participants that sought protection through this law, the inability of males to provide financial support resulted in imprisonment and women needing to re-establish new support systems. However, in the absence of interventions that focus on the individual and social-level dimensions of vulnerability, government-level interventions of vulnerability interventions can have a hollow effect for sub-groups of the population. In the case of the 21-year-old unmarried participant in this study, her immediate family (parents) couldn't support her financially after the father of her child went to prison due to an inability to support her financially and remain monogamous. As a result, she chose to be a second wife of an abusive man who provided money to buy milk for her child. This was done knowing the risk of a chronic infection but with the need to survive in the short term.

Limitations

Participants were recruited from a clinic that is located within the campus of the central hospital in the capital city of Malawi. The facility is moderately accessible, and reachable by public transport for those that can afford to pay for it. However, it is not walkable for many who do not live nearby and not able to afford public transportation. The clinic is also known for the specialized prevention, treatment and care it provides for HIV. As such, participants are more likely to be care seeking and sicker than those who tested for HIV during community-based HIV testing campaigns or antenatal service provision. Therefore, interpretation of findings from this study should be taken with the biased selection of the informants in mind.

Conclusion

In resource-limited settings, often health facilities have targeted the individual dimension while governments have targeted the programmatic dimension. The social dimensions of vulnerability are left to civil societies which are relatively poorly funded and not well equipped to undertake the demystification of chronic infections. Social norms and gender relations lag behind individual and programmatic-level advancements in healthcare. Acceptance of individuals diagnosed with HIV in the collective society will require clear revelations of implications of current gender roles and re-learning the value and consideration assigned to men, women and childless adults. Doing so will remove the powerlessness and calculated risk taken by many vulnerable sub-groups of the population increasing their vulnerability to HIV and how society views those who acquire the infection.

Chapter 5

Adjusting to living with a new HIV diagnosis in a test-and-treat era

Abstract

Background: Once people newly diagnosed with HIV decide to initiate ART, they must incorporate the news of HIV diagnosis in redefining themselves and adjusting their social capital. In this chapter, we explore how newly diagnosed individuals describe the health-related quality of life (HRQOL), adjust to their new identity and secure or maintain social support.

Methods: A total of 93 in-depth interviews (IDIs) were conducted with 13 males and 13 females that ranged from 19 to 52 years in age, and self-reported being newly diagnosed with HIV at a high burden urban HIV clinic in Lilongwe, Malawi. The IDIs were conducted at 1, 2, 4, and 6 months after the day of new HIV diagnosis. After transcripts were read, raw data, themes, and conceptual categories were systematically analyzed and compared using ATLAS.ti. Participants also reported on their health-related quality of life (HRQOL), which were combined with their self-described process of management of health was used to generate a synthesized narrative that described how they incorporated the new diagnosis with their daily lives, acted on it, and moved beyond it.

Results: Assessment of HRQOL demonstrate that newly diagnosed PLHIV were resilient while vulnerable. They described their heath in terms of observed symptoms, energy levels, limitations in activities, and in association with the behavior they believe to have caused the HIV infection. During the initial months after diagnosis, management of additional health conditions resulted in added pill burden and clinic visit. Regained health enabled them to have dignity and resume social

activities. Emotional, physical and financial support were obtained from current marital and non-marital partners, kin (siblings, parents and children), and close friends. For many, facility- and community-based social groups provided financial and emotional support, while a religious framework provided emotional support.

Conclusions: The newly diagnosed individuals demonstrated forms of both resilience and vulnerability. To be resilient, support for self-management of health was sought and obtained from health care providers, experiences and advice shared from persons in their social network, and religious thought processes. Public health approaches should take into consideration that positive health outcomes are hard to achieve by availing clinical services alone. Comprehensive health services should target the individuals and their social network and facilitate the supplementation of clinical services with social support.

Introduction

In settings where antiretroviral therapy (ART) is accessible, HIV is no longer a probable cause of death, but a chronic infection people can live with. This chronic infection can now be managed by a combination of self-care, biomedical disease management, and social normalization (McGrath et al., 2014). However, this construct is challenged by the need to maintain privacy and the high cost of self-management of health. In many settings, being HIV positive still has a stigma associated with it. In addition to this, the required clinic visits add tremendous monetary and non-monetary costs to a majority of the poor, who are disproportionately infected and affected by HIV. The self-management of HIV is also challenged by the long course of the infection, factors that influence the role of biomedical health systems, and individuals' continued effort to recapture normal life. In resource-limited settings, HIV is highly associated with disability, economic

incapacity and mortality, which can make people living with HIV (PLHIV) be perceived as less fit in regards to norms of reciprocity (Tsai, Bangsberg, & Weiser, 2013). As a result, newly diagnosed PLHIV face layered challenges in self-management of their health that are a result of a newly incurred cost of following clinical care while maintaining privacy to manage stigma.

Although the increased ability to access ART has allowed and given promise to normalization of individuals' lives, cultural beliefs and social norms still lag behind this normalization process. 'Social death' is a concept PLHIV in most sub-Saharan Africa settings continue to live with and/or in fear of (Tsai et al., 2013). This is caused by stigma, which results in potential for loss of social status, being considered as a potential vector of viral infection despite appearing healthy and being labelled as someone that is going to die soon. Such perception of an HIV-infected person results in erosion of social support which is a key element of social relationships in the framework for self-management of chronic diseases (Swendeman et al., 2009). As a result of this cost, even individuals who suspect themselves to be infected with HIV shy away from testing and/or, if tested, do not disclose their positive status to others in their social network. This sweeping of HIV infection under the rug contributes to negative and not well managed stories about HIV to continue to be the social norms. This, however, may be changing as people living with HIV (PLHIV) are being initiated on ART before there are symptomatic with a national-level universal test-and-treat (UTT) strategy. In this Chapter, we explored how persons who are newly diagnosed with HIV manage their quality of health, adjust to a new identity in their personal and social lives, and secure or maintain social support.

Methods

We conducted 93 in-depth interviews (IDIs) with 13 males and 13 females who self-reported being newly diagnosed with HIV at a high burden urban HIV clinic in Lilongwe, Malawi. The IDIs were conducted at 1, 2, 4, and 6 months post the new HIV diagnosis. Further details on study design, study population, recruitment strategy, data handling and analysis processes are described in Chapter 4.

The health status of participants was first assessed using the Health-Related Quality of Life core module (CDC HRQOL-4), also known as "*Healthy Days*" (Appendix II), at the time of recruitment (on the day of diagnosis) and then at the beginning of each follow-up in-depth interview. This chapter focuses on the self-reported health-related quality of life (HRQOL) of participants, and their self-described process of management of health as they incorporate the new diagnosis with their daily lives, act on it, and move beyond it. The themes discussed include understanding of illness and wellness, self-management of health, and the process of securing social support as participants adjusted to living with modified identities while living with a chronic and stigmatized infection.

Results

The IDI participants were 13 males and 13 females that ranged from 19 to 52 in age. The sociodemographic characteristics and interview profiles of the 93 IDIs conducted are summarized in Table 8 of Chapter 4.

Health-related quality of life of participants

The self-reported HRQOL of interviewees focused on the health condition of the participants at the time of their recruitment and during their follow-up interviews, including their perception of their general health, number of days physical health was not good due to physical illness and injury, number of days mental health was not good due to stress, depression, and problems with emotions, and number of days poor physical or mental health limited their usual activities, such as self-care, work, or recreation. None of the individuals described their general health as excellent at any time during the initial 6 months. The proportion of participants that described their health as good or very good increased over time (Figure 2). In few individuals, self-reported dissatisfaction with health persisted until the 4-month follow up.

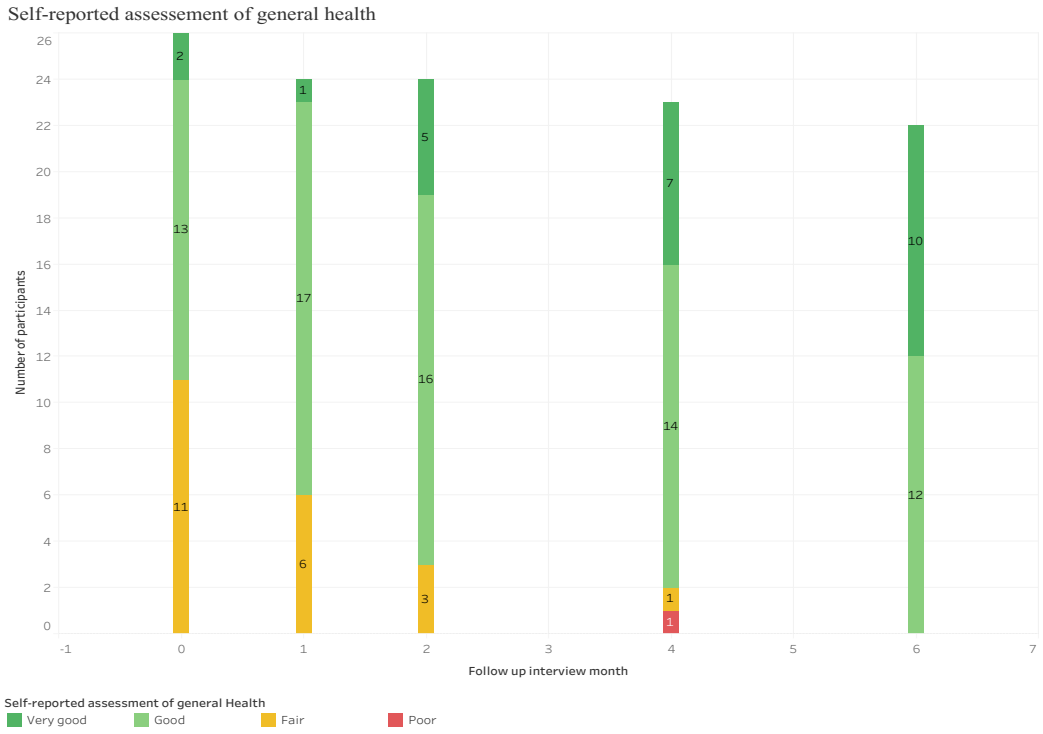

Figure 2. Self-reported self-assessment of general health by 26 persons newly diagnosed with HIV during the 6 months after their new diagnosis

At the time of diagnosis, few individuals reported spending more than half of their past month with poor physical and mental health. The self-reported number of days with poor physical and mental health reduced over time. Despite reporting a substantial amount of days affected with poor physical and mental health, participants reported a minimal number of days that were limited from usual activities due to poor physical or mental health (Figure 3). The number days with poor physical health also decreased with time on treatment.

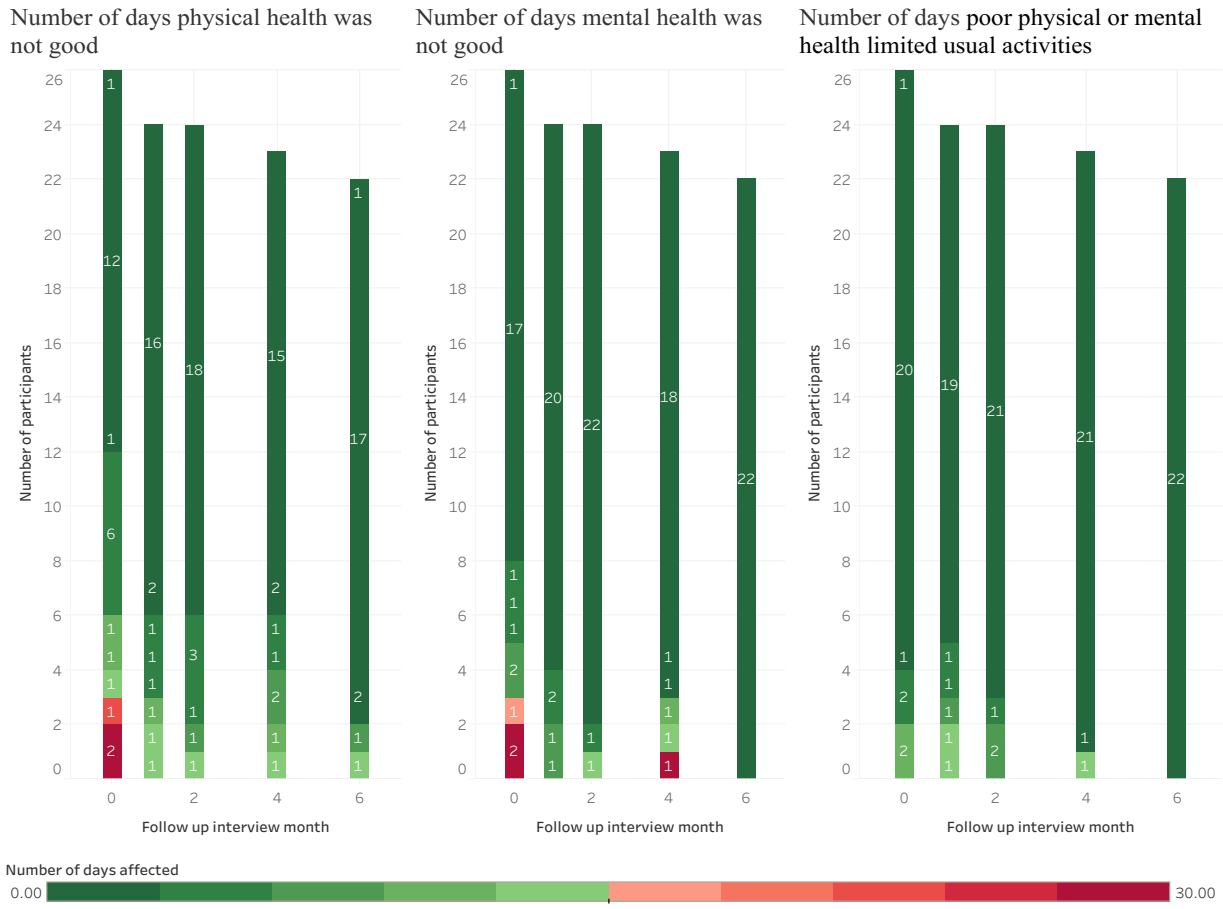

Figure 3. Number of days affected by poor physical and mental health during the initial 6 months for 26 individuals newly diagnosed with HIV from October 2016 to November 2017

Understanding illness and wellness

Participants described illnesses in terms of symptoms (e.g. - weight loss, sores, diarrhea, loss of appetite, dizziness), energy levels, limitations in activities, and in association with the behavior they believe to have caused it – except in cases of common diagnoses such as tuberculosis and malaria. In the case of young persons, some of the suspicions about their symptoms were informed by knowledge gained at school.

> "I noticed that things were changing. They said if a person is feeling like that, it might be that you are infected with HIV. I came to have the test so that I should know my status, whether I have the AIDS virus. I once had shingles, diarrhea and headache which were some of the things that I learnt at school as the signs of HIV. That is why I decided that it might be like that." – *21-year-old female at 1-month follow-up*

Taking HIV medications as prescribed was considered a key element of monitoring and self-managing health. This included making additional arrangements in order to continue to take antiretroviral drugs (ARVs) as prescribed even when staying away from their homes.

> "I make sure that I take the drugs accordingly, I take them every night as I am about to sleep. I remember to take the drugs every time when I have finished eating. I went out to visit my mother who was sick, but I carried the drugs. She was admitted at central hospital and I stayed for one week and I carried the drugs with me." - *25-year-old female at 4-month follow-up*

Since ARVs could be obtained without a fee once a person pays the opportunity cost of making a clinic visit (including time away from work and other routine activities), most individuals focused on good nutrition as another key resource that needed to be secured.

"I am taking care of my health especially in relation to diet, by eating fruits, and a variety of food which is different from how it was. I used to not eat fruits as one should." – *33-year-old male at 6 months follow-up*

"I am taking care of [my health] by buying different kinds of relish and fruits. I think my body may change by eating that kind of food." – *48-year-old male at 4-month follow-up*

"I should be energetic so that I should be able to do some work and find money and required food. I also made a decision to avoid certain food. Broiler chickens, I stopped eating them. The drinks that have a lot of sugar like Coca-Cola, I avoid these nowadays. [I am] taking care of my health because the body is like a house that you sweep when it is dirty. You don't take in dirty things inside. You clean it." - *42-year-old male at 6-month follow-up*

Those without the financial means to secure a good diet were concerned about their daily meals and what a lack of good diet may imply. For those that did not depend on others for financial means, securing the financial means (to buy food) by itself was considered as part of self-management of their health.

"I care for my health by working, by doing piece work whenever I want. I also wash (clothes) whenever someone calls me to." - *48-years-old female at 6-month follow-up*

"I am just continuing to conduct my business so that I can take care of my health. I also eat a right variety of food." - *24-year-old female at 2-month follow-up*

"There are challenges in how I source food. Sometimes I would skip meals and the drugs would not function properly. Sometimes we would find food for a day and we would eat for that day. If we haven't, we would not eat that day. Sometimes I force myself to take the drugs for the sake of taking care of my health. I would burp a lot when I take the drugs without food, and

this means that there is need for something (food). I work as a guard and sometimes we do not get paid. It is difficult to have sufficient budget. I do piece work in the afternoon (assisting at construction sites). [The money] is not enough. Sometimes we would work for some days, but it is difficult to go back to work at the same place. We find that we have been replaced." – *40-year-old-male at 4-month follow-up*

Declined health after initiation of clinical treatment

Most participants had a compromised physical health that had continued to persist at the time they started ART. Ailments reported included diarrhea, general body pains, tuberculosis, malaria, stomach problems, heavy sweating, rashes, high blood pressure, urinary tract infection, reduced sex drive, itchy eyes, numbness, and migraines. After initiating ART, some participants reported new physical health issues such as general weakness, dizziness, loss of appetite, and strong feelings of hunger. Participants described being prescribed additional medications, such as antibiotics, Oral Rehydration Salts (ORS), and TB medications, that helped them mange opportunistic infections, in addition to taking antiretroviral drugs. While taking ART for the first time and attempting to manage other health conditions with prescription medication, dizziness and drowsy feelings affected routine activities such as praying and studying for school exams, which were highly regarded and considered important in their lives.

"Sometimes I wake up feeling weak. I am not as active as I was. Most of the times I am weak. I cannot work the way I used to and that's one thing that is unusual. I interact with friends just fine. I like praying. I used to pray for a long time but that is not possible when I take the drugs. I feel like I have to sleep. I get sleepy early. It is the time that I have already taken the drugs and it becomes difficult to proceed." – *42-year-old male at 2-month follow-up*

"It happened that I have taken the drugs before sleep, but I would need to have much time to rest. I would wake up early and feel somethings, like a bad feeling that my body is not that fresh as the drugs are still working. My study time was limited because I would wake up late, and my brain was not that refreshed to enter into an exam. So, I would not force myself to study." - *19-year-old female at 4-month follow-up*

Infectious co-morbidities such as TB resulted in the need to make different visits for each type of illness -i.e.- one visit to follow TB care at one facility, and another visit to a different facility to follow HIV care. Participants also made additional visits to clinics due to acute illness such as malaria. In a number of such cases, management of co-morbidities increased the pill burden significantly, though for a short term, or added the number of additional clinic visits needed in order to be screened or tested for the suspected illness.

"I developed rashes. I didn't know whether the drugs that I was given were for what I had reported about (the rash). I was given three kinds of drugs (in addition to ARVs). They just told me how I should be taking them. I am taking them, and I now remain with 5, if not 6 tablets." – *33-year-old male at 2-month follow-up*

"The first day, I took two antibiotic, two penicillin and this tablet (ARVs) including Panado. Together, they were 5 tablets and I felt hot after one hour. It was my first time taking the drugs and I thought I overdosed. I went outside to have fresh air and that's when I realized that it was a reaction of the drugs. I also had dizziness and I asked people in the morning. They told me that that's how things are and that they will stop with time." - *52-year-old male at 1-month follow-up*

"I only feel that my eyes itch. It's been almost a month and I have been feeling itchy in my eyes. Today I was told to report to eye department." - *25-year-old female at 4-month follow-up*

"My life is going on well, only that my fingers are numb, and I have severe headache since last month. That was the first time that I started taking the drugs, and now that I am continuing, I am seeing some changes. I also used to feel warm most of the time, but I no longer feel the warmth." – *48-year-old female at 4-month follow-up*

Some illnesses were managed using prescription drugs if the person communicated it to health care providers during routine follow-up of care, or a clinic visit made specifically for that illness.

Regained physical health

Improvements in health were most frequently described in terms of weigh increase and improved appetite. Most used the loss and gain in weight in their description of declined and improved health, respectively.

"[My weight] has dropped. The lowered weight could have been because I coughed a lot and it was difficult for me to eat. I had pain in my neck. I coughed for one week, then it got better." - *25-year-old female at 4-month follow-up*

"I used to weigh myself before I got sick and I was weighing 65kg and when I came here, I weighed 60 something. It is now back. There is an addition of 5 kg making it 65. It is getting normal. It is because I am taking the drugs accordingly. I do not skip." – *48-year-old male at 4-month follow-up*

Other descriptions of regained health were being more energetic, stabilized digestive systems, being pain free, and no longer needing additional medications to manage other health conditions.

"I have been noticing some changes in life for the past two months. My life is going on well unlike the way it was back then. My body's immunity has improved. I can see that I am energetic. When we arrive [at the clinic] we are weighed and I have noticed that there are some changes, unlike how it was before." - *42-year-old male at 4-month follow-up*

"I am now becoming energetic since I started taking the drugs unlike before where I was weak. My body is getting back to normal since I started taking the drugs." – *34-year-old male at 1-month follow-up*

Many side effects that were reported to have stabilized over time, sometimes within weeks and others over months.

"My life has been going on so well as I have not been experiencing some of the things that I used to feel before I had the test. I used to think that it was something to do with my body, but it was because of the virus. I feel different. It all stopped. I used to have a warm sensation in the feet. I thought that it might be as a result of putting on shoes at the time. I used to feel warm which I no longer do. I used to feel like something is moving in my flesh, like a spider. I was asking myself, 'what is this'? I no longer feel like the spider is moving in my flesh. I believe this change is because of the drugs that I am taking. I used to hear a sound like a vehicle is moving far away. I would hear that when I am just seated. As of now, the sound is fading compared to how it was at the beginning. Sometimes I hear it, and some other times it is okay." – *42-year-old male at 4-month follow-up*

"At first when I take the drugs, I would get weak and I would not be energetic. This time I can pray for a long time and I can see that the drugs have no effect on my prayer life. [I now pray] the way I was praying at first." – *42-year-old male at 4-month follow-up*

"At the beginning my body fitness was not good. I was not fit at all and not energetic. I would feel pain in my feet. I would feel a spider crawling sensation, but it is all gone now. I was also feeling a hot sensation, but it also stopped. Sometimes I would have nightmares which also stopped. I now eat normally." - *42-year-old male at 6-month follow-up*

"I am energetic and do not get constantly weak as it was at the beginning. I also do not feel dizzy. Because I am taking the drugs accordingly." – *19-year-old female at 4-month follow-up*

The majority of the improvements in health were attributed to taking ARVs as prescribed.

"I was slim or weighed less. I have noted that my weight is increasing, maybe by 1 kg. This change has happened because of the pills that I am taking because I am no longer getting sick. I am following the prescription as I was told."– *48-year-old male at 2-month follow-up*

"Things are getting back to normal, the strange sound that I was hearing, feeling like I haven't eaten when I have eaten, and the problems that I had at the toilet. Everything is back to normal. When I started taking the drugs, my body was surprised or weakened. I was weakened because of the virus." – *42-year-old male at 4-month follow-up*

"I was taking drugs for [ulcers] before, yet the problem continued. I think the ARVs might have been effective in that area." - *52-year-old male at 2-month follow-up*

Regained health was expressed in terms of regained dignity and regained social life.

"It is different now that I am taking the drugs. I am now getting my dignity. I feel better and no longer have general body pains as if I am taking some drugs. When you are sick you do not have the full dignity. You are not at peace because of the sickness. You tend to think a lot because of the sickness, and this may result in headache, the kind of headache that you are not

supposed to have. I am taking the drugs accordingly and do not have headache." – *21-year-old female at 2-month follow-up*

"When one is feeling better, then they are able to chat with friends and relatives. You find time just because you are feeling good. It is the same with me, I am better and able to find time to visit and chat with friends or relatives unlike when I was getting sick. Sometimes I tend to forget that I have been sick because I no longer suffer from different kind of diseases." – *21-year-old female at 2-month follow-up*

With time, previously held notions of their illness were abandoned and new interpretations of what it means to be on ART were adopted.

"Being diagnosed with HIV does not mean that you are a sinner. There are a lot of reasons that make one to be in problems. At the same time, we can say that people conclude that being diagnosed with HIV means you are a sinner as they connect that one contracts HIV because of adulterous life. I do not condemn myself because I am not sure how it came about. As someone who was once married, I don't know how it came about. Being diagnosed with HIV is the same as being diagnosed with Malaria. There is not much of a difference. The difference is because they say that HIV has no cure." – *42-year-old male at 2-month follow-up*

Securing social support

As individuals were going through an adjustment phase in their life, social support was sought and obtained from marital and non-marital partners, family members, close friends, social support groups, and religious engagements and thought processes. These sources supported them emotionally, physically and financially, resulting in their improved mental and physical health.

From marital and non-marital partners

Support provided by sexual partners included physical care for the severely sick, moral support, reminding and making arrangements to take pills as prescribed, reminding and enabling clinic visits on appointed dates, and being an incentive to stay healthy for the purpose of maintaining their relationship.

> "I was very sick at the time. It was difficult for me to even boil water, wash or even cook. It was very difficult for me. [My wife] was the one who took care of everything since she got back. Especially in the morning, she wakes me up. Sometimes when the phone is off, she wakes me up. Sometimes she would ask me some questions in a joking manner to say that "you were remaining with bones only and few kilograms" "would you have been here without the drugs?" We would joke as we talk about other things. I have noted some advantages. I am able to find some things and also able to find time to go out and chat with some friends. A lot of things are good at home and I know I will find food already prepared. [When she was away] I didn't have time to mop as I had time to wash, I had no free time." – *34-year-old male at 4-month follow-up*
>
> "In case I am supposed to go and work somewhere, she puts them aside [my bag] and tells me 'carry these and take them as you will spend the night there'. She gives me food." - *48-years old male at 2-month follow-up*
>
> "Most of the time, he does not want to see me angry. He encourages me in my education. He encourages me to take the drugs because once I stop taking the drugs then I will not look good and he will stay away from me. He encourages me on a lot of things." - *19-year-old female at 4-month follow-up*

From family

Immediate family members such as siblings, parents and children were the main sources of emotional, physical and financial support cited. The support provided included assistance in escorting participants to come and get tested for HIV to begin with, helping them navigate choices and the process of disclosure, reminding them to take their pills, providing food to eat, providing public transportation money for clinic visits, giving general advice in how to manage their health and being available to consult about when to seek additional clinical care, especially during the initial months of taking ARVs and when managing new side effects.

> "[My father] is the one who accompanied me and entered [the testing room]. He accepted that over seeing me suffer from different sicknesses. It is better once a person starts taking the drugs. He received [the news] and encouraged me to be taking [the drugs]." – *21-year-old female at 1-month follow-up*

> I was just dizzy and sometimes my heart would beat faster as if I am hungry. Sometimes I would feel like I would fall and not be able to wake up. On that day, my husband went to work, and I was not able to wake up to prepare the child for school. It was a neighbor who booked the car and took me to my mother's place. I stayed there for 5 days and then I went home. My sister accompanied me. She went back home when I was getting better." - *25-year-old female at 1-month follow-up*

> "That is why I come to the clinic late. I make sure that I wait for one of the children from school so that I should leave the children with my (14-year-old) child. She takes care of them very well because I make sure that I have prepared food and fed them before I leave." – *48-year-old female at 6-month follow-up*

"My sister, whom I live with, asked how I was. I told her that I felt dizzy during the night and she told me that as time goes it will stop. I still experience it, but I am not as worried as I was at the time." – *52-year-old male at 1-month follow-up*

"[My wife and I] just remind each other on reporting to the clinic. Sometimes we have money problems but still we make sure that we have food in the house, so that we should be able to eat in line with our bodies." – *52-year-old male at 2-month follow-up*

Female participants that lived away from their close same-gender family members lacked emotional support and struggled in self-management of their overall health. Coping mechanisms that were used to overcome this void usually added to their experience of stress and anxiety as they were adjusting to live with HIV.

"I would like to ask [my biological mother] some questions because she is the mother. She can be the best to encourage me since she knows what is good and bad. But there is no one who I talk to. If there are issues that I can't talk to a male person, then I keep them to myself. [My step mothers] are away and it is difficult for me to communicate with them. When I have issues that I can share with any person, I talk to my brother who gives me some ideas. For the other issues, I just keep them to myself. Who else would I talk to? Sometimes I just forget about them. I can tell another person who will end up telling other people, but that means they have not kept the secret." - *19-year-old female at 4-month follow-up*

"I shared with her but not all of them, because I didn't feel comfortable as I have stayed a long time without interacting with her. It was difficult to open up to her. I think I was just scared. She thought she was helping me but to me it was not helpful. I should just say that I did not manage to open up to her during the time I visited her. I don't know why but it was difficult." - *19-year-old female at 6-month follow-up*

From friends

Close friends were another layer of social network most participants relied on for their emotional, physical and financial needs. This included helping them keep or establish new social support systems, and also helping them in processing the news of a new chronic diagnosis and sharing tips on how to self-manage their mental and physical health.

> "He brings some items like peanut butter. When there is no electricity in the afternoon, they come to keep me company." – *34-years-old male at 2-month follow-up*

> "I can say that I rely on my friends whom I was conducting business with. They assist me as compared to my relatives who are in the home village. My friends are the ones who stand by me in difficult times. It's not that they support me because I was diagnosed with HIV as such. My business dropped. Those who understand things tend to know how to stand by me. They would share with me money." – *42-year-old male at 6-month follow-up*

> "I told [my HIV positive friend] after I had the test. It was surprising to her as in how it is possible at my age. I told her that I don't know. She said that maybe they made a mistake and that we should go for another test. So, we went for another test at [another] hospital. I was found to be having it (HIV positive) and she told me that "I am also like that. Don't worry we are still best friends". Nothing changed. We still continue and not have disagreements or talk behind anyone's back. I was the one who liked her, and she told me at the time that we were young. We may have been 9 or 10-year-olds. It's been a long time." - *19-year-old female at 2-month follow-up*

"[My friend] encourages me that 'There is need to be eating variety of foods and also do not be anxious. Look at me I had the test long ago but I am still healthy.'" – *48-year-old female at 2-month follow-up*

Support provided by family and friends was interpreted as expressions of love and concern.

"[My younger brother] encouraged me that this is normal because there is nothing that can be disturbed. The only change that I can talk about is that he respects me and we chat very well. He would like to know about my life on everyday basis. He never asked those kinds of questions before. He now makes sure he finds out in case there is something unusual." - *42-year-old-male at 2-month follow-up*

From social groups

Participants also described social groups as a source of support. Such groups included community-based tribal groups and facility- and community-based peer support groups. Social groups mainly provided financial and emotional support, which included provision of monetary support, comfort of being amongst peers that have a shared experience, changing participants' outlooks about clinic visits, being means of engagement in community activities, and giving the security of physical assistance in case of worsened health condition.

"We have a Ngoni group (tribal group) and I told the chairman. It was established so that when one is in problems or is facing some challenges. They come home every week to give us some money so that we should be assisted. I just told them that I am sick." – *34-year-old male at 4-month follow-up*

"At the CBO as support group (of about 30 people), every member is given porridge. Sometimes when the porridge is not available, we are not given. When it is available, we are

given. We mostly help each other not to be anxious. They say that it is not good to be thinking that I was diagnosed with the virus or I am like this. It is not good that we should be thinking about that. We should be living the way we were living in the past and that will be good for us. There is singing sometimes and other activities. Sometimes we visit patients. They tell us that we have to visit anyone who is not feeling well. We wash, clean, and draw water for them." - *48-year-old female at 4-month follow-up*

The experience of a 19-year-old female participant describes the role of a facility-based age-tailored service in her process of adjusting interpretations about living with HIV and continuing to follow treatment. This young woman was initially intimidated by the relatively older people in the waiting area. She describes,

> "When I got to the clinic, first I looked at the people in the queue. I realized that they were all adults, so I felt like that means this disease is for the older people. It's not for someone like me. I would just sit at the veranda like I am waiting for someone. When a lot of people have been assisted and it is almost time to close the clinic, I would go to get assistance even though I came in the morning. I was asking myself questions, there are older people there. If I go (and wait in queue), will they not be wondering where a child like me contracted the virus? Who infected her? I was just thinking, and I thought they may think that I am of bad behavior. So, to avoid all that I just sat where I was. I was alone. I wanted to leave and not get the drugs. I also thought that I have spent transport money. Once I go back home, I may have a certain problem in relation to the disease. I should just have courage to get the drugs but at a later time."

Clinic waiting areas are usually lighter in the afternoon and towards the end of the work day. Even though she received good customer service from the hospital staff, she remembers being

unimpressed. She was more focused on meaning of the clinic visit. “I was thinking that if I had started taking the drugs at this age that means I will be taking them up until I die.” Because a specific nurse had observed her internal struggles, she received extra advice during her initial solo clinic visit. During her follow-up visit, she states, “[For my next clinic appointment,] I went to the clinic. I was still feeling guilty and I didn’t wait on the line. I went straight to the same person (nurse) and I didn’t even get the file (patient chart from reception). I told her that I came to get the drugs. I was asked if I got the file or a number, weighed on the scale and I said I haven’t done all that. They said that I am funny. They took the [health passport] from me and obtained the file for me, told me to be weighed at the scale, received the drugs for me from the pharmacy and gave me in the room. They asked me if I had any problems and I said no. That is when they suggested I needed to be in an adolescent group.” Her follow-up visits were arranged for a specialized age-tailored service, which she enjoyed. “The adolescent tailored visit is better than people of my age being included among the older people. The adolescent group is better because you feel comfortable as you can relate to others who are older, younger or the same age as you. I love it just because we had a lot of fun. Once you are there, you tend to forget that you are positive. I now have courage. I can even stand in front of people to say that I am positive. I noted that nowadays life is about living positive and when you are shy you are just compromising your future.”

From religion

Some individuals mentioned getting emotional support, specifically acceptance and hope, from religion. The framework of religious thinking was able to provide them a means to provide explanations and obtain assurance they were not able to get anywhere else, including from health care providers.

"When I see [my children] I get courage. I asked God, as he has all the power to forgive, to forgive me as I had no idea how this might have happened. I asked him to forgive me, if I had sinned and that I want to start afresh. As I am passing through this time, I asked God to be my helper." - *39-year-old female at 1-month follow-up*

"As a Christian [my friend] just encouraged me and he told me not to worry. 'Don't get discouraged the journey still continues.' We understand each other in a lot of things. Even when I am in trouble and I tell him. He takes a step even at a time that he can't manage. He is a true friend. [The pastor] encouraged me in the same way as my friend did. He said I have to continue believing in God. The bible says what is impossible with men is possible with God. Just accept, continue taking the drugs and also continue believing in God. God can intervene. I should make it clearer. When God says what is impossible with man is possible with God, this statement is not going to any person. It is going to somebody who believes in God, who trusts in God, not anybody." - *42-year-old male at 1-month follow-up*

A religious framework was used in the advice family and friends provided them. Such thought processes assisted them in interpreting their HIV status and also the need to keep living.

"That's how God planned my life. Most of my friend don't have (the virus) yet I do have it. Maybe He wanted my life to be an example to others in such a way that's when they see me they should say 'We should not became like him.'" – 33-year-old male at 2-month follow-up

"When I am with my relatives, they are negative and I am the only one who is positive, I can't survive, then when my brother noted that most of the time I was absent minded he told me 'It is something that has happened and it happens to anyone. You just have to be strong. Concentrate on what you are doing. If you concentrate, God will put his hands on it and you

will succeed in everything that you need in life.' So, I decided to try my best and see what life will be like." - *19-year-old female at 2-month follow-up*

"No matter what you face, you don't even get worried when someone talks about you. Even Jesus was insulted. That gives you courage. When you are not leading a prayerful life, you tend to be worried in life. Praying encourages me to be happy. One time when I was experiencing numbness and felt so hot, I went to report to [the pastor]. I told him and he prayed for me. It all stopped when he prayed. He supports me and does not consider someone's status. If it was someone else, they could have just said it is because of the drugs that I am taking. He could have said that, but he didn't. He was encouraging me and made sure that he helped me." - *26-year-old female at 2-month follow-up*

Discussions

Our findings highlight social support as a key component of self-management of HIV. As newly diagnosed PLHIV re-interpreted the meaning of HIV in their life, their social network was instrumental in making sure they were tested for HIV to begin with, facilitating their acceptance of the test result, convincing them about the need to follow treatment, enabling adherence to take pills as prescribed and to clinic visits as appointed, and encouraging them to resume social activities. Their social support systems also assisted with securing nutritious food and in management of side effects, including doing their daily chores in their most affected days. Previous studies that have generated important concepts about the adjustment process of living with a new HIV diagnosis interviewed or conducted in-depth interviews and focus group discussions with PLHIV to understand their perspective (J. Perazzo, Martsolf, Pritchard, & Tehan, 2015). While these approaches have begun the exploration, they are also prone to recall bias and may not capture

the changing decisions and perspectives PLHIV go through at different stages of their adjustment process. The individual that is interviewed at a given point is a product of influences, support or its lack, and physical and emotional strengths or dents as a result. These snapshots continue to change over time and change fast in transitional times. Our study followed participants prospectively and obtained information as concepts developed and their interpretation modified with continual adjustments based on participant's evolving understanding of the new diagnosis.

The findings from this chapter confirm the previously described phenomenon of PLHIV being resilient while vulnerable (J. P. De Santis & Deleon, 2013). Despite their compromised health status and feeling of powerlessness in the beginning, participants in this study demonstrate how PLHIV overcome these initial conditions. This process of adjustment was described in THE earlier days of HIV in the US (Siegel & Meyer, 1999). Overtime PLHIV were able to overcome the initial shock and progress to acceptance and re-commitment to life by updating their definition of what it means to live with HIV, adjusting their sense of control over life, securing the necessary support systems and reappraising their personal goals. Similarly, in the group of individuals newly diagnosed with HIV and followed during the initial 6 months for this study in Malawi, management of health required making adjustments and re-interpretation of living with HIV at the individual level. This depended and was guided by support from persons and concepts in the social network.

Resilience has previously been explained as a combination of commitment to life, a sense of control of one's life course, and acceptance of challenge as part of life (Farber et al., 2000), a protection from a variety of risks that contributes to survival from extreme circumstances without debilitating disabilities (Pivnick & Villegas, 2000), strengthening and empowerment in the face of adversity (Cadell et al., 2001), a period of uncertainty in which the individual adapts to living with

HIV infection as a chronic illness (Thompson, 2003), the process whereby an individual is confronted with adversity and yet is able to move forward with life (Dyer et al., 2004) and success in life despite the challenges of living with HIV infection (Bletzer, 2007). The individuals we followed mostly reported their HRQOL with positive outlook despite their experienced ailments when probed about specifics. Even though a substantial number of days were reported to have been affected by poor physical and mental health, most individuals reported that their routine activities were affected minimally. While this may be done by choice in some circumstances, in other times it may also be because resilience was the only choice available to survive.

The *Healthy Days* tool (Appendix II) we used in our study utilized A core set of questions used by the Department of Health and Human Services in the United States as part of the Behavioral Risk Factor Surveillance System (BRFSS) since 1993 (Ross, 2000). It has an expanded version that measures additional symptoms, functional status and other HRQOL variables. Both DHHS and other smaller-scale health providers have found the core and expanded questions as a predictor and outcome measure of aggregate level health burden on health systems and the populations they serve. Given that the core questions of the *Healthy Days* tool measures an individual's perception of the quality of their health at a given time, it is one of the potential tools health care provider can also use to get a snapshot of an individual's level of resilience despite their health status and cumulative vulnerability. Previous studies that hypothesized that vulnerability would mediate health status and HRQOL have found that it did not (van Servellen et al., 2002). However, they have demonstrated that HRQOL could be used to measure individuals' health status. As described in detail in chapter 1, vulnerability mediated exposure to illnesses especially in the setting of poverty. In this case, health status itself is an outcome and HRQOL a measure of how the person perceives the health status (outcome). Given that vulnerability has both physical and psychological

domains that need to be measured, while resilience mainly focuses on the psychological domain, the *Healthy Days* tool can be used to assess how individuals are coping with the current condition of their health status.

Source of support	Type of support		
	Physical	**Emotional**	**Financial**
Marital and non-marital partner	Yes	Yes	Yes
Kin (sibling, parent, child)	Yes	Yes	Yes
Close Friends	Yes	Yes	Yes
Social support groups	No	Yes	Yes
Religion	No	Yes	No

Table 10. Types of support obtained by persons newly diagnosed with HIV from their social network as they adjust to living with HIV

Findings from this study highlight that emotional, physical and financial support were obtained from current marital and non-marital partners, kin (siblings, parents and children), and close friends. Facility- and community-based social groups provided financial and emotional support, while religious framework provided emotional support (Table 10). Similar to previous studies in this area, societal norms and belief systems about HIV infection and its treatment affected how individuals go about pursuing HIV-related care once newly diagnosed (Roura et al., 2010). When participants chose to consult health care providers during treatment initiation and follow up, they were able to find resolutions with the help of additional prescription drugs and explanations provided by health care providers that assisted them in re-gaining their health. However, this came with the cost of additional clinic visits and added pill burden. Despite these added inconveniences, simple information gained during vital sign assessment (e.g. weight monitoring) done in clinic

settings were used to gauge health status and guide what they need to do or should feel good about.

The role of religion as a coping mechanism in times of stress has been well studied by other researchers (Sosis, 2007, 2008). A religious framework was able to help individuals in unpredictable situations to give them a sense of control and normalize their daily routine (Sosis & Handwerker, 2011). In a context where HIV is still stigmatized and with a potential of a lowered social capital, being a PLHIV was explained and its management assured by the forgiveness and purpose a religious framework provided. When they were not able to articulate why they acquired an HIV infection and when side effects of clinical treatment were not bearable, religious constructs were able to provide them a sense of forgiveness and a sense of resolution for ailments they experienced and were not controlled by prescription pills.

Despite the lessons generated from this exploration, it is important to remember that participants from this study were selected from a specialized urban HIV clinic. While their seeking HIV testing services may be influenced by lack of resolution from other clinical and non-clinical option, it may mean that either participants or someone in their social network was likely to seek clinical care for sicknesses and convinced about the positive health outcomes of ART. Further interpretation should be done with this selection bias in mind.

Conclusion

The newly diagnosed individuals demonstrated forms of both resilience and vulnerability. Despite their affected physical and mental health, they attempted to maintain routine activities unaffected. When self-managing their health, they focused on taking prescribed medications as advised and securing good nutrition. In the initial months where physical health was highly affected, they sought and obtained support from health care providers, experiences and advice shared from persons in their social network, and religious thought processes. In a time of a potential negative

life event, it took a village to regain emotional, physical and financial stability.

Without social support, a newly diagnosed person would face a wide range of obstacles in order to achieve positive health outcomes. Public health approaches should take into consideration that availing clinical services alone is not enough. Comprehensive health services should target the individuals and their social network and facilitate the supplementation of clinical services with social support.

Chapter 6

Conclusions

In resource limited contexts, vulnerabilities mediate exposure to HIV. Individuals with high levels of vulnerability are at increased risk of being infected with HIV. Once infected with HIV, they will need to manage existing vulnerabilities and newly acquired vulnerabilities associated to persons living with HIV. In contexts where HIV is stigmatized, new vulnerabilities include modified social capital, affected physical health, limited fertility options, and dependence on social support. However, the impact of cumulative vulnerability on health outcomes is dependent on the individual's self-management of HIV. In addition to adhering to ART and clinic appointments, individuals need to continue to cope with their cumulative vulnerabilities that affect their psychological functioning and social relationships. This study has demonstrated social support as a key determinant of how well individuals cope with vulnerabilities in the context of HIV. Anticipation of sustained social support helped determine whether individuals followed clinical treatment, and further influenced the day-to-day self-management of HIV.

Coping with vulnerabilities in the context of HIV changes continually and is highly influenced by available resources (including social support) during the transitional time after diagnosis. In the initial months after a new diagnosis, decisions and perceptions changed continually until the individual found his/her niche. In this study, we observed that individuals disclosed to those whom they had initially thought they would not disclose to. They experienced unwanted disclosure which forced them to manage unplanned social interactions. Those who were stigmatized by employers and regretted having disclosed their status later found a new employer that embraced their health status and enabled clinic visits. How life would progress was unpredictable. Navigation of this

unpredictability requires adequate resources, beyond availing medications and monitoring of physical health.

Applications for public health

Health service providers are part of the support system for patients. Allowing consultations on topics beyond physical health may enable care providers to gauge the coping level of a person living with HIV. Use of vulnerability screening tools may guide this process and prioritize need for additional support. This dissertation has demonstrated that the four core questions of *Healthy Days* tools can be one way of screening for non-clinical support individuals may need. Actual provision of non-clinical care provision cannot be done by clinical providers, given their already full workload. However, use of differentiated models of care allow for minimization of opportunity cost for stable patients, and allowing more screening and consultation time with patients with complex cases. For the latter, referrals to the appropriate social support groups may be one way of linking vulnerable individuals with resources that can help them cope better. Once newly diagnosed persons stabilize on ART, approaches that ease the opportunity cost of following care should be explored. Some of these differentiated models of care include age-tailored service provision, extended service hours, and provision of medication for longer periods of time.

At the societal levels, gender norms and fertility intentions led individuals to explore options that were risky in terms of possible HIV transmission. The choices made subsequently affected their health outcomes. Given the context specific benefits of both, the risks and opportunities of gender norms and value of fertility will need to be continually be influenced by providing examples that serve as models and presenting alternatives to culturally accepted norms, at a society level. Doing so may prevent behaviors that expose vulnerability individuals to HIV infection and minimize

their vulnerability in the context of infection once infected.

Recommendations for further research

Tools similar to *Healthy Days* can be used to explore the functional status and social support level of PLHIV during routine visits. The operationalization of such tools in a routine service delivery setting is yet to be done. Clinical assessment tools already provide the physical health status of patients. However, the psychological functioning and social relationship aspects of self-management of HIV are not captured in these tools (Swendeman et al., 2009). Future operation research should explore the effectiveness and feasibility of using tools that are culturally fit and able to assess the two aspects of self-health management periodically.

This dissertation highlighted the key determinants of following care. Decisions varied over time, based on health status and influences of social network. However, individual-level changes over time were not quantified for each concept. Further studies should explore the process of vulnerability and resilience in the initial transitional time, and its determinants in order to gain insights on how to retain individuals who are diagnosed with HIV on ART.

Appendix I: In-depth interview guide for persons newly diagnosed with HIV (English)

A. Receiving the news

1. What made you get tested for HIV?
2. How did you receive your HIV diagnosis at the time the counselor told you about it?
3. At the time of your diagnosis, were there people you knew that lived with HIV? If yes, who? *(capture relationship only; not names)*
4. At the time of your diagnosis, did you know people that were on HIV treatment? If yes, who? *(capture relationship only; not names)*
5. Before you were tested, have you anticipated that you may be infected with HIV?

B. Interpreting the news

6. What do you think contributed to your being infected with HIV? How do you think you contacted HIV?
7. If and when you tell them:
    a. *(If the interviewee has a spouse),* what would your spouse think about your being HIV positive?
    b. What about your immediate family members?
    c. What about extended family members?
    d. What about your friends?
    e. What about your co-workers?
    f. What about other people? (neighbors, administrative authorities, etc.)

C. Incorporating the news

8. What has the diagnosis meant to your life and the way you see yourself?

    Probe: What changed? What did not change?

9. What lifestyle adjustments have you made to date?
10. What lifestyle adjustment do you plan to make in the next 3 months? What about in the long term?

D. Acting on the news

11. Who will you tell (have you told) about your HIV diagnosis? Why? Why not?

    Probe: spouse, immediate family members (specify relationship), extended family members (specify), friends (specify), co-workers, and other (specify)

12. How do you plan to take care of your health going forward?

    Probe: Do you plan to go to clinics?

E. Moving beyond the news

13. What things do you do to monitor your physical health?
14. What things are you doing to secure your financial stability?
15. What things are you doing to secure your emotional stability?
16. *(If initiated on ART,)* what adjustments have you made in your life to start and continue to be on treatment?

    (If NOT initiated on ART,) what adjustments will you need to make in your life to start and continue to be on treatment?

    Probe: what types of costs have you acquired or anticipate incurring because of your taking ART? What have you found to be easy or difficult about taking ART?

17. What things do you do to take your mind off your HIV diagnosis?
18. What kind of support would help you in coping better with living with HIV?

    Probe: have you tried/do you plan to get that? Is yes, how? If not, why not?

Appendix II. Healthy days – core module (CDC HRQOL– 4) (English)

1. Would you say that in **general** your health is:

Please read

a.	Excellent	*1*
b.	Very good	*2*
c.	Good	*3*
d.	Fair	*4*
	or	
e.	Poor	*5*

Do not read these responses

Don't know/Not sure	*7*
Refused	*9*

2. Now thinking about your **physical health**, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

a.	Number of Days	_ _
b.	None	8 8
	Don't know/Not sure	7 7
	Refused	9 9

3. Now thinking about your **mental health**, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

    a. Number of Days _ _
    b. None 8 8

    *If both Q2 AND Q3 = "None", skip to **Question 4** and thank the participant.*

    Don't know/Not sure 7 7

    Refused 9 9

4. During the past 30 days, for about how many days did poor physical or mental health **keep you from doing your usual activities**, such as self-care, work, or recreation?

    a. Number of Days _ _
    b. None 8 8

    Don't know/Not sure 7 7

    Refused 9 9

Appendix III: Survey questionnaire for persons newly diagnosed with HIV (English)

A. Socio demographic information

1. What is your gender? _____

2. How old are you? __ __

3. What is the maximum formal education you have obtained?

   _____

4. What do you do to support yourself financially?

   _____

5. Do you actively follow any religion?

   [ ] Yes [ ] No

   If yes, what religion do you follow? _____

6. Marital status: _____

   If married or in partnership:

   a. What does your spouse/partner do to support your family financially?

      _____

   b. Do you know if your spouse/partner has tested for HIV before today?

      [ ] Yes [ ] No [ ] I don't know

   c. Do you know the HIV status of your spouse/partner?

      [ ] Yes [ ] No [ ] I don't know

d. If yes, what is the HIV status of your spouse/partner?

[ ] Positive [ ] Negative [ ] I don't know

e. *If Positive*, is your spouse/partner on HIV treatment?

[ ] Yes [ ] No [ ] I don't know

7. Do you have any children?

[ ] Yes [ ] No

If yes, how many children do you have? __ __

B. Status of physical health

8. Would you say that in **general** your health is:

Please read

f. Excellent 1

g. Very good 2

h. Good 3

i. Fair 4

j. Poor 5

Do not read these responses:

Don't know/Not sure 7

Refused 9

9. Now thinking about your **physical health**, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

c.	*Number of Days*	_ _
d.	*None*	8 8
	Don't know/Not sure	7 7
	Refused	9 9

10. Have you tested for HIV before?

[ ] Yes [ ] No

If yes, when did you get your most recent HIV test? _____

11. What was the result of your most recent HIV test other than today?

[ ] Positive [ ] Negative [ ] Refused

12. Why did you get tested at that time? _____

_____

13. Why did you get tested now? _____

_____

14. Was there anyone present during the time the counsellor was telling you about the result of the HIV test today?

[ ] Yes [ ] No

If yes, who? _____

15. What are your major physical health concerns outside HIV infection?

_____

16. Going forward, are you **willing** to monitor your health by yourself?

[ ] Yes [ ] No [ ] Not sure

17. Going forward, are you **able** to monitor your health by yourself?

[ ] Yes [ ] No [ ] Not sure

18. Going forward, who do you think will be able and willing to assist you in monitoring your health?

_____

C. Profile of psychological functioning

19. Now thinking about your **mental health**, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

c. Number of Days	_ _
d. None	*8 8*
Don't know/Not sure	*7 7*
Refused	*9 9*

20. During the past 30 days, for about how many days did poor physical or mental health **keep you from doing your usual activities**, such as self-care, work, or recreation?

c. Number of Days	_ _
d. None	*8 8*
Don't know/Not sure	*7 7*
Refused	*9 9*

21. Before coming to get tested for HIV today, did you anticipate that you may be HIV positive?

[ ] Yes [ ] No [ ] Not sure

Can you explain why? _____

_____

D. Social environment

22. Do you personally know anyone who is HIV positive?

[ ] Yes [ ] No [ ] Not sure

If yes, what is the relationship of that person (those persons) to you?

_____

23. What are your views about living with HIV? _____

_____

24. Do you personally know anyone who is taking HIV treatment?

[ ] Yes [ ] No [ ] Not sure

If yes, what is the relationship of that person (those persons) to you?

_____

25. What are your views about being on HIV treatment? _____

_____

26. Can you tell me 5 people whom you rely on the most for your physical, emotional and financial well-being **to date**? *(Please state only the relationship of the persons to the interviewee. Example: mother, child, uncle, brother)*

    i. Person 1: My _____ for _____ reasons

    ii. Person 2: My _____ for _____ reasons

    iii. Person 3: My _____ for _____ reasons

    iv. Person 4: My _____ for _____ reasons

    v. Person 5: My _____ for _____ reasons

    Or

    [ ] I can't think of 5 persons that provide me physical, emotional and financial support.

27. Thinking about the people you stated that you rely on for support, do you think they will continue to support you if you told them about the HIV test result from today?

    i. Person 1: [ ] Yes [ ] No If no, please state why:_____

    _____

    ii. Person 2: [ ] Yes [ ] No If no, please state why: _____

_____

iii. Person 3: [ ] Yes [ ] No If no, please state why: _____

_____

iv. Person 4: [ ] Yes [ ] No If no, please state why: _____

_____

v. Person 5: [ ] Yes [ ] No If no, please state why: _____

_____

[ ] Please check here is the participant did not state 5 persons.

28. Thinking about the people you stated that you rely on for support, do you plan to tell them about the HIV test result from today within the next 4 weeks?

i. Person 1: [ ] Yes [ ] No If no, please state why:_____

_____

ii. Person 2: [ ] Yes [ ] No If no, please state why: _____

_____

iii. Person 3: [ ] Yes [ ] No If no, please state why: _____

_____

iv. Person 4: [ ] Yes [ ] No If no, please state why: _____

_____

v. Person 5: [ ] Yes [ ] No If no, please state why: _____

_____

[ ] Please check here is the participant did not state 5 persons.

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