

UNDERSTANDING GAPS IN THE RETENTION OF HIV POSITIVE MEMBERS OF KEY
POPULATIONS IN KENYA BASED ON THE HEALTH BELIEF MODEL

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ABSTRACT

UNDERSTANDING GAPS IN THE RETENTION OF HIV POSITIVE MEMBERS OF KEY POPULATIONS IN KENYA BASED ON THE HEALTH BELIEF MODEL

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This study is a qualitative exploratory study assessing perceptions of barriers to retention of key populations living with HIV in HIV treatment among health care workers and program workers in key population-led organizations in Kenya. Structured interviews with the participants were conducted and analyzed thematically using themes derived from the Health Beliefs Model. Barriers that emerged from the interviews included individual barriers such as alcohol abuse, stigma, disclosure issues, faith-based healings, migration; and structural barriers such as the location of comprehensive care center in linking facilities, mishandling by health care workers after missed appointments, understaffing at health care facilities, and impersonalized care. Innovative means to improve retention included the use of peer navigators to follow up with HIV positive individuals that have defaulted from treatment, social support groups held by health facilities and key population organizations, storage of medication in key population organizations drop-in centers by HIV positive individuals because of non-disclosure issues, and having antiretroviral therapy dispensing sites within key population organizations. Additionally, it was suggested that peer evaluators currently working as volunteers should be made full time employees of key population led organizations and all key population led organizations should be made antiretroviral sites to improve retention rates of members of key population groups living with HIV.

Dedicated to the loving memory of my mother, Dorcas Osoro, who gave me the wings to fly and made me the woman I am today.

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KEY TO ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CCC	Comprehensive care center
FSW	Female Sex Worker
GF	Global Fund
HIV	Human Immunodeficiency Virus
KASF	Kenya AIDS Strategic Framework
KP	Key Populations
KPLHIV	Key populations Living with HIV
LDL	Low detectable levels
MSM	Men who have sex with Men
NACC	National AIDS Control Council
NASCOP	National AIDS and STI Control Program
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief
PMTCT	Prevention of mother-to-child HIV transmission
PWID	People who Inject drugs
PLHIV	People Living with HIV
STI	Sexually Transmitted Infection
STF	Soluble Mycobacterium tuberculosis factor
SW	Sex workers
TCA	To come again

UNAIDS	The Joint United Nations Programme on HIV/AIDS
VCT	voluntary counselling and testing
WHO	World Health Organization

INTRODUCTION

Alongside Tanzania, Kenya has the fourth largest HIV epidemic in the world (UNAIDS, n.d.). By the end of 2018, approximately 1.6 million people were living with HIV/AIDS in the country, 46,000 people were newly infected with the disease and 25,000 people had succumbed to HIV related illnesses(Kenya, n.d.).

The HIV epidemic in the country is characterized as severe, generalized, and heterogeneous; it manifests differently in different regions and different populations within the country, and while HIV is profoundly felt among the general population in some parts of Kenya, it is also heightened and disproportionately affects members of Key Population groups(KPs) (NACC, 2015). Key population groups, identified as sex workers, men who have sex with men (MSM), transgenders and people who inject drugs (PWID), are at a significant risk of acquiring and transmitting HIV. According to the Joint United Nations Program on HIV/AIDS (UNAIDS, 2019), the risk of acquiring HIV is 13 times higher in female sex workers (FSWs), 22 times higher in PWID, 28 times higher in gay people and other MSM, and 13 times higher in Transgender women, compared to the general population. Moreover, members of key population groups living with HIV (KPLHIV) and their sexual partners are said to account for an estimated 54% of all new HIV infections in the world (UNAIDS, 2018).

In Kenya, While HIV has maintained a prevalence of 6% in the general population since 2006, the prevalence of the epidemic in key population groups is at 29.3% for female sex workers (FSWS), 18.2% for men who have sex with men (MSM) and 18.3% for people who inject drugs (PWID). Key population groups are also said to account for at least 30% of new HIV infections in the country (NACC, 2014). This indicates that key population groups play a significant role in the spread of HIV/AIDS and highlights the significance of having HIV

interventions that are strategic and tailored for KPs in order to address the HIV epidemic in the country. Even so, in the world and especially in countries with a generalized HIV epidemic like Kenya, key population groups have historically been underprioritized in the fight against the HIV epidemic (Beyrer, 2016).

For instance, in 2014, UNAIDS set ambitious targets of having 90% of people living with HIV (PLHIV) in the world diagnosed, 90% of all PLHIV diagnosed started on antiretroviral therapy (ART), and 90% of PLHIV on ART reach viral suppression by the year 2020. In combination, the achievement of the three targets was estimated to lead to 73% of all people living with HIV being virally suppressed, in turn ending the HIV epidemic by 2030 (UNAIDS, 2019). As of 2019, however, the world had achieved only 79-62-53 of the 90-90-90 target set by the UNAIDS, and key population groups were mentioned to be some of the populations that were left behind in the acceleration of the UNAIDS targets (UNAIDS, 2018).

Similarly, in Kenya, the most recent data indicates an achievement of 79 - 95 - 88 of the 90-90-90 target (NASCOP, 2020), although data specific to KPs indicate that, while at least 93% key population groups have been reached by preventative and testing services through key population programs in Kenya (95.5% of sex workers and 94% PWID know their status), only 73% of FSWs living with HIV, 62.8% of MSMs living with HIV and 67.7% of PWID living with HIV are on ART. Even lower percentages of KPLHIV have reached viral suppression.

Kenya's response to HIV in Key population groups

Kenya has approximately 133,675 FSWs, 18,460 MSM and 18,327 PWID. This number cited as “too large to ignore”, led to key population groups in Kenya being made a priority group in the fight against HIV (NASCOP, 2016, pg. 2). In response, the National AIDS and STI Control Program (NASCOP), which was established to scale up HIV prevention programs for

key population groups in the country, joined with the National AIDS Control Council (NACC), which was established in 1999 with the mandate “to coordinate stakeholders in the multisectoral response to HIV and AIDS in Kenya”, in launching The Kenya AIDS Strategic Framework 2014/15-2018/19, which acts as a strategic guide for Kenya’s response to the HIV epidemic at both national and county levels (NACC, 2014).

The launch of the strategic framework in Kenya followed the large number of changes made on the guidelines for HIV response in the world. In 2014, key populations who had not been given enough emphasis in the fight against HIV were put at the forefront of the fight and important funding commitments and policy developments were put in place to counter the disproportionate HIV burden that they shoulder (Wolf et al., 2018). The World Health Organization (WHO) acknowledged that a sustainable HIV response would not be achieved without addressing the needs of key populations. To address these needs, they released guidelines for KPs’ HIV prevention, testing and treatment needs (Beyrer, 2016); The Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) launched the “Key Populations Action Plan” committing to help key populations “meet their HIV prevention, care and treatment needs and rights” (Global Fund, 2014); and The President’s Emergency Plan for AIDS Relief [PEPFAR], largely supported by the U.S Government, put forward initiatives to better understand and aid key populations, as well as to build the capacity of KP programs that had so far proven to have a scope and scale that was insufficient to address the HIV epidemic and overcome the barriers that face key population in accessing HIV services (Lillie et al., 2018; Wolf et al., 2018).

Furthermore, with the strategic framework and the scale-up of HIV prevention programs, through eighty-one key population organizations in 31 of the 47 counties in Kenya,

key population programs were designed to provide sustainable *peer driven interventions* which, to date, are working to reach KPs with HIV preventative services and clinical services (Bhattacharjee, Morales, et al., 2018; Bhattacharjee, Musyoki, et al., 2018; *PEPFAR*, 2019). Aligning with the UNAIDS 90-90-90 these organizations also adopted the *combination HIV prevention strategy*, simultaneously dealing with *behavioral, structural, and biomedical factors* that lead to an increase in HIV risk in KPs. Further, they utilize the *HIV care continuum* framework to not only help them track how individuals move through the HIV care continuum from the starting point of being diagnosed with HIV to when they are virally suppressed, but also to guide key population programs on where to direct specific interventions during the process of HIV treatment (Lillie et al., 2018).

For instance, Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES) is one of the key population programs launched in Kenya to manage the HIV epidemic in key population groups. The program was launched to fast-track the ability of KP programs in implementing HIV services that would reduce tremendously the transmission of HIV amongst key populations and their sexual partners, while improving the health outcomes of those who had already been infected with the virus (Lillie et al., 2018; fhi360, 2014). An outline of their strategy is presented in Figure 1.

Working in over 30 countries, and following the WHO consolidated guidance, the LINKAGES project adopts the *HIV continuum framework* to help KP programs track how individuals move through the HIV care continuum from the starting point of being diagnosed with HIV to when they are virally suppressed (Lillie et al., 2018). This is considered very useful in indicating the shortcomings of the programs in reaching, linking and retaining key

populations in care, pinpointing exactly where in the Continuum more work needs to be done to make improvements within a particular KP program (Wolf et al., 2018).

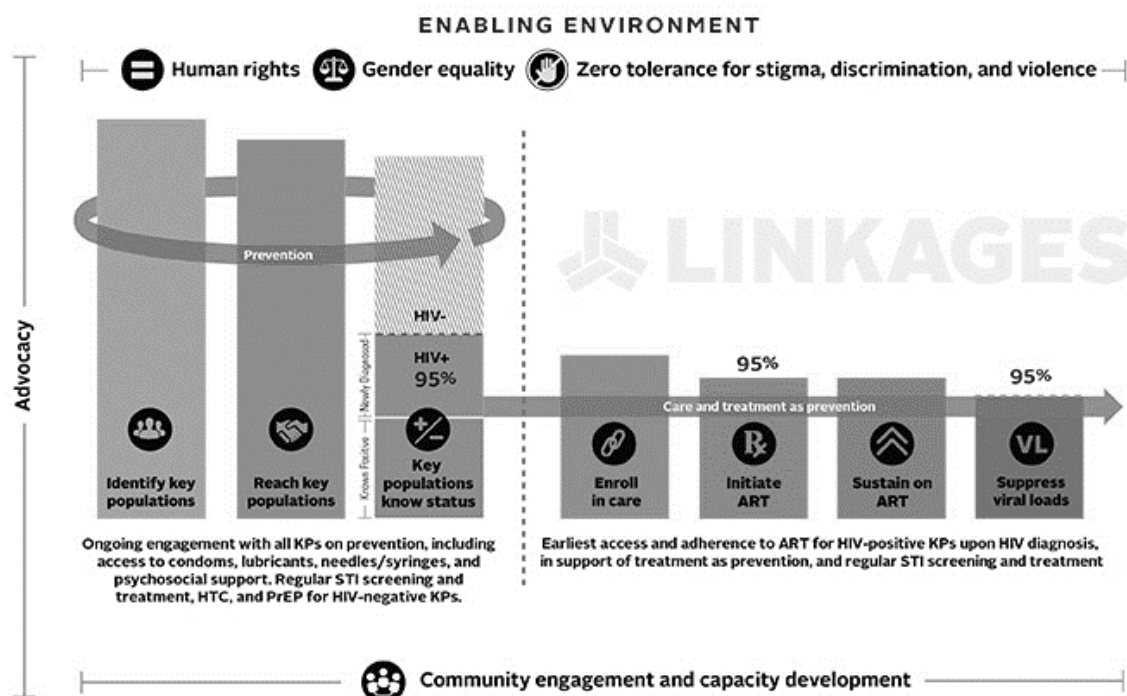


Figure 1: Key population HIV prevention, care, and treatment services
Source: FHI360 website

Additionally, LINKAGES project, like other key population programs in Kenya, operates with a control model that dictates that key populations should, through a *combination of interventions* that are strongly linked within the different stages of the HIV treatment continuum, progress seamlessly from being diagnosed with HIV to being virally suppressed. If they don't, they create a gap and gaps experienced within the continuum are equated to "A leaky pipe" (see Figure 2) which causes a weakness in the linkage continuum (Linkages, 2015).

In other words, the very first step in the LINKAGES continuum is to, through *peer driven interventions*, identify key populations, reach them with health information and prevention services and then refer them for HIV testing. A leakage would be experienced in the process if most of the people reached and referred for testing do not actually go for testing. Since it is advisable for key populations to be tested frequently (at least every three months) too, if the first test shows that a KP is negative and he/she never gets tested again despite being constantly at risk of acquiring HIV, then they introduce another leakage to the continuum. A person who turns out to be positive is supposed to be referred to a health care facility where they are required to be linked and retained in HIV treatment. If a person is not referred or linked to HIV treatment, and if a person is linked but drops out of treatment after a period of time, they also causes major leaks to the care continuum making interventions inadequate in preventing infection and managing the HIV epidemic.

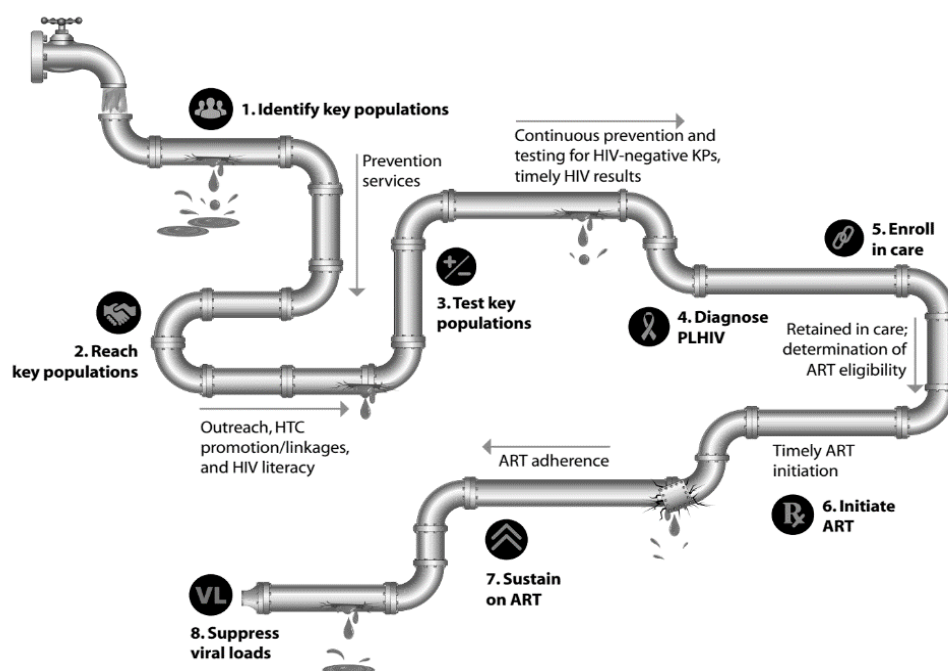


Figure 2: The Leaky Pipe of the HIV Continuum of Prevention, Care, and Treatment Cascade
Source: *HIV cascade framework for key populations, October 2015*

Peer driven interventions

Peer driven interventions are community outreach strategies used by KP led organizations that utilize peer-to-peer outreach and education to reach members of key population groups. Peer-to-peer outreach is done with peer educators who are active KPs that are “knowledgeable about the local context, acceptable and accountable to the community and program, able to maintain confidentiality, and have good listening, communication, and interpersonal skills” (Bhattacharjee, Musyoki, et al., 2018, pg. 2).

Peer-to-peer outreach is considered a two-way channel that simultaneously provides key populations with HIV prevention services while providing organizations and public health authorities with information that is used in program management (NASCOP, 2014). Furthermore, it is an intervention that is not only meant for behavioral change, it is also used as a pathway for linking key population groups to structural interventions and clinical services (Bhattacharjee, Musyoki, et al., 2018).

Essentially, the first step in the peer outreach approach is recruitment of peer educators. This is because peer educators are best situated to regularly reach their peers in their places of work or their hotspots. The peer educators, who are usually assigned 60-80 peers from their hotspot (place of work), are considered volunteers who work part-time to conduct regular outreach and one-on-one interaction with the key populations in their designated hotspots (Bhattacharjee, Musyoki, et al., 2018).

The next step in peer outreach is micro-planning where each key population member is considered to have risks and needs unique only to them. The program therefore works to address the risks that key populations have on a case by case basis (NASCOP, 2014). Micro-planning is important for peer educators because it enables them to use their extensive

knowledge of their peers to plan outreaches. On a weekly basis they also document their interactions with their peers including, whether they distributed condoms and lubricants to their peers, whether they talked with them about safe sex and whether they referred them for clinical services. The data from the documents show which peers have been reached and which peers have not and this helps peer educators plan for outreach to reach the peers that had not been reached before by preventative and clinical services(NASCOP, 2014).

When KPs are referred for clinical services by peer educators, they are mostly directed to a KP-led organization's drop in center (DIC), where the organization has employed at least two clinical staff, that is, a HIV testing and counselling (HTC) personnel and a program physician. The HTC personnel counsels and tests the KPs for HIV and the program physician tests them for HPV, STDs and provides them with treatment services for other minor ailments. The project physician also links and starts the KPLHIV on HIV treatment in a KP-led organization that is big enough to host a comprehensive care center (CCC) or refers them for linkage to a bigger health facility where they can access the CCC if the KP-led organization is small.

The effectiveness of peer interventions has been documented extensively (Cottler et al., 1998; Cunningham et al., 2018; Doull et al., 2017; Fogarty et al., 2001; Genberg et al., 2016; Martinez et al., 2019; Medley et al., 2009; Shangani et al., 2017; Simoni et al., 2011). In relation to members of key population groups living with HIV, peer education has been associated with improved HIV knowledge, reduced needle sharing, increased condom use and decrease in sexually transmitted infections (Ford et al., 2000; Leonard et al., 2000; Medley et al., 2009; Morisky et al., 2006). In Kenya, a study assessing the effects of peer interventions on sexual behavior and sexually transmitted infections in sex workers found that after five years of being

exposed to the intervention, the sex workers had consistent condom use with their partners, sex workers were more empowered to make decisions regarding condom usage with their partners, and more sex workers were aware of their HIV status (Luchters et al., 2008). Similarly, a study assessing the impact of peer outreach on HIV knowledge and prevention behaviors in male sex workers found positive changes in HIV preventative behaviors, consistent condom and lubricant use and increased HIV knowledge (Geibel et al., 2012).

Combination HIV prevention strategy

Combination HIV treatment interventions are meant to simultaneously deal with behavioral, structural, and biomedical factors that lead to an increase in HIV risk in KPs (KASF, 2014; NASCOP, 2018). Key factors that have been identified to increase HIV risk in KPs include, stigma, social exclusion/ discrimination, hostile environments due to homophobia, criminalization, and insensitivity of health professionals (Baral et al., 2013; Njab et al., 2018).

In Kenya, following the combination HIV prevention strategy to combat the high HIV rate in KPs, the recommended actions that were provided by the NACC to be directed towards behavioral interventions include and are not limited to, behavior change interventions using outreach and peer education; the recommended actions for biomedical interventions include, providing members of key population groups with condoms and lubricants, Screening for Human Papilloma Virus (HPV) on FSW, treating KPs for sexually transmitted infections and providing them with Pre-exposure prophylaxis services (PREP); and the recommended actions for structural interventions include, developing policies that reduces key population groups exposure and positively impacts key population groups engagement with HIV preventative and treatment services (KASF, 2014).

Reports from studies assessing key population program outcomes in Kenya show that the combination HIV prevention strategy in KPs, attacks the factors that increase the risk of KPs in acquiring and transmitting HIV from different sides and substantially improves outcomes among the population. For instance, one study by Bhattacharjee et al. (2015), found that combination prevention interventions were successful in convincing members of key population groups to accept HIV testing and counselling services and in a recent study assessing the changes that had occurred since their initial study in 2015, Musyoki et al. (2018), found significant increase in condom use, significant increase in clean needle usage in PWID, more exposure of members of key population groups to peer outreach, increased HIV knowledge, increased HIV testing and less frequent reports of violence. Nevertheless, the study suggested that more needs to be done to improve their clinical and treatment services, such as ART initiation and retention of KPLHIV in HIV treatment.(Bhattacharjee, Musyoki, et al., 2018; Musyoki et al., 2018).

HIV care continuum

The HIV care continuum, represented graphically in Figure 3, is the process of HIV treatment, starting from HIV diagnosis, linkage to care, retention in care, start of ART and eventually viral suppression (Mugavero, 2016; Yehia et al., 2015).

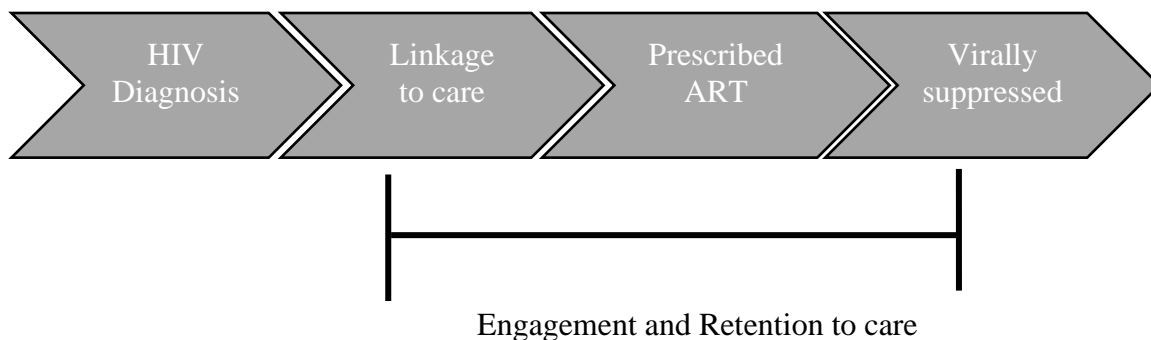


Figure 3: HIV care continuum

In the HIV care continuum, *HIV diagnosis* is the entry way to HIV care and is therefore a very important step in achieving viral suppression (Govindasamy et al., 2014). One must know their status in order to start treatment. KPs are especially encouraged to get tested because they are at a higher risk of getting infected and infecting others, but many of them are unaware of their status or are diagnosed at a later stage of the disease resulting in poor health outcomes and more HIV transmission (Mountain et al., 2014). In Kenya, due to the scale up of KP programs, 95.5% of female sex workers and 94% of PWID are aware of their HIV status, however there is no data on MSM and transgender people awareness of their status (UNAIDS, n.d.).

Linkage to care is the next step in the care continuum and is important for monitoring PLHIV's viral load and CD4+ T cell counts. CD4+ T cells are key immune effector cells and are meant to trigger the human body's response to external pathogens by stimulating other cells in the body to fight infection (Lewthwaite & Wilkins, 2009). Linkage to care provides a structure for a PLHIV to be evaluated for the eligibility of ART and initiated into ART as fast as possible. Because a series of tests may be involved, it is also a chance for a PLHIV to be diagnosed and treated for secondary infections that they may have (Mountain et al., 2014). Rapid linkage into care after diagnosis is highly advised because attrition rates are high between HIV diagnosis and start of ART (Am, 2017; Govindasamy et al., 2014; Mountain et al., 2014).

In fact, to avoid unnecessary attrition and increase uptake of ART, The World Health Organization (WHO) recently updated its guidelines to “test-and-treat” all, advising that Treatment should be offered to PLHIV as soon as they have been diagnosed regardless of CD4+ T cell count, age or gender (Brown et al., 2016; World Health Organization, 2016). This has increased substantially the number of people on HIV treatment (Grimsrud et al., 2017). In Kenya, 73% of HIV positive sex workers, 67.7% of PWID and 62.8% MSM were linked and were on ART by the end of 2017. There is no data for transgender people (UNAIDS, n.d.).

A PLHIV is expected to progress through the continuum seamlessly but that is often not the case. The largest drop-offs from the HIV care continuum occur at the *Retention to care* step (Colasanti et al., 2017) Nevertheless, it is well known that poor retention in HIV treatment is a key barrier to optimum HIV care. In contrast, good retention in treatment is strongly correlated with viral suppression, improved health outcomes, and lower HIV transmission rates (Colasanti et al., 2017; Hall et al., 2017; Holland et al., 2015; Moitra et al., 2017). People living with HIV are therefore obliged to access and remain engaged fully in HIV treatment in order to receive the benefits of ART (Monroe et al., 2016). Defined as consistent and lifelong engagement in HIV treatment, retention to care is a challenge to maintain. HIV being a chronic illness, PLHIV are required to adopt a completely new lifestyle, stick to their medication regimen and engage in HIV care by consistently attending appointments and actively being involved in their health care with medical providers for the rest of their life. They must also learn to cope with the physical, social and psychological stressors associated with their status. This is a highly complex behavior change and just like Prochaska and DiClemente’s (1992) stages of change model suggests, behavior change is a continuous process (Prochaska et al., 1992; Slater, 1999)

characterized with progressing and relapsing throughout the change process, moving in a spiral through the stages of change before it is finally enacted .

Thus, progression across the different stages in the HIV care continuum is neither linear nor stable. PLHIV may spiral in and out of the continuum overtime, sometimes experiencing a long period of time where they are engaged in treatment, are lost to treatment or are engaged very little in treatment .

Mugavero (2016), shares a clear case of how individuals may move across the HIV care continuum.

“Consider the case of a 21-year-old man diagnosed with HIV infection in June 2009. He entered care at the HIV clinic in August 2009, with a plasma HIV RNA level of approximately 100,000 copies/mL and a CD4+ cell count of 78/μL. He initiated antiretroviral therapy, and his viral load was undetectable in November 2009 and February 2010; his CD4+cell count increased to 376/μL and 455/μL, respectively, at these visits. From a global perspective of the HIV care continuum, he rapidly and successfully spanned the successive steps from diagnosis through viral suppression. However, he then missed several visits and returned to the clinic in November 2010 with an HIV RNA level of 22,700 copies/mL and a CD4+ cell count of 248/μL, after which he was lost to care for approximately 2 years despite clinic efforts to contact and locate him. At a visit for laboratory evaluation in November 2012, he had an HIV RNA level of 80,300 copies/mL and a CD4+ cell count of 108/μL. It was not until April 2013, 5 months later, that he returned to the clinic for a visit with his practitioner, with an HIV RNA level of 200,000 copies/mL and a CD4+cell count of 64/μL. He

presented with a cough, weight loss, night sweats, and cutaneous Kaposi sarcoma-associated lesions; a chest x-ray showed bilateral opacification of the lungs. There was no response to empiric treatment for Pneumocystis jiroveci pneumonia. He was admitted to the hospital, and a bronchoscopy revealed pulmonary Kaposi sarcoma. This picture is encountered too commonly in clinical practice, in which as many as 50% of individuals diagnosed with HIV infection are lost to care.”.

PLHIV who do not maintain a regular visit with their health provider run the risk of having viral load increase that goes undetected. High viral load leads to a decline in CD4+ cells, which once less than 200 cells/mm³ may be harmful for their immune system and their overall health. Additionally, not maintaining a regular visit may lead to non-adherence to ART, subsequently leading to resistant virus strains that may cause even more complications (Moitra et al., 2017). According to Nosyk et al. (2015), attrition from the HIV care continuum is heterogenous in nature, ranging from PLHIV never accessing care to PLHIV disengaging from care overtime. This includes PLHIV who are first time treatment dropouts, those who continuously miss appointments and have multiple discontinuations of treatment and those who have been lost completely to care (Nosyk et al., 2015). For KPLHIV, the attrition rates from the HIV care continuum may be worse given the numerous social, political and structural barriers that they face due to their sexual orientation, the nature of their work and their HIV status (Ampt et al., 2017).

The last step in the HIV care continuum is *viral suppression*. It is evident that viral suppression would be hard to achieve without retention in care. This is because PLHIV not retained in care are less likely to be adherent to their medication regimen, more likely to have

less CD4+ T cell counts and high viral loads, risking progression to acquired immunodeficiency syndrome(AIDS) and ultimately death (Moitra et al., 2017). It is however probable that a PLHIV may reach viral suppression even with no retention. There are cases of PLHIV who are not engaged fully in care but are virally suppressed and PLHIV who are retained in care yet have not reached viral suppression, although, viral suppression is almost usually never sustained in people who are not retained in care (Yehia et al., 2015). It is important to mention that viral suppression is when a PLHIV's viral loads have been made undetectable by ART. A person with undetectable viral loads cannot transmit HIV, but they must adhere to their ART to maintain the undetectable viral loads. That is why constant monitoring and engagement in care is of utmost importance to a PLHIV(UNAIDS, 2018)

Kenya has not provided data on how many members of key population groups are virally suppressed (UNAIDS, n.d.). Adopting the HIV care continuum framework, nevertheless, has enabled Kenya to use cascade analysis to evaluate Key population group access and uptake of HIV related services, and identify the multiple entry and exit points of KPLHIV from the HIV care continuum(Bhattacharjee et al., 2019). Cascade analysis is the utilization of clinical data to identify gaps in engagement in care through the assessment of the HIV care continuum, which then informs HIV program improvement especially in countries using biomedical interventions to fight HIV (Bhattacharjee et al., 2019; Hladik et al., 2016; S. Schwartz et al., 2017). Recent data from the cascade analysis on key population groups in Kenya revealed that although the reach for key population groups with HIV preventive and testing services is high, when it gets to linking/initiating HIV positive KPs on treatment, and retaining them in treatment, the numbers considerably drop. PEPFAR (2020), reported that despite the availability of services, ART coverage in FSWs, MSM and PWID is at 50%.

Statement of the problem

What has been accomplished so far in Kenya has been critical in pushing forward the fight against HIV. It is, however, ever more clear that in order to change the course of the HIV epidemic in Kenya, more attention needs to be focused on the linking and retention of KPLHIV in care which has so far remained sub-optimal in the country (Bhattacharjee et al., 2019; Schwartz et al., 2017). Recognized as a requirement for achieving viral suppression, retention to care has not received enough attention. In Kenya there is poor documentation of retention in care not only for KPLHIV, but also for general populations living with HIV; an issue experienced all over Sub Sahara Africa (UNAIDS, 2019). Further, there is a suboptimal amount of studies assessing barriers and facilitators of retention in care for KPLHIV in the country.

The purpose of this study, therefore, was to explore why given the extensive key population programming in Kenya, the percentage of KPLHIV retained in HIV treatment is still low in the country. Specifically, the researcher aimed to, (1) Identify the barriers that lead to poor retention of KPLHIV in HIV treatment, (2) Identify the interventions key population programs have put in place to address those barriers and whether those interventions are effective and (3) Identify what interventions key population programs think should be strengthened or introduced to improve retention.

Theoretical Framework

Theories give us an organized way of piecing together incidents, behaviors, and circumstances. For instance, behavioral theories can be used to understand and predict behaviors through considering a variety of factors that influence the decisions people make on whether to engage or disengage in healthy behaviors. Therefore, to improve the retention of KPLHIV in HIV treatment, theory driven research may help us gain the knowledge needed to

close the gaps experienced by KP programs in retaining KPLHIV in HIV treatment, and create interventions meant to greatly improve retention in KPLHIV to HIV treatment.

For this study, the Health Beliefs model concepts were used to formulate the research questions and create themes during data analysis. The Health belief model, which was developed in early 1950s to assess why people don't embrace prevention behavior or screening behavior for the early detection of disease is one of the most widely used theories of health behavior (Becker & Maiman, 1975; Rosenstock et al., 1988) including within the context of HIV prevention and treatment (Evangeli et al., 2016; E. J. King et al., 2017; Leidel et al., 2017; Montanaro & Bryan, 2013).

It is important to mention that although all the components of the health beliefs model was analyzed and reported, during data collection the researcher focused most of her interview questions on barriers to retention because that was the specific component of the health belief model that she was interested in. Chapter 2 provides more details regarding the Health beliefs model and its relevance to the study.

Significance of the study

Inadequate retention of KPLHIV in HIV treatment undermines all the progress that the country has made against HIV in the past several years. Consequently, Kenya needs to create interventions meant to drastically improve KPLHIV retention in HIV treatment. However, understanding a problem is crucial to finding its solution. Therefore, identifying what barriers affect the linkage and retention of KPLHIV in HIV treatment is a significant step in coming up with ways to improve retention. Once the barriers are identified, effective interventions can then be formulated targeting the specific barriers to retention that are identified.

The HIV treatment continuum used by key population programs to identify gaps in prevention and treatment services of key population groups also provides an organizing framework for incorporating interventions targeting retention of KPLHIV in HIV treatment. Furthermore, the combination prevention strategy also used by key population programs offers infinite opportunities for engaging health communication and behavioral change interventions to improve linkage and retention. Free access to antiretroviral therapy is not enough to change HIV incidence rates or KPLHIV sexual behaviors. Engagement with treatment and adherence to HIV treatment require both complex individual and group behavioral responses that can be inspired and sustained using behavioral change interventions that apply health communication strategies.

According to Schiavo (2013), Health communication is a “multifaceted and multidisciplinary approach to reach different audiences and share health-related information with the goal of influencing, engaging, and supporting individuals, communities, health professionals, special groups, policymakers and the public to champion, introduce, adopt, or sustain a behavior, practice, or policy that will ultimately improve health outcomes (pg. 7). In the HIV context, while health communication has no direct effect on the HIV virus, it has a powerful effect on the “knowledge, attitudes, social norms, risk perceptions, and behavioral decisions that affect if and when the [HIV] virus is transmitted, where and when testing and/or care is sought, how care is delivered, and how well adherence to antiretroviral therapy (ART) is maintained” (Storey et al., 2014, pg.243).

KP-led organizations have already provided the infrastructure within which health communication can be used to affect behavioral change. There is in fact an incorporation of health communication and other behavioral interventions in the early steps of the HIV care

continuum for KPLHIV as part of the combination prevention (Tomori et al., 2014). For instance, key population programs employing peer-to peer interventions to encourage members of key population groups to engage in preventative and testing behaviors is one of the ways health communication has been utilized through community mobilization.

Moreover, health communication has been integrated into the biomedical interventions already offered by key population programs; key population programs use peer educators to supply condoms and educate members of key population groups on the importance of using condoms during sexual encounters. This is important because studies suggest that most biomedical interventions that have been considered successful in addressing the HIV epidemic have in one way or another relied on a behavioral change intervention of some sort (Campbell & Cornish, 2010; Gregson et al., 2011; Pettifor et al., 2013; Shoptaw et al., 2013; Vermund et al., 2014). If Behavioral interventions applying health communication strategies have been effectively used in HIV prevention efforts (Sutton et al., 2017; Vermund et al., 2014), they can also be used effectively to address barriers to linkage and retention in HIV treatment once they are identified.

Conclusion

This chapter provided an explanation of the research background, the problem statement, the purpose, and the significance of the study. This study addressed the barriers of linkage and retention in HIV treatment for KPLHIV in Kenya. In Chapter 2, the literature related to the topic is reviewed.

LITERATURE REVIEW

Key population groups are disproportionately affected with HIV/AIDS in Sub-Saharan Africa and in the world at large (Beyrer et al., 2015; Lillie et al., 2018); they also have higher morbidity and mortality rates than the general population (Global Fund, 2019). Key population groups are defined as people who, due to their engagement in certain patterns of behavior, are at increased risk of acquiring and transmitting HIV; they also in one way or another face legal, social, structural and other contextual issues which increase their vulnerability to HIV while limiting their access to prevention and treatment services (Beyrer, 2016; Mayer & Allan-Blitz, 2019).

According to the WHO Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations (2016), while key population groups have biological and behavioral risks that put them at risk of acquiring HIV (see table 1), the HIV epidemic in key population groups is mainly fueled by factors outside of members of key population groups control including, “ stigma and discrimination, gender inequality, violence, lack of community empowerment, violations of human rights, and laws and policies criminalizing drug use and diverse forms of gender identity and sexuality” (pg. 84). To understand the needs of key population groups, therefore, understanding the diverse geographical, social and political contexts in which they live is encouraged (Beyrer, 2016). Further, to provide targeted services that are tailored to their unique needs and preferences, recognizing the heterogeneity of each key population group, and each member of a key population group is encouraged (Herce et al., 2018).

Table 1: Factors that increase HIV risk in KP members

Key population group	Biological	Behavioral	Structural
MSM	<ul style="list-style-type: none"> • Increased efficiency of Anal sex transmission • Sexually transmitted infections increasing the chances of HIV transmission 	<ul style="list-style-type: none"> • Open relationships (number of partners) • Substance use • Role changeability (MSM can be the insertive or receptive partner) • No using condoms during sex 	<ul style="list-style-type: none"> • Systematic Homophobia • Exclusion from policy/programming • Criminalization • Poverty • violence
FSW	<ul style="list-style-type: none"> • Sexually transmitted infections (co-factor) 	<ul style="list-style-type: none"> • Substance use • No using condoms during sex • Multiple partners • Sexualized solicitation spaces (brothels, Hostels) 	<ul style="list-style-type: none"> • Criminalization • Incarceration • Exclusion from policy/programming • Criminalization • Poverty • violence

Table 1 (cont'd)

PWID	<ul style="list-style-type: none"> • Blood-borne infections • The efficiency of sharing needles 	<ul style="list-style-type: none"> • Needle sharing • Risk of unprotected sex while using 	<ul style="list-style-type: none"> • Criminalization • Incarceration • Banning of interventions that are effective in helping them
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The HIV rates in key population groups cannot be attributed to one single factor. Multiple behavioral, structural, and biological factors intricately interconnect to heighten their risk (Mayer & Allan-Blitz, 2019). Further, more often than not members of key population groups simultaneously belong to more than one key population group. For instance, there are MSM who are also sex workers and there are sex workers who also inject drugs.

According to Risher et al. (2015), those people often experience “syndemics, synergistically interacting co-prevalent diseases and psychosocial conditions” (pg. 2) which exacerbates the disease burden they experience and makes their prognosis worse. The significance of accessing HIV preventative and treatment services in these populations can therefore not be emphasized enough. Regardless, the structural barriers they experience not only directly affects their risk of acquiring and transmitting the disease, it also shapes their health seeking attitudes by increasing their fear of seeking preventative and treatment services leading to reduced utilization of those services (Mayer & Allan-Blitz, 2019).

In Kenya, a connection of the social-structural barriers provides a firm basis for the epidemiology of HIV. In the country the criminalization of sex work and same sex relations, coupled with stigma and violence work to create a disabling environment to members of key population groups in the country (Bhattacharjee, Morales, et al., 2018a). Mgbako (2016), explaining how much harm criminalization of sex work causes sex workers captures perfectly

how structural factors strengthen each other to increase the marginalization of key population groups.

“Criminalization harms sex workers in many ways. The fact that their work is illegal means they are pushed underground and into the shadows with little to no access to labor rights protections, health care services, and other social and economic safety nets. It emboldens police officers and other state agents to use the shield of law as an excuse to take advantage of sex workers. Because police view sex workers as criminals, they rarely provide them with protection of the law when they are the victims of crime. This lack of access to justice emboldens clients with violent inclinations who know that their abuse of sex workers will be met with impunity. It also empowers third-party managers who know that without the benefits of labor protections, including occupational and safety standards, they’re free to take advantage of sex workers in brothels, massage parlors, and other indoor venues who may be exposed to dangerous and unfair working conditions. This cycle of violence and impunity involving police, clients, and bosses, coupled with health care discrimination and the underground nature of the work, increases sex workers’ vulnerability to HIV and other health issues. And, of course, the social status of people regarded as criminals is very low.”

The interconnection of the above-mentioned structural barriers that sex workers face is increased tenfold when it comes to MSM. This is because on top of criminalization, stigma and violence, MSM are subjected to homophobia (Njagi et al., 2019). It is even worse if they are HIV positive because they then experience an interconnection of stigmas due to having same

sex relations and being HIV positive, which exponentially reduces their confidence and ability to seek treatment. Baral et al. (2013) explains that due to fear of discrimination and violence, many MSM hide their sexual orientation or their HIV status and do not show up for testing or treatment.

Structural interventions targeting key population groups in Kenya

Key population programming in Kenya utilizes the combination prevention packages comprising of effective behavioral, biomedical, and structural interventions. Studies suggest that prevention efforts targeting key population groups will always provide modest effects if structural barriers are not addressed (Mayer & Allan-Blitz, 2019 ;NASCOP, 2014; Shannon et al., 2015; Wolf et al., 2018). Owing to that, Kenya has strived to build an empowering environment for key population group through structural interventions that expand access to HIV preventative and treatment services and enhance community mobilization in key population groups (Musyoki et al., 2018).

The critical structural interventions that Kenya has tried to enforce in the country include,

1. *Addressing the policies and legal environment that are limiting to key population groups uptake of effective HIV services:* They have done this by putting in place programs that help members of key population groups know and understand their rights. Further, they have done this by encouraging community mobilization and involvement of members of key population groups in the planning, management, and implementation of key population HIV programs. From a recent study by van Stapele et al. (2019) exploring the tensions between the government of Kenya and key population-led organizations (sex worker-led), however, there is

clear evidence that there are still contradictions and mistrust of the government by key population groups due to (1) policy makers not really including the input or contribution of members of key population groups in policy development and (2) the government as a whole not favoring decriminalization of sex work and same sex relations.

2. *Reducing stigma and discrimination:* Because health care providers are perceived as some of the greatest perpetrators of stigma, Kenya has put programs in place meant to provide sensitization to health care workers on stigma and discrimination against key population groups. Kenya has also, through key population-led organizations, tried to provide services tailored specific to their needs and also KP-friendly environments where members of key population groups can receive HIV services.
3. *Providing violence prevention services and violence response:* Although each key population group has unique experiences with violence, members of key population groups experience with violence in the Kenya is so common to the extent of them considering violence a normal part of the job or a normal occurrence in their day to day lives (NASCOP, 2014). KPs face considerable physical violence, sexual violence, and emotional violence at at their places of work and in the society at large; and these forms of violence are perpetrated by different perpetrators, including their intimate partners, gangs, strangers and even law enforcement officers(Bhattacharjee, Morales, et al., 2018b). This violence just as Mgbako (2016) explained, is further fueled by the Kenyan legal system

which criminalize sex work and same sex relations leading to increase in HIV risk and reduced HIV services uptake in members of KP groups.

Owing to that, Kenya came up with violence prevention and response strategies including, empowering of KP members through advocacy and capacity building on how to respond during an assault, awareness creation of their rights as human beings, promoting security for them through creating safe spaces for them, setting up a 24-hour crisis support line and promoting workplace security for them (NASCOP, 2014). Shannon et al. (2015), through a modelling study, found that if Kenya eliminated violence against only female sex workers, 17% of new HIV infections could be averted among female sex workers and their clients over a period of 10 years.

Just like behavioral and biomedical interventions would produce suboptimal results if implemented alone, it is important to acknowledge that structural interventions can also not work alone; that is why the combination prevention packages is emphasized in key population programming in Kenya. As mentioned elsewhere in this study, the combination prevention strategy paired with peer to peer interventions used by key population programs in Kenya have greatly influenced the HIV risk and HIV service uptake among members of key population groups. However, from results in recent cascade analysis in the country, there was evidence that gaps were still being experienced in the uptake of HIV treatment by HIV positive members of key population groups. PEPFAR (2020), reported a 50% ART coverage in FSWs, MSM and PWID; this is 45% less than the percentage of KPLHIV that Kenya was targeting to be in treatment by the end of the year 2020.

According to the HIV treatment continuum (see chapter 1), a person starts to take HIV medication immediately after being linked into HIV treatment services; and once a person living with HIV is linked into HIV treatment he/she is supposed to engage with treatment services for the rest of their lives so that they can reach and maintain viral suppression. There is no way of knowing that a person after being initiated in HIV treatment is going to be retained in HIV treatment; multiple personal, social and environmental factors will determine whether they are going to be retained or not(see chapter 1).

Members of key population groups that are HIV positive are faced with multiple challenges that lead to their poor retention in HIV treatment. These challenges are exacerbated by the structural barriers that key population groups face at large and while key population programs have tried to make the process of testing and treatment as seamless as possible in Kenya, there is still a great need to focus interventions on ways to retain KPLHIV in HIV treatment.

Barriers to retention of KPLHIV in HIV treatment

While not a lot of studies have specifically looked into barriers to retention of PLHIV in HIV treatment, a lot of studies have either explored barriers to linkage of PLHIV in HIV treatment or barriers to linkage in combination with barriers to retention of KPLHIV in HIV treatment (Ahmed et al., 2018; Govindasamy et al., 2012; Njab et al., 2018; S. R. Schwartz et al., 2017; Wanyenze et al., 2017). Linkage to treatment is the first step towards retention of PLHIV in HIV treatment because it is their initial engagement with treatment services, and it is during that step that PLHIV are initiated on ART. Barriers to linkage in HIV treatment can therefore be said to be more or less barriers to retention.

From research studies assessing the factors affecting linkage and retention of people living with HIV in HIV care, multiple psychosocial, healthcare delivery, and structural factors that are either barriers or facilitators of linkage and retention in HIV care have been identified. For instance, in a recent review on why people living with HIV do not initiate treatment, Ahmed et al. (2018) established that personal and social factors such as, gender differences, poverty and financial burden, health status of patient at time of diagnosis, the emotional and mental state of patient regarding stigma and disclosure, a patients coping mechanism, a patient's social and emotional support system; and healthcare delivery factors such as "inconvenient clinic hours, long queues, difficulty in scheduling appointments" (pg.78), affects whether a person living with HIV will initiate treatment or not. On the other hand, Bigna et al., (2016) found that people living with HIV who were diagnosed through home based diagnosis are less likely to be linked in care than those tested at a HIV clinic.

Moreover, from the limited research focusing specifically on linkage and retention of KPLHIV in HIV care, it has been determined that other than the barriers KPLHIV experience as HIV positive individuals, they face further structural barriers including stigma, discrimination, high violence exposure, economic insecurity, criminalization, hostility coupled with health care workers insensitivity, which work to further limit their access to treatment and preventative services (Goldenberg et al., 2016; Macdonald et al., 2017; Njab et al., 2018; S. Schwartz et al., 2017; Wolf et al., 2018). For instance, Mtetwa et al. (2013), from their focus group discussions with sex workers to assess the of barriers to engagement in HIV treatment for sex workers, established that some of the barriers FSWs faced in HIV treatment included discrimination and hostility from health care workers, public humiliation from health care workers, stigma associated with sex work, no sense of urgency from health care workers when providing

services to them (long wait times), financial and logistical constraint and lack of nutritious food. Similarly, Goldenberg et al. (2016) in their longitudinal study that drew data from a cohort of 646 female sex workers found that sex workers face structural barriers such as migration and mobility and incarceration which interrupted their access to antiretroviral therapy and were major impediment to their engagement in HIV treatment. Holland et al. (2015) in their assessment of treatment coverage in MSM and FSWs in Cameroon as well as Wanyenze et al. (2017) in their assessment of female sex workers perceptions and experiences in accessing HIV treatment in Uganda found consistent findings as above research studies.

One study that focused on health provider perception of what would improve antiretroviral therapy adherence among MSM in Kenya noted that, while barriers such as information and AIDS illiteracy, HIV stigma and economic challenges are factors that affect the engagement of people living with HIV in HIV treatment, MSM face specific barriers such as biased clinical environments, prejudiced patient-provider relationships, dual stigma (MSM related stigma coupled with HIV related stigma) and impeded access to social and financial capital, that further limits their engagement in HIV treatment (Micheni et al., 2017).

Most research on barriers and facilitators of retention in HIV treatment have neglected to evaluate the views of health care workers on what they think are the reasons behind the attrition of many KPLHIV from the HIV continuum. This overlooked group together with the people who work closely with KPLHIV through intervention programs (program workers) are very important in improving the treatment outcomes of KPLHIV because they work closely with them. Their views are also important in developing interventions targeted at increasing retention in KPLHIV. This is especially important for Kenya where seamless retention systems for KPLHIV needs to be formulated.

Furthermore, it was interesting to find that most of the studies assessing barriers to linkage and retention of both PLHIV and KPLHIV in HIV treatment was not theory driven. Theories, as mentioned earlier, give us an organized way of piecing together incidents, behaviors, and circumstances. Behavioral theories especially, can be used to understand and predict behaviors through considering a variety of factors that influence the decisions people make on whether to engage or disengage in healthy behaviors. Engaging in HIV treatment by KPLHIV is huge behavioral commitment and whilst they face multiple barriers that are out of their control, behavioral theories may help us understand their beliefs and attitudes towards engaging with HIV treatment. Once we know this, targeted behavioral interventions can be implemented to help strengthen KPLHIV commitment in engaging with HIV treatment regardless of the structural barriers, by strengthening their attitudes and beliefs. Behavioral interventions may also work on a society level to change the society's beliefs, social norms and attitudes that work in conjunction with other structural factors to enhance poor retention of KPLHIV in HIV treatment.

It is also very important to train key population program workers and health care workers on how to use behavioral interventions while interacting with KPLHIV. This ensures that they are using targeted messages with KPLHIV on a regular basis. According to Bandura's (1978) social learning theory, all behaviors can be learned through conditioning. If program workers and health care workers continuously counsel and use positive role models on KPLHIV, they can encourage and reinforce retention behaviors in KPLHIV.

Present Study

This study aimed to assess what barriers affected the retention of KPLHIV in HIV treatment. Provided that numerous studies had already recorded accounts of KPLHIV on what

barriers they experience when it comes to linkage and retention in HIV treatment, this study's purpose was to assess the perceptions of people who worked closely with KPLHIV. That is, key population program workers and health care workers.

This was essential because, not only do program workers and health care workers spend most of their time serving KPLHIV and therefore have ideas on what barriers exacerbate the attrition rates of KPLHIV in care and what factors they think encourage retention, in order to come up with interventions targeting KPLHIV retention in HIV treatment, we first, (1) need a better understanding of the process KP programs follow to test, link and retain KPLHIV to care (2) need an understanding of what efforts the KP programs and health facilities have put in place to encourage retention, and (3) an understanding of what more could be done or what efforts could be strengthened, added or eliminated in order to encourage retention in HIV treatment. Health care workers and program workers were the best suited people to provide this information.

Additionally, given that most studies did not use any theory to assess the beliefs and attitudes of KPLHIV about HIV retention, this study, to assess the beliefs of program workers and healthcare workers about KPLHIV retention in HIV treatment, utilized the health beliefs model as a framework. This was important because it enabled the researcher to explore whether health care workers beliefs about KPLHIV retention in HIV treatment affected how they interacted with KPLHIV in their day to day interactions. This was important because that way, areas of improvement could be identified, and both health care workers and program workers could be equipped with skills on how to effectively target KPLHIV with retention interventions during their day to day interactions.

The health beliefs model, which has been used before in various contexts including medicine adherence (Vitalis, 2017); condom usage (Tarkang & Pencille, 2018; Volk & Koopman, 2001); HIV screening (Fang et al., 2019; Nareswara et al., 2016), has not to the researcher's knowledge, been used to assess the beliefs of KPLHIV about retention in HIV treatment. It has nevertheless been used in the assessment of members of key population groups health behaviors. For instance, Zhao et al. (2012), used it to assess the predictors of condom use behaviors among FSWs in China and found low perceived susceptibility of HIV as a result of not using condoms a weak effect on perceived severity as a positive effect on condom use, strong effect of perceived barriers and benefits to condom usage with greater perceived severity of HIV/AIDS resulting in greater perceived benefits; Nareswara et al. (2016), used it to predict testing behaviors among MSM in Bandung and found insignificant effect of perceived severity, strong positive effect of perceived susceptibility to testing behaviors, and significant positive effect of perceived benefits to treatment behaviors. They concluded that there was low uptake of testing services; Bailey & Figueroa (2016) have used it as to create intervention meant to improve sexual decision-making among FSWs in Jamaica; Jorjoran Shushtari et al. (2019) have used it to assess HIV risk perception and sexual behaviors among FSWs in Iran; and several other researchers have utilized it in the context of key population groups (see Felsher et al., 2018; Li et al., 2016; Tarkang & Pencille, 2018; Zamboni et al., 2017).

Health Belief Model (HBM)

The HBM has five components that are proposed to influence the likelihood of a person engaging in a health behavior. First is the perceived susceptibility, which refers to an individual's perceptions of being at risk of getting an illness; Second is the perceived severity, which is the individual's perception of how serious the consequences of getting the disease is;

Third is perceived benefits or the assessment by an individual of the potential advantages of taking actions against a disease; Fourth is perceived barriers or an individual's perceived obstacles to engaging in the action taken against a disease, such as, cost, time, cultural barriers, fear of results, etc.; Fifth is cues to action. Cues to action are events or factors, internal or external, that stimulate a person to engage in a health behavior such as engaging in HIV treatment (Rosenstock, 2005; Rosenstock et al., 1988).

Perceived susceptibility

This HMB construct emphasizes that the likelihood of a person engaging in a health behavior is dependent on that person's perception of their vulnerability to experiencing a dire outcome. For instance, the likelihood of a person to engage in a preventative behavior, is dependent on their perception of the risk of acquiring the disease that they would be preventing if they engaged in the preventative behavior. Thus, in the case of KPLHIV retention in HIV treatment, and for the purposes of this study, it would be the health care workers and program workers perceptions of KPLHIV vulnerability to experience HIV related opportunistic infections, malignancies and ultimately death if they are not retained in HIV treatment.

There is already a number of studies that have shown the vulnerability of people living with HIV to experiencing HIV related infections, malignancies, and death due to not being retained in HIV treatment (Giordano et al., 2007; Kempf et al., 2010; Mugavero, 2016; Mugavero et al., 2009, 2012). For this study it is therefore assumed that Program workers and Health care workers already understand or already perceive that KPLHIV would succumb to HIV related illnesses if they are not retained, and understanding what they are doing to ensure that KPLHIV understand the same is of utmost importance

Perceived severity

This construct emphasizes that if an individual perceives that the outcome of not engaging in a health behavior is going to be severe, then they are going to engage in that health behavior. That is, there is a likelihood that KPLHIV would be retained in care if there was a perception that there will be severe outcomes if KPLHIV are not retained in treatment.

HIV which was once considered fatal is now seen as chronic since antiretrovirals which help extend HIV positive individuals lives became available (Baumgartner, 2007).

Subsequently, its prognosis gets better each passing day because more and more people are living with it each year. Before antiretrovirals to slow its progression, HIV used to lead to high loss of life making its prognosis very negative, and the more negative the prognosis of a disease the more it would be perceived as severe. Now, studies show that HIV positive patients start perceiving severity of HIV outcomes when they are assailed by physical symptoms and once they go back to treatment and start feeling better, they go back to not perceiving severity (Muoghalu, 2018; Wringe et al., 2009).

For this study it was assumed that health care workers and program workers perceive severity of outcomes if KPLHIV are not retained in HIV treatment. Therefore, it was expected that program workers and health care workers would mention that they provide KPLHIV with information educating them on the severity of HIV and on the importance of engaging in HIV treatment to avoid those negative outcomes.

Perceived barriers

This construct focuses on the perceived obstacles or costs associated with performing a health behavior. For this study, it is the perceived obstacles or costs to associated with KPLHIV retention in HIV treatment. Some of the barriers that have been mentioned before that hinder

retention of people living with HIV in HIV treatment include and are not limited to: Stigma and discrimination (Hall et al., 2017); competing life activities (Yehia et al., 2015) ; young age, imprisonment, sex work, illiteracy, rural residence, self-referral for HIV testing and public hospital as the place of diagnosis (Koirala et al., 2017); and depression and mental illness (Yehia et al., 2015).

If barriers are perceived to be more than the benefits, according to HBM, the probability is high that a person will not engage in a health protective behavior. In our case, if a KPLHIV faces more barrier in being retained in HIV treatment than benefits, then KPLHIV will not be retained in care. This construct is the most important construct in this study because by understanding the barriers, interventions meant to tackle the barriers can be formed.

As mentioned before, a lot of research has been done that identified barriers that KPLHIV face in being retained in HIV treatment (Goldenberg et al., 2016; Holland et al., 2015; Macdonald et al., 2017; Mtetwa et al., 2013; Njab et al., 2018; S. Schwartz et al., 2017; Wanyenze et al., 2017; Wolf et al., 2018). Even So, these studies used accounts from KPLHIV themselves to determine the barriers to retention. Because program workers and health care workers work closely with KPLHIV, it is also important to get their account on what barriers they think leads to KPLHIV dropping out of care, what they are doing to address those barriers and whether it is working.

Perceived benefits

This construct emphasizes the benefits of engaging in a health behavior. It has to do with an individual's belief that engaging in a particular health behavior is beneficial to them and that inherently, engaging in that behavior is more advantageous than it is disadvantageous. In this

case, it is the belief that KPLHIV retention in care is beneficial to their quality of life, and that even with the barriers, it is still better if KPLHIV are retained in care than if they are not.

This construct is important because it shows that even if people perceive high susceptibility to having a dire outcome if they don't engage in a certain health behavior, and great severity of the outcome, they are not likely to engage in the health behavior unless they believe that engaging in that health behavior will be beneficial to them. Perceived benefits are considered more important than the other constructs mentioned above (Rosenstock, Strecher & Becker 1994).

For this study it was again assumed that healthcare workers and program workers perceive that it is more beneficial if KPLHIV are retained in care regardless of the barriers they face. It was therefore expected that healthcare workers and program workers would mention that they ensured that KPLHIV understood the importance of retention even in the midst of the barriers.

Cues to action

The final construct of the HBM model is the cues to action. This construct focuses on the external and internal motivators for performing a certain health behavior. These external and internal motivators include stimulations such as ways of thinking or events that increase the likelihood of an individual engaging in a health behavior. For our case, they include stimulations that increase the likelihood of KPLHIV to constantly engage in HIV treatment and therefor be retained in HIV treatment. Therefore, we expected to find out what health care workers and program workers used as cues to action in order to motivate KPLHIV to continue engaging in HIV treatment.

It is important to mention that, although cues to action are considered motivators to performing health behaviors, they are usually generally accompanied by the other constructs of the HBM. In other words, if a person has a high perception of outcome severity, along with low barrier and high benefit perception, then cues to action will be a great motivator for engaging in the health behavior. If not, then cues to action may not be helpful at all (Chen & Land 1986; Redding et al. 2000; Rosenstock, Strecher & Becker 1994).

Research Questions

As illustrated throughout the literature, retention in HIV treatment is integral to preventing the spread of HIV. This is because the more PLHIV are retained in care, the more adherent they are to ART and the more adherent they are to ART, the more virally suppressed they become. A person who is virally suppressed cannot transmit HIV, but a person who is not virally suppressed can transmit HIV; the risk of HIV transmission is connected closely to the viral load of a PLHIV (Baral et al., 2019; Eisinger et al., 2019; McNairy & El-Sadr, 2014).

HIV treatment is especially crucial when it comes to members of key population groups living with HIV because it is evident that, KPLHIV greatly influence the evolution of the HIV epidemic. First, as mentioned above, KPLHIV are at an elevated risk of acquiring and transmitting the HIV infection. MSM are at elevated risk due to the high efficiency of anal sex in HIV transmission (Griensven, 2007; Koblin et al., 2006; Morison, 2001); FSWs are at elevated risk due to the high rate of partner exchange (Paz-Bailey et al., 2016; Wamoyi et al., 2016, 2019); and PWID are at elevated risk due to the high frequency of needle sharing (Kurth et al., 2018).

Second, key population groups are not closed groups. People move in and out of the key population groups overtime (T. Brown & Peerapatanapokin, 2019; Fazito et al., 2012). For

example, a woman may engage in sex work for years, then decide to find a husband and marry. Similarly, a female sex worker's client may be involved with the FSW for a period of time then decide to stop. The same is the case with PWID; PWID may also stop injecting drugs after a period of time. When a KP stops engaging in behavior that put them at heightened risk of acquiring and transmitting HIV, they rejoin the 'general population', and if the KP is HIV positive, they move the infection from key population groups to the general population, thus increasing the HIV prevalence rates in the general population (T. Brown & Peerapatanapokin, 2019).

Third, through their intimate partners, KPs can also indirectly transmit the infection to members of the general population. For example, an FSW's client can acquire the infection from the FSW then transmit it to their wife. Similarly, an MSM may have an MSM partner and a wife at the same time. This is especially true in Africa where MSM face an intersection of stigmas and discriminations that make them a vulnerable and obscure population in the region. A recent study suggested that, African MSM are showing frequent bisexual concurrent relationships (Muraguri et al., 2015). This means that, MSM are not only contributing to the overall HIV epidemic in Africa, including in the context of heterosexual transmission of HIV, a lot of MSM also have wives or are in long-term relationships with a female partner, and are hiding their sexual orientation (Beyrer et al., 2010).

For KPLHIV therefore, getting tested and linked in care is not enough; for them, being retained in HIV treatment plays an integral part in not only their achievement of viral suppression, but also in preventing their spread of the HIV infection to their sexual partners and in extension, to the intimate partners of their sexual partners (T. Brown & Peerapatanapokin, 2019). Consequently, it is important to address the issue of poor retention of KPLHIV in HIV

treatment in Kenya. To do that, it is important to understand what is causing poor retention of KPLHIV in HIV treatment. Therefore, this thesis addresses three major research questions:

1. What do program workers and health care workers perceive to be the key barriers to retaining KPLHIV to HIV treatment?
 - a. How does the program workers perceptions of benefit of retention, susceptibility to non-retention, barriers to retention, and severity of non-retention affected their day to day interaction with KPLHIV?
 - b. How do program and health care workers use cues to action to encourage retention?
2. What efforts to retain KPLHIV in HIV treatment have program workers and health care workers put in place?
 - a. Are those efforts addressing the barriers mentioned in RQ1?
3. What more do program workers and health care workers think should be done to help retain KPLHIV better in HIV treatment?

Conclusions

This chapter presented the literature relevant to retention of KPLHIV in HIV treatment, the theoretical framework informing the study and the research questions. The following chapter covers the methodology used in the research study. The chapter will present the study design, which describes the study approach, the criteria used to recruit participants, the procedures of data collection, and the data analysis plan. Lastly, it will also explain how the researcher ensured validity and objectivity during the whole process.

METHOD

Study design

This was a qualitative exploratory study involving in-depth interviews with health care workers and KP-led organizations program workers in Kenya to understand what they perceived as barriers to retention of KPLHIV in HIV treatment. Program workers are people working in a key population led organization that implements a key population HIV program and healthcare workers are people that deliver medical care services in health facilities where key population living with HIV are linked. Both healthcare workers and program workers work directly with KPLHIV in Kenya.

Qualitative research gives a method for deeper exploration and understanding of issues because it enables the researcher to examine, describe and interpret people's feelings and experiences in human terms rather than through quantification and measurement(Blanche et al., 2006). Therefore, this qualitative research design presented a great methodological framework for getting in depth understanding of what program workers and health care workers perceived as the main barriers to KPLHIV retention and what they think should be done to facilitate retention.

Study sites

The study sites in this study were three KP-led organizations, one being Kenya National Outreach, Counselling and Training Program (KNOTE). K-NOTE is an NGO in Naivasha Kenya implementing a key population program targeting more than 3500 female sex workers and a few MSM with interventions across the continuum of HIV services for key populations. The organization is also implementing OVC-CASE program intervening in social determinants of health in the areas of care and support for 13000 orphans and vulnerable children (OVC) in

Nakuru County, Kenya. The other two KP-led organizations are huge organizations that have multiple drop-in centers, and comprehensive care centers within the organizations to facilitate linkage and retention of KPLHIV in HIV care. In other words, they do the testing, linking and follow up of their clients within the organization.

Other study sites included five health care facilities where KPLHIV were linked for treatment services. Two of the health care facilities were large facilities with one of them being a Sub-County Hospital and the other a renowned private hospital, while the rest were small facilities that were either private or government owned (see detailed description of sites in table 2).

The author of this study was affiliated with KNOTE and had built relationships with the people working in the organization and some of their clients. The author interned with the organization for close to two years. It is during that period that she developed the interest to learn more about factors that affect KPLHIV retention in HIV treatment.

Table 2: Study site description

Key Population-led Organization	Description	Participants interviewed (unique identifiers)	
K-NOTE	<ul style="list-style-type: none"> Located in Naivasha, Kenya Small key population led organization that has a drop-in center, but no comprehensive care unit 	P001	Field officer/social worker
		P002	Treatment champion
		P003	Treatment champion
		P004	HTS person
		P005	Project coordinator
		P006	Data clerk

Table 2 (cont'd)

	<ul style="list-style-type: none"> Mainly serves female sex workers (around 3500), but since it is the only key population led organization in Naivasha, Kenya, it also serves MSM in that town Refers all of their KPLHIV to the healthcare facilities of their choice within Naivasha 	P007 P008	Treatment champion Project clinician
ORG 2	<ul style="list-style-type: none"> Located in Nairobi, Kenya Mainly serves sex workers, women having sex with women (WSW), women using drugs and bar hostesses. 	P009 P010 P011 P012 P013 P014	Treatment champion Treatment champion Data clerk clinician/program coordinator HTS person HTS person

Table 2 (cont'd)

	<ul style="list-style-type: none"> • Large key population led organization that has multiple drop-in centers, each of them having a comprehensive care unit • Provide both testing and treatment services within the organization 	P015 P016	Social worker Clinician
ORG 3	<ul style="list-style-type: none"> • International organization with branches located all over Kenya. • Implements multiple HIV programs targeting different populations but is implementing a key population program in two towns in Kenya. 	P017 P018 P019	Project coordinator Treatment champion Data clerk

Table 2 (cont'd)

	<ul style="list-style-type: none"> • Data was collected from their Gilgil, Kenya branch. Mainly serves female sex workers but has other at-risk groups including truck drivers. • Large key population led organization that has a drop-in center and a comprehensive care unit • Provides both testing and treatment services within the organization 		
Health Care Facility	Description	Participants interviewed (unique identifiers)	
Facility 1	<ul style="list-style-type: none"> • Large Government Hospital that is a level 5 facility 	H002	Linkage person (CCC)

Table 2 (cont'd)

	<ul style="list-style-type: none"> Referral facility for all smaller health care facilities in Naivasha and its environs According to their website, their “daily inpatient and outpatient load is approximately 300 and 650 respectfully” Is the main link facility for K-NOTE Has a comprehensive care unit and a separate HIV wellness center for pregnant women where pregnant sex workers get referred Comprehensive care center is isolated from other health 	H003	Adherence
		H004	counselor (CCC)
		H005	Clinician (CCC)
			HTS person (PMTCT)
		H006	Nurse (PMTCT)
		H007	Mentor mother (PMTCT)

Table 2 (cont'd)

	<ul style="list-style-type: none"> • departments in the facility • Serves both general population and key population 		
Facility 2	<ul style="list-style-type: none"> • Smaller Government Hospital located in Naivasha • A comprehensive care unit within other departments in the facility • Serves both general population and key population 	H009	Clinician
Facility 3	<ul style="list-style-type: none"> • Large Non-profit Hospital that is a level 6B Teaching and Referral Hospital • Referral facility even for level five hospitals 	H001	Lead HTS provider

Table 2 (cont'd)

	<ul style="list-style-type: none"> • Has satellite facilities located all over Kenya; one located in Naivasha, Kenya • Is the second main link facility for K-NOTE • Comprehensive care center is integrated into other health departments in the facility • Serves both general population and key population 		
Facility 4	<ul style="list-style-type: none"> • Small medical center in Naivasha • Mainly meant to serve flower farm workers, but since flower farms are big hotspots for female sex workers in 	H008	Lead clinician

Table 2 (cont'd)

	<p>Naivasha, provides treatment services to female sex workers referred there.</p> <ul style="list-style-type: none"> • Comprehensive care center is integrated into other health departments in the facility • Serves both general population and key population 		
Facility 5	<ul style="list-style-type: none"> • Private flower farm owned facility • Mainly meant to serve flower farm workers, but since flower farms are big hotspots for female sex workers in Naivasha, provides treatment services to 	H010	Lead clinician

Table 2 (cont'd)

	<p>female sex workers</p> <p>referred there</p> <ul style="list-style-type: none"> • Comprehensive care center is integrated into other health • departments in the facility • Serves both general population and key population 		
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Participants

The participants were KP led organization program workers and health care workers. The participants were recruited via snowball sampling and word of mouth through a local NGO implementing a Key population program (K-NOTE), and they were eligible to be enrolled in the study only if they worked closely with KPLHIV.

This sampling method was purposive; and even though word of mouth was used, the author of the study purposely selected participants who were rich in information relevant to the study. Only the people that were (1) involved directly in testing, linking and following up of KPLHIV during HIV treatment and (2) involved with the planning and implementation of withing -organization interventions meant to increase the service uptake of KPLHIV were interviewed.

Selection procedure

The researcher approached the project coordinator of the KP program at KNOTE who helped her to identify the specific program workers in the organization that worked closely with KPLHIV. These program workers included, the program physician, the HTS provider, the field coordinator, and the project coordinator herself. The project coordinator then made phone calls to all the mentioned program workers and requested those willing to be interviewed to set up interview appointments with the researcher. She further connected the researcher with the KP program coordinators in the other two KP-led organizations where the same process of contacting and setting up interview appointments with willing participants was followed.

Additionally, the project coordinator at KNOTE helped the researcher identify the healthcare facilities where KNOTE linked members of key population groups who turn get a positive HIV diagnosis. She then connected her with comprehensive care center (CCC) leaders there who helped her recruit healthcare workers in the facility. The project coordinators from the other KP-Led organizations did not have to refer the researcher to healthcare facilities outside of the organization because their organizations were big enough to house a CCC, hence facilitating linkage and retention within the organization.

Sample size

Twenty-nine participants, 10 healthcare workers and 19 program workers, were interviewed. Of the 19 program workers 3 were program clinicians, 3 were HTS providers, 2 were a social workers/field officers, 2 were program coordinators and 6 were treatment champions/ ART case managers/ peer navigators. Three data clerks were also interviewed in the hope of getting the data on the retention rates of KPLHIV in the KP-led organizations. In the health care facilities, of the 10 participants 5 were clinicians, 2 were HTS providers, 1 was a

mentor mother, 1 was an adherence counsellor and 1 was a linkage person. It is important to mention that in one health care facility women who were pregnant and HIV positive received their treatment in the prevention of mother-to-child transmission (PMTCT) wing instead of at the CCC, therefore three of the participants were healthcare workers who worked in the PMTCT wing of the health care facility, and in the KP-led organizations it was normal to find one person holding two roles in the organization. For instance, one of the project coordinators was also a clinician in one of the organizations.

Data saturation is that point where, if a researcher goes beyond it, they will not get new information from their participants (Onwuegbuzie & Leech, 2009). It was on this basis that the researcher stopped at 29 participants.

Data collection Procedures

Semi-structured interviews were conducted for this study. The interview protocol, which was designed with the diverse participant pool in mind, was developed in a way that allowed the interviewer to not only ask participants questions that were only relevant to the roles they played either in the KP led organizations or in the healthcare facility, it was also designed to allow the interviewer to ask follow-up questions. The HBM model constructs were used to formulate the research and the interview questions, although the interview questions mainly focused on one component of the HBM (barriers). The full interview protocol is provided in Appendix A.

Interviewees were given a consent form to read and sign and were also required to verbally consent to participate in the interview with digital recording. After, the interview process began with a summary of the purpose of the study and some questions about participants work in order to begin to build rapport. Next, several questions about the

participant's understanding of the process of testing, linking, and following up of HIV patients was asked, before the interviewer specifically asked about their perceptions of the facilitators and barriers to retention of KPLHIV in HIV treatment.

The protocol was pilot tested with two program workers to ensure that the interview questions were well understood and also to determine roughly how long it would take to interview each participant. Further, from the pretest a few changes were made to the protocol including the separation of adherence to HIV medication from retention in HIV treatment. Adherence to HIV medication was defined as religiously following the HIV treatment regimen while retention in HIV treatment was defined as engaging with HIV treatment by going to appointments, getting refills of antiretrovirals, and getting viral loads taken to ensure the antiretrovirals are working. The data from the pretest was not included in the main study.

The interviews which were done between the months of August 2019 and January 2020, were conducted in a mixture of English and Swahili in private rooms at the drop-in center of the KP led organization and offices in Health care facilities and lasted approximately 1 hour each. The interviews were recorded with digital voice recorders, they were then transcribed, and the Swahili parts of the interview translated into English. After the interview, participants were given 10-dollar incentives. Going by other researchers' experience, that amount was considered to be the standard incentive in the country.

The study was approved by the Michigan State institutional review board, The Daystar University (Nairobi, Kenya) ethical review board and the Kenyan government. The health care facilities also reviewed and approved the study.

Data analysis

The researcher used qualitative thematic analysis(TA) as her method of analysis in this study. Braun & Clarke (2006) defines thematic analysis as a method for “systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a data set.” Thematic analysis, through the researcher focusing on finding sense across the whole data set, permits the researcher to “make sense of collective or shared meanings and experiences” and not just within a single data item (Braun & Clarke, 2012, p. 57). Thematic analysis, therefore, is a valuable method for summarizing the significant features of a huge dataset by analyzing different data items and highlighting the participants similarities and differences in perspective (Nowell et al., 2017).

Braun & Clarke (2006) presents a widely adopted six-step guide on how to conduct a thematic analysis. While Braun & Clarke’s six-step process is presented as a linear method of analyzing data, according to them, the process is in actuality “not a linear process of simply moving from one phase to the next. Instead, it is more recursive process, where movement is back and forth as needed, throughout the phases” (Braun & Clarke, 2006, p. 86). According to Braun & Clarke (2006), while conducting a thematic analysis, a researcher should,

1. Familiarize themselves with their data
2. Generate initial codes
3. Search for themes
4. Review the potential themes
5. Define and name the themes
6. Produce the product

Familiarizing with the data

This phase is common to all types of qualitative analysis and involves the researcher compiling all data into a form that can be easily used (Castleberry & Nolen, 2018). For instance, if the researcher collected interview data, then the first step is to transcribe the data and, then read and reread the transcriptions while listening to the audio recordings until they are intimately familiar with its content. Braun & Clarke (2012), suggests that during this phase a researcher should “immerse” themselves into the data to the extent that they are not just “reading the data”, they are instead “reading actively, analytically, and critically”, so that they start to ask critical questions about the meaning of the data as they move forward (pg. 60-61).

For this study, although the researcher did not transcribe or translate the interview data that was used during analysis, she collected the data herself and thus came to the analysis with prior knowledge of the interview data, and already formed thoughts on what the meaning of the data was. Nevertheless, once the interviews were transcribed, translated and cleaned, the researcher in an effort to strengthen her understanding of the content of the data, read through the interviews and listened to the recordings while making notes multiple times before starting the initial coding process.

Generating initial codes

Creswell (2012) defines coding as “the process of segmenting and labeling text to form descriptions and broad themes in the data” (pg. 243). Codes allow the researcher to pinpoint either semantic or latent features of the data and according to Boyatzis (1998), are “the most basic segment[s], or element[s], of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (pg. 63). Defining a code simply, King, (2004)

identifies it as “a label attached to a section of text to index it as relating to a theme or issue in the data which the researcher has identified as important to his or her interpretation” (pg. 256)

In this study, the researcher’s coding process was mainly deductive using qualitative thematic analysis (see Boyatzis, 1998; Braun & Clarke, 2006; Nowell et al., 2017; Vaismoradi et al., 2013). A deductive thematic analysis, often referred to as a theoretical thematic analysis, is a top down approach of analyzing data where the researcher does not derive the codes and themes from the content of the data, but instead brings with them a set of ideas or concepts (basically a theoretical framework) that they use to form themes and interpret the data (Braun & Clarke, 2012). This means that, in this study, the researcher utilized the health belief model’s constructs to develop a preliminary codebook that had the model’s constructs as the main codes within the study. She then, on the basis of common patterns, organized text with similar content from the transcripts into relevant themes.

Although researchers can use either deductive or inductive thematic analysis to code and create themes, it is rare to find a research that purely uses one method opposed to the other. In reality, researchers often combine the two methods because it is highly unlikely that a researcher would disregard entirely the meaning of content only because it does not fit into the theoretical constructs being coded; at the very minimum they would try to find meaning from that content (Braun & Clarke, 2012). It is on this basis that the researcher left room for development of themes that were not covered by the HBM constructs throughout the data analysis process. This inductive approach is mainly based on grounded theory (see Braun & Clarke, 2006 and Creswell, 2012), which has often been used in qualitative research because of the ability it gives qualitative researchers to develop themes as they emerged from the data.

The researcher used NVivo, a qualitative data analysis software, to sort, organize and code her data. First, following the Braun & Clarke, (2006) to qualitative thematic analysis, she selected her data set, which included all the 29 interview transcripts from her interviews and uploaded them in to the software. Next, using the health belief model, she defined five main categories – perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action – to code. The five categories were then divided into subcategories as data analysis progressed, and data extracts that could not be coded into the five predefined categories were coded within new categories. Those categories and subcategories helped the researcher to construct themes that helped her understand better the perceptions of program workers and healthcare workers on why KPLHIV have poor retention in HIV treatment.

Once the researcher defined her categories and subcategories, she began to develop a codebook that had clear definitions of the categories and subcategories, codes and examples of statements that would be coded in specific categories (see appendix C). This was an important aspect of the analysis steps because not only was the codebook used to train two other coders on how to distinguish each text and reliably code them into an appropriate category, it showed that the data was analyzed in a systematic and logical way. Moreover, while the use of NVivo helped the researcher work effectively with a large data set and complex coding schemes, the two coders that helped with the coding enhanced the credibility of the coding process.

During the coding process, the researcher provided the two coders with the codebook which had the definitions of the different constructs of interest and explained to them how to interpret the text to make sure that they code each text into the right category and subcategory. Because all the coders were using Nvivo to facilitate the coding process, one training session with an NVivo specialist was also conducted to familiarize them with the NVivo software.

Both the coders and the researcher at the beginning of the coding process coded three similar interviews independently. They then, every week, in a period of one month met to compare and discuss the similarities and differences of their codes. When there were parts that they all coded differently, they discussed their points of view and reached a consensus and after they all started having more similarity in their coding, the researcher divided the interviews equally between the two coders to code, then compared their coded transcripts with her own coded transcripts to see whether there was a discrepancy in their coding. During the whole process there was a lot of reflexivity and discussion between the researcher and the coders to analyze how, as they went deeper into the data and engaged more thoroughly with it, their thoughts and views were evolving.

Searching, reviewing, and naming themes

A theme “captures something important about the data in relation to the research question[s] and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 82). While searching for themes a researcher is supposed to examine and sort their codes and the relevant data extracts into broad themes (Kiger & Varpio, 2020; Nowell et al., 2017). In this study, searching for themes was fairly straightforward as the research questions and the interview questions were informed by a theoretical framework. This means that from the get-go, there were obvious themes already capturing important information withing the data in relation to the research questions. In fact, throughout the coding process, the researcher was already constructing themes, as the main codes were more or less used to form the main themes and were presented as the main nodes in NVivo. NVivo was also used to create subthemes where needed. This was predominantly an inductive process. For instance, one of the main themes constructed was disclosure of HIV status as a facilitator of KPLHIV retention in

HIV treatment. After further review and realizing that the content of the data set showed that not all types of disclosure are effective, however, the researcher decided to add a subtheme on facilitating the disclosure process where she coded data extracts that described effective ways way a HIV status disclosure should be done.

It is important, to mention that there were miscellaneous codes generated that did not capture information relevant to the research questions and therefore did not form any specific theme but were retained because they provided contextual information for the study.

The next phase after searching for themes is to review the themes. This is an essential step because after developing themes, it is important that a researcher does not abandon the process, they should instead make sure that they refine and quality check the themes to reveal any inadequacies in the initial development of the themes (King, 2004; Nowell et al., 2017). It is in this step that the researcher tests the validity of their individual themes and determine whether they reflect accurately what is presented in the data (Braun & Clarke, 2006; Nowell et al., 2017). It is also the step where a text that had not been coded initially can be coded, a data extract that had been coded in a wrong code can be recoded and a theme that does not have enough data support can be deleted (Nowell et al., 2017).

While coding, it is during this phase that meetings between the two coders and the researcher became especially significant. It was through the discussion sessions that the data coded were reduced from a large number of themes into a manageable set of important themes that had clear meaning and enough data support. For instance, some themes that had been constructed before including, faith-based healing as a barrier to retention and peer influence as a barrier to retention were dropped due to contradiction in accounts and little data support. This was important because by the end of the reviewing phase the researcher had a clear picture of

what her themes were and how they fit into the overall narrative of her data; and that helped her to put in writing a comprehensive analysis for each individual theme in relation to the research questions. The next section presents the final report of the study.

Trustworthiness and credibility of research

During a qualitative analysis, it is important that a researcher establishes trustworthiness. To demonstrate that the whole data collection and data analysis process was comprehensive and as objective as possible, the researcher should be able to convince themselves and their readers that the results of their research are attention worthy (Nowell et al., 2017). Graneheim & Lundman (2004) explain that the trustworthiness of a study is reliant on the extent to which the codes chosen by the researcher can be depended on to answer the research questions and represent the data being analyzed in the study. Further, a widely accepted criteria of demonstrating trustworthiness in a study is to be able to demonstrate “credibility, transferability, dependability, and confirmability to parallel the conventional quantitative assessment criteria of validity and reliability” (Nowell et al., 2017). See table 3 for descriptions.

Table 3: Description of terms that make up trustworthiness

Term	Description
Credibility	<i>Credibility</i> has to do with the fit between what the participants said and how the researcher has represented them in the final results.
Confirmability	Confirmability has to do with the researcher being able to confirm that the interpretations

Table 3 (cont'd)

	she/he has made and results she/he has come up with are clearly drawn from the data
Transferability	This can be compared to external validity in quantitative research and has to do with the generalizability of the study. Unlike in quantitative research though, this only has to do with case-to-case transfer, as there is no one true interpretation of results in qualitative analysis. The researcher that wants to transfer the findings to their own research have to judge the transferability.
Dependability	This can be compared to reliability and can be achieved through the process of auditing. Auditing ensures that the research has logic, it can be traced, and it has been documented.

Cite: Nowell et al., 2017; Tobin & Begley, 2004

In order to enhance trustworthiness of this study, the researcher started by not only pretesting the interview protocol during data collection, she also enlisted the help of two other coders to help her with the data analysis. Elo et al. (2014) argues that trustworthiness should be demonstrated throughout the research process and should be free of the researcher's bias. The researcher expected that the use of two other coders would demonstrate the dependability of the

study results. The two coders had access to the same data as the researcher, knew what was being coded for, and during the final coding came to similar conclusions as the researcher with very few discrepancies. The discrepancies only concerned the naming of the subthemes because the generation of subthemes was mainly an inductive process.

To demonstrate credibility the researcher and the two coders had multiple meetings to debrief each other on their coding process and discuss discrepancies in their coding; to demonstrate transferability the researcher during the writing of the report provided thick descriptions of results and interpretations so that researchers that may want to generalize the findings to their studies can easily make a judgement on its transferability; and confirmation was demonstrated by the researcher clearly making connections between her findings and interpretations and her dataset by regularly explaining her analytical choices throughout the study.

Further, throughout the whole process the researcher kept a reflexive account of how her values interests and experiences affected her decision making. Using the two coders also helped her be more objective and unbiased.

RESULTS

Participant description

The recruitment process of this research study yielded a research sample (n=29) of 19 program workers and 10 health care workers who work closely with KPLHIV (see table 4). Of the twenty-nine program workers, two were male and seventeen were female. All the health care workers were female.

The participants were of varying ages and held different positions in their organizations/health facilities (of the 19 program workers 3 were program clinicians, 3 were HTS providers, 3 were data clerks, 2 were a social workers/field officers, 2 were program coordinators and 6 were treatment champions/ ART case managers/ peer navigators. In the health care facilities, of the 10 participants 5 were clinicians, 2 were HTS providers, 1 was a mentor mother, 1 was an adherence counsellor and 1 was a linkage person) and of utmost importance, 7 of the participants were people living with HIV, with six of the seven people living with HIV being members of key population groups.

The inclusion of people who were members of key population groups, were HIV positive and who were also program workers in the study, made sure that the voices of members of key population groups who were HIV positive were not left out during data collection.

Table 4: Participant Descriptions

	Role	Role description	Number
KP-led organization	Clinician	Give clients health general health services, but also enroll them into the facilities if they test positive.	3

Table 4 (cont'd)

	HTS provider	Screen patients for eligibility of HIV tests, then test them	3
	Treatment champion	Members of key populations living with HIV that have accepted their status and have learnt to live well with it. They are commissioned by KP-led organizations to help physically escort KPLHIV to linking facilities for linkage and also follow up of the ones that drop out of care	6
	Field officer/ Social worker	Does support supervision visits to the Peer Educators, does micro planning meetings and planning for outreaches and then heads the outreach once they head to the field	2
	Program coordinator	Oversees the whole KP program in KP-led organizations.	2

Table 4 (cont'd)

	Data clerk	Data management within KP-led organization	3
Health facility	Clinician	Receive HIV positive patients, counsel them, and give them the required treatment	5
	HTS provider	Screen patients for eligibility of HIV tests, then test them	2
	Adherence counsellor	Do adherence counselling as treatment preparation for people that are diagnosed with HIV, then refer them to the clinician for treatment	1
	Mentor mother	Person living with HIV that has accepted their status and have learnt to live well with it. She is commissioned by the healthcare facility to help follow up on patients that drop out of care and provide support to those still in care.	1

Table 4 (cont'd)

	Linkage person	Escort patients who are diagnosed with HIV from the voluntary counselling and testing center to the comprehensive care center to receive treatment	1
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Findings for research question 1

Research question 1 (What do program workers and Health care workers perceive to be the key barriers to retaining KPLHIV in HIV treatment?) sought to explore what program workers and health care workers believed to be the barriers that KPLHIV faced in HIV treatment retention. HBM suggests that, if barriers to retention are perceived to be more than the benefits of retention, the probability is high that a KPLHIV will not engage in HIV treatment. Significantly more barriers than benefits were identified in this study, but this came as no surprise, as data in Kenya shows that only 50% of KPLHIV are in HIV treatment.

In her analysis, the researcher separated the perspectives of healthcare workers and program workers on what barriers directly affect KPLHIV retention in HIV treatment and what barriers affect healthcare facility and KP-led organizations' ability to facilitate KPLHIV retention in HIV treatment. The barriers perceived to be affecting KPLHIV in HIV treatment included lack of disclosure issues, stigma, age, alcoholism, migration and mobility, economic status and nutrition, drug side effect, violence, disease burden and defaulting, while the barriers identified to affect healthcare facilities and key population-led organization in facilitating retention include, staffing, systems of data

keeping, isolation of comprehensive care centers, disconnect between KP-led organizations and healthcare facilities, shortage of drugs, and impersonalized care .

Barriers directly affecting KPLHIV retention in HIV treatment

Disclosure issues

Both healthcare workers and program workers felt that nondisclosure was a major barrier to retention of KPLHIV in HIV treatment. Most of them mentioned that KPLHIV who do not disclose end up not being retained, especially if they do not disclose to people that they live with, particularly their main partners. For instance, participant H005, while explaining where in the process of HIV treatment continuum many KPLHIV dropout explained that, “.... *clients will drop out in different places*” and this is because “... *being HIV positive is not easy and disclosing that status is also not easy because disclosure is a process and when disclosure is not done, mostly you get a client is not able to continue with medication. Because a client might have a partner, and now you have tested [them] here, [they] have turned positive, you enroll [them], you give [them] drugs to take home, when [they] reach home it's a process on how to start it, how to tell about it, so some drop at that point.*”

Similar sentiments were echoed by treatment champions (members of key populations living with HIV that have accepted their status and have learnt to live well with it) who shared instances that would make KPLHIV drop out of care because of nondisclosure.

Participant P007 explained that,

“there are times when there is no money in the hotspots [their place of work].

Someone goes on the first day, there is no money. Someone goes on the second day, there is no money. So, when we are broke and we are used to having money, there are those old customers, those daily customers, those that you can even

give for free[engage in sexual activities with for free], like you give him on credit, whenever he doesn't have money, you give him on credit because you know when he comes back the next time he will pay. So, you can bring that customer to your place. That is why you hear people are doing sex work, but they have someone in the house. You bring this person in as your support [financial] and you have never told him your status. You bring him into your home, and you have never told him your status. Where are you going to swallow your drugs and he is there all the time? Whenever it is your time to take your drugs, that is when he comes in, or he has been in the house all day. Because first things first, that man is paying your rent, he is buying food, so you even have no reason to go to the hotspot because after all there is no money there. That's how we decide to default."

Additionally, anticipated stigma especially by younger KPLHIV was cited as the main reason why people did not disclose. Young KPLHIV were mentioned to be the group struggling the most with nondisclosure. For instance, while discussing whether age made a difference in disclosure behaviors, Participant P008 explains how most older sex workers sell sex in their homes compared to younger sex workers who are more marketable and may "*... get a client who will want to take them far away.*" If the younger KPLHIV are "*... not prepared for that, maybe they had not carried enough medication with them,*" If they find someone who wants to "*... offer more money for the sex but then they don't want the client to know that they are HIV positive*", they end up not disclosing. Further, due to fear of stigmatization, especially because they are still young and they have romantic prospects, they also do not want to share their status. Participant H002 explaining what makes key population drop out of care says,

“stigma because like the young people, maybe they are not married and would wish to marry, they might not be sure if they disclose if they will still be accepted by their potential spouses, so they decided to drop medication get married then later resume or just decide not to resume medication at all”

Another thing that was mentioned a few times, but which healthcare workers and program workers thought was another barrier to retention, was disclosure to the wrong people. Health care workers especially thought that disclosure not only needed to be facilitated, patients needed to disclose to the right people because disclosure done the wrong way and to the wrong people, also put them at risk of dropping out of care. Participant H006 advised that disclosure should be facilitated because disclosure comes with giving information. She explains that,

“It [the kind of disclosure] really matters because disclosure comes with giving information. I cannot just tell... like for example you two, you tell him you have HIV, then you live it at that. You have to give information because these people go and Google, they listen from others. So, that’s why you find even if you do disclosure and you don’t give information it becomes a problem. For me, I feel like if it is done within a facility by an experienced person, it is good. Unlike you go and just disclose. In fact, we don’t encourage them to go disclose, we tell them bring them, we do it together so that we can also give information.”

Stigma

Stigma from the community, stigma from health care workers, self-stigma and double stigma were also mentioned as major barriers to retention.

Community stigma: program workers and health care workers felt that KPLHIV faced stigma from not only the community in general, but also their communities. For instance, female sex

workers stigmatized and even discriminated against their HIV positive colleagues because they felt like they were infecting their clients. One treatment champion said that, *“for a sex worker, you cannot go to the hotspot and say you are HIV positive. Because one thing, they will destroy your work, [and] whenever a customer shows up at your spot, they will be telling him you are sick”*. Further, *“when others [sex workers] know [your status], because it doesn’t take long before it is known, they will start saying you are sleeping with the clients without a condom.”* This in one way or another led to the discrimination of HIV positive sex workers, eventually affecting their engagement with care, making them drop out.

Stigma, insensitivity, and discrimination from health care workers: stigma, insensitivity and discrimination from health care workers was specifically mentioned by the program workers from a KNOTE. KNOTE links some of their clients to a government linking facility and this specific facility was cited as having the worse stigma and discrimination against PLHIV in general. Participant P001 from KNOTE when speaking about stigma, insensitivity and discrimination of health care workers explains that, those *“link facilities are run by the government and [there are] staffs there who do not understand that [KPLHIV] are special groups that need special care so when they go and are shouted at and mistreated they just dropout and say “let it be”*. Participant P007 (a treatment champion) explaining so passionately her experiences with healthcare workers, supports P001’s sentiments on stigma and insensitivity by healthcare workers. She says,

“ For health care workers, one thing I can say, for example if you go to [the healthcare facility’s name], you go there yourself, apart from sex work, and you say you are HIV positive, but you have gone there because of an infection [that is not related to HIV], and you disclose your status to a healthcare worker, the

healthcare worker thinks that all your problems will be solved in the comprehensive care unit (CCC)... So, if you are HIV positive...the doctor terminates your treatment and sends you to the CCC. Isn't that discrimination? [Because] for one, your friend who you have not disclosed to may have accompanied you, then you get sent to the CCC. How will your friend take you? It is not like when you go to the CCC you will get express services; you have to queue. And you have a friend with you, who maybe talks ill of HIV positive people..."

Furthermore, Healthcare workers working in the CCC of the government linking facility and healthcare workers from different health care facilities also supported the program workers narrations. The healthcare workers felt like healthcare workers from other departments in the facility [other than the CCC and the PMTCT] were stigmatizing and discriminating against HIV patients. Participant H006 to show how the maternity clinic staff is stigmatizing and discriminative to KPLHIV gave an account of a pregnant mother who was publicly humiliated in the maternity ward due to her HIV status. She narrates,

"[The] complain came from the maternity clinic. Maternity a client comes, you know the way sometimes they misbehave, especially when they are in labor? She was told, "Look at the way you are behaving, so stubborn and yet you know you are HIV positive." And the client really felt, and it hurt her, and what really made us know [was that] the woman was not coming for her clinic most of the time; sometimes she was not taking medication. So, when we decided to talk, to go and ask what the issue is, that is when she told us. So, we decided we will see if there is an answer in that incident, so we noticed in maternity especially in labor

ward, it's like they are being singled out, no one wants to be there taking care of them.”

Self-stigma: of all the stigmas that KPLHIV face, self-stigma was mentioned as the worst culprit of non-retention in HIV treatment particularly in MSM, and it was tied to denial and lack of acceptance of HIV status. Participant P008 explains that due to self-stigma, MSM do not want to stay in the same region and therefore move from one facility to another making it hard for them to be retained in care because tracing them is hard. She says,

“MSMs because of self-stigma, you know men having sex with men is not accepted in our community and now again being HIV positive, then the positivity rate in MSMs is quite high, for the FSWs is quite low but MSMs very high and then they would not want... you link one in this facility you find them in another one the next day, you call them, when you go tracking them they are no longer there, where are you, like now I have three, I have tried to track them, one tells me that he is in Narok, the other one in Kinoo, the other in Nairobi”

Self-stigma was also mentioned to be the main reason KPLHIV anticipate stigma from the community and from health care workers. When asked if she had ever had a KPLHIV come to her with complaints of being discriminated against at a healthcare facility, participant P008 agrees, but she mentions that is an issue of self-stigma because, although self-stigma is borne out of stigma from other people, self-stigma is worse because, with self-stigma “ *when she goes [to the healthcare facility], she sees as if everyone there knows that she is positive and that’s why when she goes at the counter [and] she is told go sit there[at the reception] first and wait, because of self-stigma, she thinks everyone is looking at her like, this one is HIV positive which is not the case.*” Therefore, “*self-stigma is a bad thing than anything else*”

Stigma directed to health care workers by other healthcare workers: Other than health care workers stigmatizing HIV positive patients, it was clear that they stigmatized and discriminated healthcare workers working HIV patients too. Health care workers felt like this coupled with stigma directed to HIV patients affected their service delivery to their patients and thus indirectly led to poor retention in the health care facilities. Some of the health care workers said,

“people from CCC we are usually...[segregated?] [agrees] if you go to the OPT[outpatient], even if it’s your grandmother who has just asked you to assist them get to the doctor, when you get there they begin asking, “is this a CCC case? Is it CCC case?” [H002]

“you just get people avoiding you, to the extent of not coming near you, because you are working with people who are positive...the other side we know that there are boundaries, including having people separate their cups from others, we know there is a boundary but life must continue, if we meet here, they take tea with their cup, I take with the one provided and life goes on.” [H005]

Age

Both Health care workers and program workers agreed that age is major barrier to retention of KPLHIV in HIV treatment. This is because, according to them, younger members of key population groups face a large number of barriers to retention because of their age. Young members of key population groups not only migrate more because they are more “marketable”, they face more violence, they abuse alcohol more, they have more self-stigma and denial, they are poorer, and they also disclose less. According to healthcare workers and program workers,

1. “Mostly the young ones are more in the work and they are also very mobile. You find her in Naivasha today, two weeks' time she is in

Mombasa, the next time you call her she is Kisumu, they are marketable, so adhering to treatment becomes a big challenge to them and this is the same group that is mostly on alcohol and they also want to please the client and they don't want to show the client that they are HIV positive, they sometime want to go without condoms, they cannot negotiate because of /being young and they are the most who pass the infection.”... “they are also the most affected by violence because they can't even negotiate their way through.” [P001]

2. They are “hard to retain and link them because it's a group that it's hard for them to accept that at that age they are already positive.” [P012]
3. “it's hard [for them]to disclose. They will come to the support group, yes, but because no one in the clinic knows them, like it's a safe zone, but when she is out there she will continue having sex without condoms, she has not accepted herself, [and] she has not disclosed to anyone” [P015]

Alcoholism

Members of key population groups, especially sex workers, were mentioned to be at a risk of defaulting or falling out of treatment because of alcohol abuse. For some it was said, “*because of that stigma of being a HIV positive sex worker, most of them resort to taking drugs and alcohol which jeopardize their treatment regime*”, and for others it was said that because of the nature of their work, they have to drink alcohol and this affects their adherence to ART and their retention in HIV treatment. For instance, participant [P007] explains that, “*Many leave their drugs because of alcohol*” and that it is “*tricky because you find this person, her*

customers are drunkards; she must go and drink with them as they make a deal. So, if she does not drink with them, it means she does not have a customer”

One treatment champion shared her experiences of how alcohol made affected her engagement with treatment. She said,

“... the side effects that I had from the drugs [ARVs] I was swallowing then, came from me drinking alcohol. I was buying expensive alcohol and putting it in the house, so, my work was just drinking alcohol. I was not drinking at the club or with people, but I was drinking excessively... there is a time, other than peeing in bed, when I went for sex work, I was doing it ignorantly; I was finding someone who would be willing to spend the night, so that I can make my one thousand shillings [10dollars]. So, it affected me a lot. Whenever I went back to my house, and I have kids, my kids saw me getting sick. Taking that alcohol and my liver....so, I started getting sick and being taken to the ward. I was in the ward on and off. I was swollen everywhere, I couldn't see, my legs were swollen, it was a big problem”

Mobility and migration

A lot of studies have looked into the mobility and migration of both female sex workers and men who have sex with men and how it affects their access to health services. In this study the mobility of KPLHIV and specifically of sex workers was mentioned as a barrier to retention in HIV treatment. For instance, participant P004 when explaining why some KPLHIV drop out of care after two or three visits to the doctor's office says,

“you understand KPLHIV, Most of the time [KPLHIV] are not located at one hotspot or even if they are in Naivasha, they will just stay for a period of time

just because there was a season or there is something that made that KPLHIV to be here. So, in some situations you might get these KPLHIV moving from Naivasha, relocation from Naivasha to another town. So, they get to them because one thing, maybe they don't know the refilling or the sites that they can get their drugs refills.”

Further, participant H003 explains that with migration came the risk of KPLHIV attending other HIV clinics as new patients and this presented other issues such as consistently high viral loads. She says,

“the key populations also keep on migrating. Harvesting is taking place, for instance wheat harvesting is taking place in Narok, she won't be in Naivasha, and she will go there for three four months. The clinic appointments she has not shown, she does not have medication, she opens a new file in Narok and when harvesting is done, she comes back and continues with the clinic here, so it's like she has 2-3 clinics. For instance, there is one who we were doing some follow up and we found that she has more than 3 clinics so anytime she relocates she has a clinic to attend so she does not come to Naivasha to collect her drugs... it affects their health because you find that some of them are STF[soluble Mycobacterium tuberculosis factor] and in as much as we are campaigning for them to be LDL[low detectable levels], so that they can be given longer appointments considering the nature of their work, failing to come to the clinics and taking medication on time has an effect on their viral load so you find that some of them end up having viral load. In high viral load you cannot be given a supply of more than one month, you need to be seen frequently for close monitoring and

supervision so that you do another viral load in three months' time, so it's also a challenge to us because in as much as we feel that these people are always on the move we need to give them a long TCA[to come again] but we are tied because they have high viral load and they need to suppress first and you cannot keep them here, you won't hold them here, they will go."

Economic status and nutrition

Poverty was suggested to not only affect KPLHIV risk behaviors, but also their uptake of ART and their retention in care. Issues to do with poverty were said to play a big role not only in determining condom using behaviors amongst KPLHIV, it played a big role in determining whether a KPLHIV will show up to an appointment on his/her assigned date of appointment. Participant H002 explains that *"unless you will be giving them [bus] fare, some [KPLHIV] do not come to the clinic because they lack fare, some go for a week without work, so if you tell them to come and promise to reimburse them the fare..."* the response would be good.

Further due to their economic situations it was mentioned that most of KPLHIV felt like they did not have a diet that was nutritional enough to take with their medication and were afraid that without a nutritious diet, they would experience drug side effects. Participant H002 explains that *"most of them say they don't have food,"* and that *"if you take the medication on an empty stomach you feel dizzy"* she explains that that is true because *"the drugs are strong you must eat well before taking [and] if you take before having a meal it will make you dizzy, when [KPLHIV] feel dizzy two times they drop [out of care]"*

Drug side effect

Drug side effect was also mentioned as another barrier in itself, especially to sex workers. Because sex workers are in the business of selling their bodies, they want to look good all the time. Therefore, when a HIV positive sex workers experiences body changes, such as skin irritation or decrease/increase in weight due to ARV side effect, they are likely to stop using the ARVs and eventually drop out of treatment. Participant P007 reflecting on her and other people's experiences with ARVs explained,

“they have side effects. So, they [healthcare providers] got rid of TDF and I remained with 3 TC ABC [types of ARVs]. Then I started getting dizzy, feeling sleepy, every time when I am seated talking with someone, I feel sleepy, so they had to change again and try another regimen... for others, their legs start slimming down, their breasts increase in size, their buttocks decrease in size... there is a time there was a drug, I don't remember the name, it had those deformities and people have never recovered, people have never gone back to normal...whenever the people that got those deformities from the drugs encounter a small issue, they feel like they are tired, they call me and tell me, “me where it has reached, I am tired of the journey”.

Violence

Violence was talked about specifically by program workers. Although most of them thought that members of key population groups, whether they were HIV positive or HIV negative were equally affected with violence, there was a consensus as mentioned before [see age] that younger members of key population groups faced more violence than the older members due to their excessive abuse of alcohol and their less negotiation power. Further

KPLHIV risk facing violence from their colleagues because of stigma. Participant P005 explains,

“it does more than any other KP[violence affects KPLHIV more than any other KP] because like I said, one there will be double stigma and actually even violence and black mailing begins the minute anybody gets to know my status, one am selling sex and like I said, everybody knows you will get HIV by having sex with somebody who is HIV positive, so one form of violence that is experienced by KPL HIV is black mail, somebody knows you are taking ARVs, black mail is you either leave clients for, vacate hotspots you have more clients than I do or I let people know that you are HIV positive, the second form blackmail is a client wants to leave with you not pay rent, not pay you for services or they'll let people know you are HIV positive”

And Participant P008 when talking about the effects of alcoholism says,

“alcoholism...it puts them into very great risk, other than not taking the ARVs properly, it puts them into higher risk of violence... when they are drunk, any man can have sex with them without a condom and then infect them with STIs that will make the HIV status worse”

Other barriers

Other barriers that program workers and healthcare workers thought were affecting KPLHIV retention in HIV treatment include, disease burden and defaulting.

Disease burden

Some program workers and healthcare workers felt like some people got to a point where they got tired of taking medication and just gave up. Because adhering to

treatment and engaging with HIV treatment is a lifelong thing, some KPLHIV will “*see it's a long period of time [they are] going to take this{medication}, so they reach a certain period of time [where] they say, enough is enough and they just drop.*”

Once a defaulter always a defaulter

Health care workers and program workers also mentioned that the KPLHIV who defaulted from treatment did not do that once. Instead they had a tendency of forming a defaulting habit “and they end up by going to other institution health facilities as new clients”. Participant P005 explains that,

“once you have defaulted you have a tendency to default again” and so, together with “new cases, people who have tendencies to default or get lost somewhere, and again people who are there, not really marked as defaulters, but have high viral loads, they are not reaching suppression after 12 months, you [need to] bring them back because you have to walk [that] journey with them”

Barriers affecting healthcare facility and KP-led organizations’ ability to facilitate KPLHIV retention in HIV treatment.

Staffing

Both the healthcare workers and program workers thought that health care facilities, especially government owned health care facilities needed more staff, as they served a large number of patients to one health care worker. KP-led organizations clinicians and HTS providers also felt a little overwhelmed by having to do clinical duties and also report on those duties on a daily basis. Participant H004 explaining the situation at the CCC of facility one says,

“the clinic is congested, so it's contributing to them[KPLHIV] defaulting or maybe missing appointments... like currently staffing has been an issue, yeah

because with staffing compared to the work load, you know if staffing could be improved the flow of the clinic could be fast, maybe by at least, one, there would be nobody at the queue because that one contributes to the number of defaulters in our facility, the number of people, the long queues, so it really discourages the clients.”

Systems of data keeping

Both KP-led organizations and healthcare facilities did not have a connected and computerized data system that could enable them to track KPLHIV if they decided to move and start treatment in another facility. This made it hard for both the organizations and facilities to track them down whenever they defaulted and also led to other barriers in retention such as KPLHIV posing as new patients in other facilities. Participant P008 explains that this situation is because *“the use of computers [had only] come recently. Before, [health facilities] had been using hard copies and even up to now there are still facilities that are using files not computers”*. Participant H003 supported this by saying,

“we don't have a system because initially we were doing things manually whereby we were opening files for our clients, manual files, but at the moment we have migrated to the system, we are using DQ, the system is called what, each facility has it's different system which it's using it's not a uniform.”

Additionally, as per the government guidelines, every person living with HIV that needed to move from taking her medication from one facility to taking it in another facility, was required to ask for a transfer letter from their current link facility before they moved to other facility, otherwise they would not be started on treatment. For KPLHIV, who are very mobile, this rule was thought to be a little restraining, and according to healthcare workers and program workers

it was more or less “*messing up data at the facility...messing up national data... also messing up clients,*” because as one program worker said,

“when you pose as a new client and you are not ART naïve, what treatment will they give you? Could you have moved even to another regiment and then they return you to something that is not working and maybe you start developing...will they start asking questions like, you have been on treatment for more than six months or for more than a year and yet you are not achieving viral suppression? Because the systems that the government has put in place that you must give me a transfer letter from where you are coming from, I don't care what you are saying, people who know ART is important to them pose as new clients, because I know I must take my drugs, if I go maybe they'll ask me for a transfer letter, now how do you get a transfer letter [and you have already moved]?”

Isolation of comprehensive care center

Program workers and health care workers felt like clients were afraid of going to the government health care facilities because the comprehensive care center was separate from every other department in the facility. They felt like anyone going to the comprehensive care center was instantly perceived to be HIV positive. This, because of stigma that KPLHIV face and because many had not disclosed, lead to their drop out of HIV treatment. One health care worker talking about the location of the CCC in their facility explains,

“Because like for now in this particular facility the place to take HIV drugs it's different compared to other facilities around, so it's like everybody knows when you see a person being escorted to that department, the CCC department, that person is reactive. Again when they get to that place, people are many, like here

now the number enrolled yesterday was 10153, so you agree with me that number is enormous and you can see, so there are those when they get to the place, they anticipate the people around knows them, like they are my neighbor and due to that they refuse to be enrolled and they disappear.” [H005]

Disconnect between KP-led organizations and health care facilities

Just the action of taking a KPLHIV who has been tested at a KP-led organization’s drop-in center or a KP-led organization run outreach, and linking them to a separate healthcare facility was seen as a barrier to retention because, for instance, a KPLHIV who has been tested at an outreach or a DIC is not linked to a treatment facility immediately and this gives them a chance of dropping out even before linkage. Furthermore, after having a safe space and receiving personalized care within the KP-led organizations, they may feel like they are not getting enough care at the healthcare facilities.

Shortage of drugs

This barrier was mainly experienced by KP-led organizations that had comprehensive care centers within the organizations and were therefore ART sites. The program workers explain that sometimes they encounter a shortage in ARVs within the organization and when their clients find that they do not have the drugs, they migrate to other facilities or drop out.

“sometimes there could be challenge maybe if the ARVs are not available on site and the client comes for the drugs and finds the drugs are not there, you know the client might even migrate to another facility” [P011]

Impersonalized care

Health care facilities provide care to not only KPLHIVs, they also provide care to the general population; they therefore do not have specialized care for KPLHIV. For instance, they

fail to recognize the challenge to FSWs who work nights and sleep during the day and must adhere to the structured times that the healthcare facilities have in order to be served. Participant P019 when asked what he thought caused defaulting of KPLHIV from HIV treatment, he answered,

“I would say one thing the way their services are structured, it's so rigid in terms of; you have to come for drugs at this at this point, you have to do ABCD... and you find that these people at times want flexibility. Can these drugs get delivered to me if maybe I am at this point, can I come at my very convenient time, like I want to come at 8, I don't want anyone to see me coming, you get.. because there is a sense of stigma it is still not totally out, like... and also there is that self-stigma, others they have not really accepted themselves. So, it's still part of the struggle.”

Findings for research question 1(a)

Research question 1(a) (How does the program workers perceptions of benefit of retention, susceptibility to non-retention, barriers to retention, and severity of non-retention affected their day to day interaction with KPLHIV?) sought to understand program workers and health care workers beliefs regarding the retention of KPLHIV in HIV treatment and explore what they did to ensure that KPLHIV believed they were susceptible to bad health outcomes if they are not retained in treatment, they were going to experience severe outcomes if they were not retained in treatment and retention in treatment was more beneficial to them than the barriers they experienced. Further, the researcher explored the cues to action that the health care workers used to remind KPLHIV to engage with HIV treatment.

Perceived susceptibility

HBM suggests that the likelihood of a person to engage in a health behavior, is dependent on their perception of the risk of facing the dire outcomes that they would be preventing if they engaged in the health behavior. From the interaction of the researcher with the program workers and healthcare workers, it was clear that the program workers and healthcare workers believed this and used their beliefs to constantly remind KPLHIV that if they did not engage in treatment, then they were going to be sick or die. For instance, some participants said,

“...mostly we tell them, like if you do not recognize the virus, the virus will get you, meaning if you are not ready to take these drugs, definitely the virus will bring you down. So, let it be real to them that the only way to live is to take the medicine. It’s to take the ARVs.” [P004]

And,

“the first thing I tell them is, “This journey is not easy, the journey is hard. So, the first thing to do is to accept to use medication every day. And using medication every day is not easy, it must come from your heart. So, do you want to live, or do you want to die fast?” That you just tell them the truth, that the moment they stop taking drugs they will die” [P007]

Further, the health care workers and program workers implied that KPLHIV themselves did not perceive susceptibility to dire outcomes if they did not engage in HIV treatment. A healthcare worker talking about female sex workers who were HIV positive mentioned,

“We have to continue doing adherence because most of them will, okay you know they are a bit... What will I say...? they have many sexual partners and then

they really do not fear, like they are not scared about [the outcomes]... so they really don't mind so we keep on insisting and insisting..." [H010]

Citing that lack of enough knowledge of treatment importance by KPLHIV, another healthcare worker said,

"we feel like these new clients who have been newly diagnosed have like zero knowledge on ARVs, have zero knowledge on how one can live positively."

Most health care workers especially thought that more counseling should be done on KPLHIV and highlighted that KPLHIV actually received more counselling than the general population.

Nevertheless, as participant H008 states below, they sometimes end up losing them. That is,

"We emphasize more on adherence counselling, so when we realize one is a key population, we enhance adherence counselling so much, but most of them at the end of the day we lose them."

Perceived severity

Perceived severity suggests that if an individual perceives that the outcome of not engaging in a health behavior is going to be severe, then they are going to engage in that health behavior. That is, there is a likelihood that KPLHIV would be retained in care if there was a perception that there will be severe outcomes if KPLHIV are not retained in treatment. The data from the program workers and health care workers suggested that KPLHIV often do not understand or ignore the severity of not engaging with HIV treatment until they get really ill and have to go back to treatment. For instance, some health care workers and a program worker explaining KPLHIV perceptions of severity of non-retention in HIV treatment explain,

"most of them fall out after they start treatment, okay fine, especially the clients who have been having the idea that they are positive, they come when they feel

better, after sometime they come and feel better, they feel they are normal, they don't have any issue and they are not suffering from anything, so of course they feel they really don't need anything so of course they feel they really don't need this treatment, so automatically they just decide, why not and they do away with them.” [H10]

“After some time, when the complications have started, that is when you will see these patients coming for their medicine again, to seek for that medication.”

[H009]

“there are those who go down first (become sick). Once they are really down (really sick), when they are just about to die, that’s when they come back.”

[P007]

Treatment champions who are ART adherent KPLHIV commissioned by KP-led organizations to help with linking and following up other KPLHIV, cemented this finding by sharing their experiences of when they really understood the extent of HIV severity if they were not retained in HIV treatment. One treatment champion said,

“I started having flu constantly and chest congestions. Weird things. Feeling like my body is not okay. Like it started having a certain weakness. This forced me to go back fast. I even stopped desiring my boyfriend because I was always sickly, and he kept telling me to go to the hospital. So, I just told myself that I will go back to taking drugs. So, I went back to taking them.”

Additionally, they also perceived severity after seeing other people living with HIV getting sick and die. For instance, a treatment champion said,

“I saw my ex-husband die. So, when I went... You obviously know that even after separating I had to go bury him. So, after burying him and coming back, I started losing weight and whenever I wore pants they fell. So, I said to myself, “I see myself dying.” So, I went back to taking drugs.”

“So, I was imagining when I pictured other HIV positive people, their shoulders looked this way (crunched shoulders), and at that time an organization was providing them with porridge. I imagined myself getting to that point and it scared me” [P010].

Healthcare workers and program workers therefore through counseling ensure that KPLHIV understand the severity of not engaging in HIV treatment.

Perceived benefits

Both the health care workers and the program workers understood the importance of KPLHIV retention in HIV treatment and the importance of emphasizing those benefits to KPLHIV. They all defined retention to HIV treatment as engaging in HIV treatment by both health care workers and program workers. More or less they defined it as,

“The need [for KPLHIV] to attend to their return dates as required, each time they are supposed to go back for review or to collect their drugs because when they go consistently that’s when we say they are retained and again they follow up with their viral load tests as well we say this person retained.”

Further, they all agreed that without retention, adherence to HIV treatment was impossible for KPLHIV. This was because, one, KPLHIV would not be able to get refills of their ARVs if they didn’t honor their appointments, two, they would have no way of knowing whether their viral loads were going down, as their viral loads are usually observed when they attend their

treatment appointments, and three, they were unlikely to catch opportunistic infections and malignancies early because they would miss a chance of getting checked up for infections. There was, however, a possibility of having KPLHIV who were retained in treatment but were not adherent to ART. This was perceived to be very dangerous because patients had previously been proved to develop clinical failure and die due to inconsistent adherence to ART. When asked whether they had patients who were retained but not adherent, a health care worker explained,

“yes, but unfortunately it reaches a point that they just become drastically sick, acutely sick. I had another key population, the same, but her issues were just...she could not take alcohol and drugs at the same time, so she decided to take alcohol. At some point she decided to start another business [stop sex work], she decided to sell watermelon then she begun looking for laundry jobs and she became adherent, but after a month I lost her. Why? Because she went into treatment failure, clinical failure, you know what these drugs do, if you keep on taking drugs and stopping, taking medication, and stopping, you develop clinical failure and that’s is the worst. You better develop treatment failure, we change treatment, but clinical failure, it becomes an issue because you cannot take drugs. And even some time we push them. Like, for one, we pushed her tremendously and she became adherent, but she died the following month because of clinical failure. When they did a postmortem, her organs were not okay, the liver had an issue, the kidneys had issues because even at some point she was unable to go to the toilet”

Thus, program workers and health care workers, ensure that they explain the benefit of adherence to KPLHIV throughout the process of testing them, linking them, and enrolling them in treatment, until they reach viral suppression. A health care worker explained,

“we gather the clients and enroll them to care so yes I take over and enroll the clients to care explain to them the importance of taking their drugs every day, adherence counselling, importance of disclosure and everything as far as the taking of ARVs is concerned.”

Further, even after they drop out of treatment and come back, the healthcare workers and program workers find the root cause of their drop out and try to address it while also strengthening adherence counselling for that KPLHIV. For instance, a healthcare worker explains,

“[after dropping out and coming back], you start again, to counsel that patient, because first of all, that patient is tired. She/he has reached a point where he/she has lost hope. “Will I keep taking this drug every day? Can I just let it go once and for all?” You are supposed to counsel that patient, pull him from the darkness. You are trying to pull her back to light, to life, there is more to life, there is more needed for her, there is that part [where] we need him. You see, most cases when you do that, try to check the background, the family members, you try to show them that there is someone who still needs them. That’s when they start seeing that now there is hope.”

Findings for research question 1(b)

Cues to action

Question 1 (b) sought to explore how program workers and health care workers utilize cues to action to encourage retention. Cues to action are the external and internal motivators expected to increase the likelihood of an individual engaging in a certain health behavior. For this study, they included stimulations that increased the likelihood of KPLHIV to constantly engage in HIV treatment and therefore be retained in HIV treatment.

Some of the cues to action that healthcare workers and program workers thought stimulated KPLHIV to engage in HIV treatment include,

Alarm clock setting: Healthcare workers and program workers encouraged KPLHIV to set alarms to remind them to take medication. This helped with their adherence and thus boosted their engagement in HIV treatment. A treatment champion explains how she uses this cue to action as a reminder to take medication,

“I set my alarm for three minutes before the time I am supposed to take medication. So, when the alarm rings, I know the time for taking the medication is near, so the alarm alerts me to get water and the drugs and put them near me”

Reminder calls/ text messages: Health care workers call or sends a text to each HIV patient that has an appointment at the hospital a few days prior to their appointment date to remind them of their appointments. This acts as a reminder for KPLHIV who had forgotten they had an appointment, that they have one.

Promise of longer TCA[to come again]: Patients who had fallen out of treatment before then came back were usually given shorter period of times between their appointment dates so that healthcare workers could monitor them and check changes in their viral loads. Therefore, to

encourage retention and discourage defaulting, health care workers also used the promise of longer periods of time between appointments to stimulate KPLHIV to engage in HIV treatment.

When asked what they do to encourage retention, a healthcare worker explains,

“we are giving them long appointments; we encourage them to suppress so that they can be given long appointment”

Findings for research question 2

Research question 2 (What efforts to retain KPLHIV in HIV treatment have program workers and health care workers put in place?) sought to delve into what healthcare workers and program workers thought facilitated retention, and what they had done to help retain KPLHIV in HIV treatment. Further, it sought to explore whether the efforts they had put in place to facilitate retention were addressing the barriers mentioned in the findings for research question

1

Facilitators of KPLHIV retention in HIV treatment

Disclosure

One of the major facilitators of retention that both healthcare worker and program workers mentioned was disclosure, and the main reason that they thought disclosure was important, was because of the support a PLHIV needs when they are taking medication. Moreover, while disclosing to the wrong people was mentioned as major barrier to retention, disclosing to the right people was associated with continued support and in turn continued retention in HIV treatment. For instance, participant P016 explaining the importance of disclosure to retention says,

“It[disclosure] does[makes a difference in retention], it really does especially if you disclose to someone you are close to, someone you are living with, it really

does because it's always easy to adhere to medication, because that person will always remind you time has come for you to take medication and yes we have examples who have disclosed and either the partners or the daughters will remind the clients the time for taking medication is here, and they take their medication and they are always virally suppressed”

When asked whether they had patients who had not disclosed but were adherent to ART and retained in care, healthcare workers agreed that there were a few, but insisted that it was always better to disclose because most of the patients that had not disclosed were not really doing well. Participant H005 said,

“they are not doing really well, but I have them who have not disclosed. A client tells you, “doctor if this one is disclosed I have no life”, but with time, you give them time, walk together with the partner because at the end of it a client has what it takes to solve their problems. Because it is not good if the client tells you, “this one if I tell them now, they will be done with me right now”, and then you do not want to be patient. No, you must give them time and listen to them, because it is a journey. Aaah the positive living is a journey and it is a must for someone to decide. And, if I conclude you have not decided, we walk together with you”

Being pregnant or having children

Surprisingly, the researcher found that, especially for female sex workers, being pregnant or having children was a major facilitator of retention in HIV treatment. Female sex workers would engage in HIV treatment when they are pregnant and drop out after they give birth and realize their child is HIV negative, but those female sex workers with children at home

could also use their children as motivation to continue with treatment, and also to remind them to take medication. Participant P009 who is a treatment champion shares her experience of how being pregnant got her out of a state of self-worthlessness and gave her motivation to engage in HIV treatment. She says,

“What made me change my mind was my pregnancy. When I gave birth and saw my child, and my child was negative, that gave me morale”

Moreover, healthcare workers and program workers also use their patient’s children to motivate their patients to be retained in treatment during adherence counselling sessions. Participant P018 explains,

“we try to give them encouragement it's not a matter of everybody will die so I will also die, you tell them they have kids. There are those kids that still need their support. If you encourage them as you tell them the kind of family members that still need them, that is the time that it clocks and they say, “okay let me try to change; let me try to focus” and see that, yes, I have family and kids that need my support”

What health facilities and KP-led organizations have done to help facilitate retention

Follow up before and after linkage in HIV treatment: Retention in treatment starts from the moment a person living with HIV is linked in HIV care until he/she reaches viral suppression. KP-led organizations who have two models of testing KPLHIV, that is, in their drop-in centers and during outreaches, link their clients either to a healthcare facility or the CCC within their organizations immediately after testing as required by the “test and treat” guidelines. If a patient refuses to be linked, he/she is given time to come to terms with their HIV status but is not completely left on his/her own. Instead the program workers keep on following up with the

patient until the patient is ready to be linked. Once the patient is ready, the program workers [clinician/HTS provider/treatment champions] physically escort them to a link facility of their choice and initiate them on treatment. Similarly, health care facilities also follow the “test and treat” guideline and have link desk personnel who direct their HIV positive clients from the voluntary counselling and testing center [VCT], to the CCC where they receive treatment.

Physical escort to linking facility

Physical escort to facilitate linkage is the first step program workers and healthcare facilities take to ensure retention of KPLHIV and HIV patients in HIV treatment. This helps KPLHIV who are afraid to go to the link facilities by themselves to feel confident, it also means that they do not have to queue because they get express services once they reach the link facility, and at the same time ensures that they do not have a chance to disappear before they get to the link facility. Participant P005 explains how this process works,

“From where I stand as a coordinator, it cuts across. Because for us to be able to identify new cases or to find a case of a KP who is HIV positive, we basically need first to have done prevention bit, prevention bit involves knowing where the KPs are, reaching them and after they have reached... reaching which means you are talking to them, you providing commodities and you are providing information. That information translates to referral for services; the first referral entry point is HIV testing services and now once somebody has been tested that's where we draw the line. Once somebody gets tested, if you are HIV negative you continue with the prevention counselling, but if you are HIV positive, now we move you in. Where do we link you for ease of services? For us, linkage is not about sending you, because our program is not an ART site, for us linkage is not

sending you with a piece of paper as a referral, we have actually converted that into actually escorting somebody to the facility. So, from where I stand we've got to get somebody, we call them treatment champions, in other programs they are called peer navigators; So, you attach that person to another person that is the same situation, that understands the journey, that has been there longer, they escort them to the facility. If it's not a clinician, it's a peer navigator or a treatment champion who is also living with HIV. They take them to the facility such that they ensure that they have gotten there, and that they have gotten the service. And, proof of they have gotten the service is the CCC number.”

Good relationship between KP-led organizations and link facilities

To make linkage and follow up easy, health care facilities and KP-led organizations have also created good relationships with each other. Whenever a KP-led organization has a client they need to link to the health care facility, they may call ahead of time and get the express services once they get there. Participant P001 explains,

“we have a rapport and an MOU[memorandum of understanding] with the facilities that we will bring our clients but we don’t want them to queue and be stigmatized, so they go straight and they are linked and start their treatment.”

This relationship is also important for healthcare facilities because whenever a KPLHIV defaults and the link facility cannot reach them, they can also use the help of program workers to trace them and bring them back to treatment. While it is the responsibility of the link facility to follow up patients, key population programs have more information on KPLHIV and know them and their networks better than the link facilities. They are therefore in a better position to

trace and have success finding them, so they work with the link facilities to do defaulter tracing.

One program worker says,

“For us it’s a bit easier I cannot say it’s good 100% but the facilities its much difficult because we know their hotspots well, we know their places of residence we have their contacts phone numbers and we have their friends among us, so we will know that she is around or she has moved somewhere so we follow her up on the phone and ask her to go to a facility where she is and we can make calls to the facility.” [P001]

Defaulter tracing

While health care facilities would typically call to follow up defaulter patients for three months, then declare them lost to follow up, For KPLHIV there is continuous follow up because they have KP-led organizations looking out for them. However, both healthcare facilities and KP-led organizations make phone calls to KPLHIV not only to check on their wellbeing,

“We do follow up because there is a place where we indicate, in our books, where they live and the nearest area to where they live, they leave us their phone numbers, so after a week of starting medication, we call them after a day or two to ask how they are faring with medication, if they say they have issues with the medication we go and check what the issue is, for those who can make to the hospital we ask them to come, so yes, we do follow up to their home.”

but also, to remind them of missed appointments.

“we do text messages, standardized text message 24 hours before their visit, then from there we ensure for those who have not attended clinic, we call them immediately, like today for those who have not attended clinic, at 5 we'll start

calling them reminding them today was their clinic and they dint come, for those who have missed their appointments for 3 days or more, we do every three days, at least in a week we call them once or twice to remind them that they have come and we have a defaulter register where we track them.”

If a KPLHIV cannot be reached via phone call, KP-led organizations send peer navigators/treatment champions to trace them and link them back to treatment, while health care workers use community health volunteers. Although, health care workers mentioned that, due to budget cuts, community health volunteers no longer assisted them, as they did not have any monetary motivation. Further, after a person has defaulted from treatment and returned to care, the health care workers would give that person short TCAs[to come again], so that they could better monitor their adherence and their viral loads until they trusted that the person could handle longer TCAs. Moreover, the healthcare workers and program workers would try and give the people who were linked back to treatment a more personalized care by trying to address the specific problems that led to their defaulting in the first place,

“we always, you know after identifying a client who has gotten lost to follow up, we identify the cause, the problem, why has this client defaulted, maybe because of the queue maybe because of disclosure then we try to sort out the issue first before continuing with care” [H004]

Open communication channel: Other than calling to follow up on KPLHIV, program workers and health care workers have provided them with phone numbers where they can reach them whenever they needed assistance. Further, some healthcare workers and program clinicians have gone to the extent of giving them personal numbers so that KPLHIV can reach them whenever

they had an emergency. Participant H003 explains that when clients are linked to the CCC they are given the CCC number where they can call with their concerns,

“when clients are linked to the CCC when they are new, we give them the CCC number. During counselling I ensure I write the CCC number on their cards and encourage them in case they have a problem they can call the numbers during clinic hours and also in case they are in need or maybe they just have a question they can call these numbers. We have 2 phones at the CCC they are usually loaded with airtime 1000, 1000, though it is depleted even before end month, of doing follow up or some flash they don't even call so you need to call back the client and confirm. Some tell you they won't make it to the clinic, they are feeling unwell, and these drugs have side effects and things like that, so there is a way of reaching out.”

And P008 explains that she has even gone an extra mile as to give KPLHIV her personal number in case of emergency,

“some who have confidence in us, in me, let me say me because it's me that they call, they'll call me even during weekends, they'll call me and tell me I am going home to my mother to see her and my return date will be on Tuesday and I see I will be away, how can you assist me to get my drugs”

Other things they did to facilitate retention

Ability to take drugs emergency drugs from a facility that they are not linked in

For KPLHIV who have moved from one town to another, for a short period of time, and have found themselves out of their drugs, there is a chance for them to visit any government facility and request for emergency drugs without the need to provide a transfer letter.

“We have drugs on transit. Say, I gave you drugs and they depleted, we normally tell all the PLHIV, let’s say you are going to Salgaa, we don't open on Saturday or Sunday, your drugs have depleted abruptly, or you just forgot, just go to any government facility” [P018]

Crisis response team to address violence issues

In case of an encounter with physical, emotional or sexual violence KP-led organizations have come up with crisis response teams and have a crisis response line that is 24/7 that a KPLHIV and any other member of key population groups can call to get assistance. Participant P005 explains,

“we have crisis response team, we have been working with everybody, every stake holder; we want cases of KPLHIV to be tackled like a case of any other woman. You blackmail me, I warned you, my case is taken like any other woman who is blackmailed who have evidence that they are HIV positive”

And participant P017 explains,

“for violence we have been able to partner with various partners to be able to manage the situation whereby we have a team, ...team that is responsible for cases of violence whereby they also have a hot line to respond to such cases, we also have an advisory committee we call them gate keepers, the community, the police, the chiefs, bar owners for us to be able to have an interactive session where the KPLHIV brings about their issues and they are able to address at the gathering, that particular session”

Good rapport with KPLHIV

Both health care workers and program workers mentioned that they strived to have a good relationship with KPLHIV, so that, in the words of one health care worker,

“as the time goes by, they are very comfortable they can tell you anything, so you are very sure the progress of that patient”, and “you are able to know [whether] they are experiencing some challenges, and be able to tackle them before they happen”

One stop shop

For KP-led organizations that had a comprehensive care center within the organization, the fact that they could provide all the services the KPLHIV needed in one place was mentioned as major facilitator of retention. One program worker from a big enough organization to house a CCC says,

“Our clients love the fact that we are a one stop shop. So, they can also do family planning, we can also offer structural interventions like for violence, so there is a lot we offer here it’s a one stop shop that encourages our clients to come again and again”

Locating CCC with other departments

Health care workers from facilities that were not government health facilities also mentioned that having the CCC mixed together with other departments facilitated retention because, *“all patients are served the same, even if you come with flu or malaria, all patients are seen by one ... you'll never identify that this patient is positive”*, so patients in those facilities did not fear meeting people they knew and get stigmatized.

Innovative ways KP-led organizations are trying to facilitate retention in KPLHIV

Peer navigators: KP-led organizations use peer navigators, also known as, treatment champions or art case managers, in different capacities in order to facilitate retention of KPHIV in HIV treatment. Peer navigators are members of key populations living with HIV that have accepted their status and have learnt to live well with it. KP-led organizations use them to

1. Support program clinician with linking and following up other KPLHIV in the organization. Their status as members of key population groups and HIV positive individuals places them in a better position to create rapport with the other patients, making linking and following them up easier.

“I forgot to say during testing it's the case managers who refer most of the sex workers to come and be tested, so if a client turns positive they are mandated to be confidential about it, they follow up these clients they know these clients from the community level, they can tell me this client doesn't take her drugs or takes a lot of drugs or has sex with men without a condom”

2. Do defaulter tracing whenever a KPLHIV drops out of care

“what we do, through the ART case manager there is a defaulter book whereby we track them, we call them there are reminders through phone call if at all we don't succeed we go to the next of kin then their locations, location markers for us to be able to get their residence, if that is not achieved then we go to the community health worker who are based in that certain area and then now we try to locate them through those channels”

3. Act as ambassadors of hope to other KPLHIV by being their role models and encouraging them, through their experiences, to have hope and continue engaging in treatment.

“this is where the case managers come in, all the case managers by the way are people key populations living positive so they talk to them at length in that way they will say ooh, am not alone in this”

4. Provide general support to other KPLHIV including and not limited to, emotional support, psychosocial support, adherence support and even simple day to day support, just to give them hope and courage to move forward despite the hardships that come with being HIV positive.

Healthcare facilities also have their version of peer navigator whom they call mentor mothers.

Mentor mothers perform the same role in the health care facility that peer navigators perform in the KP-led organization.

Peer support groups: KP-led organizations provide financial incentives to encourage KPLHIV to go for peer support groups at least once a month where,

1. KP-led organizations invite health care workers “*who have been sensitized*” to come talk with them about different health issues relating to living positively.
2. KP-led organizations invite other KPLHIV who are living positively to encourage them and talk to them about adherence and positive living.

“we have ones whom we call ambassadors of hope those who have lived with HIV for about 20 years or more and come to them with hope to encourage them.”

3. KPLHIV meet and form networks of support amongst themselves, *“where they open up about their own challenges, not just involving drugs, even family issues that can be discussed among them, so that if there is a new client or someone who is struggling with medication they can be able to share their experience and encourage each other,”*

Storage of drugs: for KPLHIV who have not disclosed and are afraid of being discovered, KP-led organizations have offered the use of their drop-in center as a storage space in order to help keep their status a secret.

“we also have those who unable to disclose to their clients, we have some that we keep their medications here so that when they are having their clients in their house, they may not see that they are using drugs, we keep the drugs for them and they come only when they want to take them and go away.”

Further, to hide drugs in plain sight, they have also assisted the KPLHIV to package the ARVs in a way that would not draw suspicion.

“others will put in an empty match box that they put in their bra or just put in their pocket, so you may not know. they will do as if they are removing a matchstick, but they are removing their drugs to take, which is a good measure”

“when the clients come, we reassure them and if it's about taking drugs when their friends or family members are seeing we just look for alternative ways maybe you can hide them somewhere and when they are out you pack them in an envelope so it's easier unlike the bottle if you remove them, the shake and maybe that is another form of stigma, you can put like two tablets then it's easier to take them, just make sure you are in a separate room”

Findings for research question 2(a)

Question 2a sought to answer whether the efforts put in place by KP-led organizations and health facilities to facilitate retention addressed the barriers that were mentioned in research question 1. From the researcher's perspective, the health facilities and KP-led organizations are trying their best to address the major barriers to retention that KPLHIV face. For instance, one of the major barriers to retention is age of KPLHIV, and although, some KP-led organizations do not have a specific way to address poor retention in younger KPLHIV, they held peer support groups where younger KPLHIV could build networks with older KPLHIV and in the process learn ways to adhere in treatment and how to not fall out of care. Further, some health care facilities and KP-led organizations [ones with CCC in the organization] held support groups based on age groups of their HIV patients, giving the patients from different age groups space to discuss issues relevant to them. When asked if they had any specific interventions in place designed considering the age groups of KPLHIV to encourage retention to care, participant P016 answered,

“of course the support groups for the young only and we do like we have people who have been in care for a longer period so that they can at least give them their experiences and everything and the discuss about the side effects and everything, we make everything fun for them including a movie Friday, they come here, movies and discuss a few issues they are having, that way we are keeping them closer and we just don't want them to go always.”

Another major barrier to retention in HIV treatment that was mentioned was non-disclosure of HIV status. From their accounts, health care workers, other than encouraging disclosure, they

were also doing assisted disclosure. A healthcare worker explained what they do to assist with disclosure,

“you direct them. If it will be a problem with disclosure and they have already disclosed to you that my sex partner is this, use your own method to meet the sex partner. Actually what we do, when we become close with them, they will tell you my partner will be hostile with me if I try tell him he is required in hospital, but you as a Doctor if you call him he has no problem, if he knows the Doctor is the one who requires him, he will come and listen. And actually that is what I do, though I would not call them, telling them I've called them because of HIV issues, I will not even mention their partners, but now for instance those who are pregnant, if you call the partner, you explain to them that there are some things they are both supposed to know because they are one and there is something they are expecting together, they are waiting [for] this baby, so you tell him there are some things that they supposed to know together, including things to do with blood group, and HB, all those. Then lastly, you conclude with HIV because that's what you are targeting. But you will not go disclosing that I tested this one and she turned HIV positive. Now when it gets there, you counsel until you get a consent of testing the two of them, and when you test the two of them, you know what direction to go whether they are concordant or discordant and then from there you have enhanced adherence whether it will be that they are serodiscordant or concordant. So at least there you will have hopes that, I will retain this, client. This client will adhere and when they adhere, they'll acquire viral suppression.” [H005]

Additionally, the health care workers and program workers mentioned three types of stigma, that is, stigma from the community, stigma from healthcare workers and self-stigma. From the program workers accounts, it was evident that KP-led organizations were trying their best to sensitize health care workers on stigma issues. For instance, one program worker said,

“we’ve had a CME (Continuous Medical Education), which are done by [the organization’s] staffs to the link facilities staffs, so they get to be sensitized”

[P001]

However, there was no mention of efforts put in place to counter self-stigma and community stigma.

Overall, when asked whether they thought what they were doing to help facilitate retention for KPLHIV in HIV treatment was enough, there were varied answers from health care workers and program workers, where some of them felt like they did enough, while others felt like they had room for improvement.

Findings for research question 3

Research question 3 (What more do program workers and health care workers think should be done to help retain KPLHIV better in HIV treatment?) sought to explore healthcare workers and program workers ideas of what more could be done to ensure that retention is facilitated in KPLHIV. Program workers more than health care workers had a lot of suggestions. For instance,

1. Program workers from KNOTE felt like their drop-in centers should be made ART sites in order to avoid the hustles of taking a client to another facility for medication. They also thought it will help reduce the anticipated stigma that their clients experience when

they are linked to health care facilities because their clients are already used to the drop-in centers being like a safe space for them.

“maybe the government or the donor could fund KP programs to make them ART sites it could be different. Because these programs specifically target KPs so they will not discriminate on them. They have been sensitized. The program workers have been sensitized so they know needs of the sex workers. So, if at all the DICs could be made ARTS there would be a very big difference.”

2. Program workers also thought that making KP-led organization drop-in center a one stop shop, where all services that KPLHIV need can be provided at the same place, would strengthen retention because the KPLHIV will not only have express services, they will have specialized care specific only to their needs.

“I know I said we need to offer them whatever we have been offering, we need to do more tests for them, some lab tests for them, clients come and you are not able to do even a test for malaria for them, so if only they could come and get somewhere they are treated fully they are given services fully, as much as it's a one stop shop they are able to access everything over here and also for their children then that would really help”

3. They felt like peer navigators should be made full time employees and be put on a payroll because they thought that peer navigators had made such a great difference in helping track down KPLHIV that had defaulted from treatment and also mentor new KPLHIV on adherence issues.

“we've seen improvement since they came in, but I think if they were like full time staffs it could be better because these are people who comes when we need them so maybe three times in a week”

4. Some of them felt like community ART groups would be helpful to decongest CCCs in health care facilities. That is, they would take drugs directly to KPLHIV in the community, just like they took outreaches to them for testing.

“maybe having, dispensing them drugs like we do in the outreaches we can go with the ART and dispensing them there as in taking it to them, the community, it will be much easier maybe someone doesn't have fare”

“basically, you know, even suggesting that we get community ART groups. That there are three people who leave in a certain area and they would want to do community or differentiated care at that point will look like a very expensive investment, but it is a way that especially the MSMs feel like it's something that will work for them.”

However, some mentioned that when they took the idea to their clients, the clients were afraid that that would increase stigma directed towards them by the society because it will put them at risk of being discovered that they are HIV positive.

“When I am giving them health talk here, I tell them they are transitioning from facility to community, in fact most of them are very mad at me to the extent of some of them are talking out there

saying we are forcing the CAG[community ART groups] on them and they are not tired of coming to the hospital and they have not lacked fare, but I tell them that it's not me, it's the government policy and where we are heading, that's what will be taking place...they are not comfortable because of stigma because they say, they have not disclosed to their family members maybe they are doubting their family members are using medication but they've not confirmed. So, you want us to be known out there, we disclose ourselves.”

5. Health care workers and program workers both thought that personalized care for KPLHIV should be strengthened

“I think one of the things to do is have these more of a customized personalized, its client ABCD they have a family, this is a package for them, you get, it is so personalized to the point that, there is that relationship that you build and trust with these people.”

Overall, the program workers and health care workers showed that they had an idea of what was impending the retention of KPLHIV in HIV treatment, they had put in place what they thought would better facilitate retention of KPLHIV in HIV treatment but they knew also more needed to be done for them to be successful. However, because of factors out of their control, they could not scale up some of the best practice and needed their funders and the government support in order to do so.

DISCUSSION

This study explored the perceptions of health care workers and program workers on what barriers affect retention of KPLHIV in HIV treatment and what their beliefs were regarding the susceptibility, severity, and benefits of KPLHIV retention in HIV treatment. It also explored what efforts to retain KPLHIV in HIV treatment program workers and health care workers have put in place, whether those efforts were working to address the barriers to retention that KPLHIV face, and what more they think should be done to help retain KPLHIV better in HIV treatment. Using HBM model as a framework, the researcher aimed to understand the low retention of KPLHIV in HIV treatment in Kenya.

After a qualitative thematic analysis of all the interview data collected for the study, five main results stood out. One, KPLHIV faced considerably more barriers to retention than benefits, but younger KPLHIV face an interconnection of barriers due to their young age, which put them at more risk of dropping out of care than their older counterparts; two, program workers and healthcare workers believed that KPLHIV did not perceive susceptibility to dire outcomes if they were not retained, did not perceive severity of not being retained until they had experienced symptoms or they had seen someone die from AIDS and were not knowledgeable enough to understand the benefits of retention in HIV treatment; therefore, three, program workers and health care workers utilized adherence counseling to increase KPLHIV's perception of susceptibility, severity and benefits; other than counselling, four, KP-led organizations and health care facilities have created some effective interventions to help facilitate retention of KPLHIV in HIV treatment, but have not addressed most of the barriers they perceive to affect KPLHIV retention in HIV treatment; and five, if the retention rates of

KPLHV are going to be improved, the thoughts and ideas of health care workers and program workers on how to improve the retention rates needs to be listened to and implemented.

Although this study tested all the constructs of the HBM model, most of the interview questions in the study centered on barriers to retention because identifying barriers is important for ensuring that the right interventions targeting the right barriers are formulated. From program workers' and health care workers' perspectives, KPLHIV face barriers including, stigma from the community from health care workers and self-stigma, lack of disclosure, mobility, poverty, alcoholism, violence, drug side effects and disease burden, that make them fall out of care. To counter these barriers, the health care facilities and KP-led organizations have developed interventions including the use of peer educators and mentor mothers to follow up on KPLHIV when they default, offering drug storage space for KPLHIV who were afraid of disclosing their status, offering assisted disclosure whenever needed and holding peer support groups to educate and encourage KPLHIV to adhere and continue engaging in HIV treatment. However, most of the barriers were still not tackled by the interventions that they implemented. For examples, these interventions do not address poverty, alcoholism, barriers brought about by migration, and stigma from the community.

Furthermore, something that was of great interest from the indepth-interviews was the suggestion that being a young KPLHIV puts one at risk of experiencing an interconnection of all the other barriers making young KPLHIV fall out of treatment more than older KPLHIV. This finding shows that there is need for KP programs to construct innovative interventions that specifically target younger KPLHIV and the barriers that they face while engaging with HIV treatment. This is because despite the emphasis from health care workers and program workers that younger KPLHIV drop out of treatment more than older KPHIV, health care facilities and

program facilities did not have any intervention implemented that specifically targeted young KPLHIV.

Moreover, the application of the health belief model showed that theory should be utilized to create targeted interventions meant to increase perceptions of KPLHIV that they are susceptible to dire outcomes if they are not retained in HIV treatment, to increase their perception of severity of not being retained and increase their perception of how beneficial being retained in HIV treatment is regardless of the barriers. If program workers and health care workers were trained on how to tailor messages, that would condition KPLHIV to believe that retention is important or reinforce KPLHIV retention behaviors, and include them in their counselling session, then a great improvement may be seen in their retention.

Moreover, from research question two, which looked into what interventions healthcare facilities and KP-led organizations put in place to encourage retention, it was clear that while barriers like nondisclosure were being dealt with from different fronts (health care workers offered assisted disclosure, and program workers and healthcare workers did continuous counselling on the importance of disclosure), the issue of stigma was not well addressed. Other than KP-led organizations doing sensitization and educating health care workers on issues of stigma, there was no intervention in place targeting self-stigma or community stigma. It came as no surprise to the researcher that there was no intervention directly addressing stigma despite the fact that there is a lot of research done on stigma and its effects on Key population groups access to HIV services (and the complete agreement by both health care workers and program workers that stigma was a major barrier to retention). Addressing the issue of stigma is a complex task and it requires multiple interventions targeting stigma at a community level, at a system level and at an individual level. Although, there is dire need for stigma mitigation

interventions to be combined with the other interventions put in place by healthcare facilities and KP-led organizations in order to facilitate retention of KPLHIV in HIV treatment, stigma may not be able to be addressed until systematic barriers like criminalization of sex work and same sex relations is stopped. This is because criminalization is really the fuel for contempt and discrimination against KPLHIV. Nevertheless, community mobilization, mass media and education entertainment can be used to start sensitizing the community about stigma and its effects on KPLHIV and all people living with HIV.

Some interventions that KP-led organizations implemented to encourage retention stood out. For instance, the use of peer navigators addressed quite a number of barriers that are associated with KPLHIV falling out of treatment. Peer navigators not only helped address issues of denial, they walked the journey together with other KPLHIV thus helping ease the disease burden that came with HIV. Furthermore, they also eased the work for clinicians by helping physically to escort KPLHIV to linking facilities for ART initiation and also follow them up to ensure that they were retained in care. It was unfortunate that peer navigators were volunteers and therefore could have a stronger presence at the KP-led organizations because, as volunteers, they still needed to work their other job as sex workers in order to sustain themselves. Program workers' suggestions to make these peer navigators full time employees, therefore, were valid. If this were done, one could expect that they would have a stronger impact as fulltime employees because they were already making so much difference as just volunteers.

From research question three, where the researcher wanted to learn about what intervention program workers and health care workers thought should be strengthened or introduced, the researcher also learned that some of their suggestions may not be feasible. For instance, it is probably not feasible to make all KP-led organizations ART sites, as program

workers suggested, because there are 81 KP-led organizations in Kenya and likely not enough funding to support ART sites in all the organizations, due to budget cut from funding organizations (PEPFAR, 2019). However, from the interventions that they themselves described, including the use of peer navigators, building rapport with healthcare facilities so that they can get quicker services for their clients, and sensitizing health care workers on stigma issues, it was clear that they knew what barriers they were facing and what to do to address those barriers, but they needed the support of the government or the funding bodies to implement those interventions and sustain them.

Limitations

Although there are multiple studies assessing barriers to linkage and retention of KPLHIV in HIV treatment, none of those studies collected data from KPLHIV in the regions of Kenya where the author of this study collected her data from. The researcher assuming that the barriers that KPLHIV in those studies experienced are comparable to the barriers that KPLHIV experience in Kenya was a limitation of this study. The researcher did not collect data about the barriers to retention of KPLHIV in HIV treatment from the KPLHIV themselves but assumed that whatever healthcare workers and program workers perceived as barriers could be comparable to what the KPLHIV themselves perceive as barriers. This study cannot, therefore, make any claims about KPLHIV perceptions of barriers to retention in HIV treatment in Kenya. Nevertheless, the inclusion of treatment champions as program workers made sure that the voices of KPLHIV were not completely shut out of the study and understanding the perceptions of the program workers and health care workers was also still very important because they are the ones working closely with KPLHIV and delivering interventions meant to improve retention to KPLHIV.

Another limitation relates to the researcher studying KPLHIV in general and not looking at the different key population groups separate from each other; that is, MSM and FSWs separate from each other. Exploring the barriers facing the different groups separate from each other might uncover more nuanced results on what barriers lead to their poor retention in HIV treatment. Furthermore, the researcher did not include program workers from KP-led organizations that implemented programs for PWID, therefore challenges facing that key population group was not captured in the results of this study.

The third limitation relates to language. The interviews were done in both English and Swahili in order to accommodate every participant's level of proficiency in the two languages. The researcher being fully bilingual translated the interviews into English and in translating, noticed that some of the words that were said in Swahili lost their emotional weight or their valence when they were translated into English. For instance, the term sex worker does not carry the same level of valence or stigma that it carries when a sex worker is called "Malaya" [the Swahili term for sex worker], because "malaya" is pronounced with more malevolence and carries a lot of stigma. This issue of language may undermine the significance of addressing a barrier because it does not sound as harmful as it actually is.

The fourth and the most significant limitation has to do with the biases and the positionality of the researcher. Reflecting on her positionality, the researcher was both an outsider and insider to the environment of her study and in the eyes of the people that participated in the interviews. She was an outsider because she was more privileged, as she was a researcher going in to the organizations, holding the power to define what got conveyed as problematic, and what was considered relevant to what she decided was the topic that needed to be tackled; and she was an insider because she had worked as a program worker in one of the

organizations, and this made her kin to some of the program workers. Being an insider meant that, although the researcher managed to remain as objective as possible in the collection of her data, the relationship she had with some of the program workers may have affected how the program workers answered their questions during data collection. Further, being someone who has taken care of people living with HIV, and someone who has lost people to HIV/AIDS, the researcher might have been subconsciously biased in her data analysis. Nevertheless, the researcher subjected herself to deep reflexivity throughout the research process in order to produce results that were as objective as possible and used the help of two other coders in order to ensure as much objectivity as possible.

Conclusions

Data from this study reinforce the need for interventions specifically targeted at young members of key population groups living with HIV to optimize their engagement with HIV treatment and prevent their attrition from the HIV treatment continuum. Studies meant to identify accurate and generalizable data on young members of key population groups living with HIV are therefore needed so that strategies tailored to their specific needs can be formulated and implemented.

Further, there is an urgent need to address issues of stigma in order to improve the retention rates of members of key population groups living with HIV in Kenya. Boesten & Poku (2013) describes a “social cognition approach” to challenging stigma where people are educated about HIV/AIDS related stigma through a variety of educational programs; and a “participatory intervention programs” which mobilize and empower stigmatized populations through collective action(Boesten & Poku, 2013, pg. 33). KP-led organizations can facilitate the mobilization of KPLHIV for both stigma education and collective action against people who

stigmatized them. Social identity theory provides a good framework for understanding the concept of collective action. Tajfel & Turner (1979), defines social identity as, “the part of an individual’s self-concept that derives from his knowledge of his membership in a social group together with the value and emotional significance attached to that group membership”. In their explanation they state that people also strive to maintain a positive social identity and that when put in social contexts, they get their self-esteem from the membership of their groups (Crabtree et al., 2010), so that, when individuals belonging in a stigmatized group are faced with threat that result in negative self-esteem, they find ways of getting positive self-esteem. Similarly, if KPLHIV identify closely with other KPLHIV facing an stigma, they will react in what (Corrigan & Watson, 2006) call “righteous anger” and this righteous anger is said to empower and motivate stigmatized persons to take charge(Corrigan & Watson, 2006).

Finally, there is need for the barriers that affect KPLHIV retention in HIV treatment to be dealt with using a bottom up approach. The needs of KPLHIV and People who work closely with KPLHIV should be placed at the forefront and their ideas should be given a chance because they know better what their needs are.

APPENDICES

APPENDIX A

Interview protocol

Introduction statement

Hi, thank you for agreeing to speak with me today. I really appreciate it.

My name is----- . I am a -----
-----and a research assistant for this project.

The study we are conducting is meant to partly fulfill the requirements of the researcher's thesis in the Health and Risk Communication program at Michigan State University. It will also provide preliminary data for a future grant proposal that may facilitate a larger study.

The study is an assessment of what KP led organization program workers and Health care workers perceive as barriers or facilitators to KPLHIV being retained in treatment services. Following the 90-90-90 targets that all KP programs observe, it's been reported that organizations are doing very well in the first two 90s but are lagging when it comes to the last 90. We would like to pick your brains on what you think are the key reasons for KPLHIV dropout from the HIV treatment services and what you think is dragging KP programs back when it comes to the 3rd 90.

We have about an hour's worth of questions; our conversation will be audio recorded and we can use both Swahili and English to pass our thoughts across.

Do you give a verbal consent to being audio recorded for this interview?

I would like you to repeat that you agree to be interviewed and recorded during the interview on record.

Thank you.

- So, first thing, please tell us a little bit about your professional background and the role you play in this organization/facility.
- How did you come to be in the position that you are in? what's the story behind you taking this position?
- How long have you held the position and what has been the experience? Take me through your typical day. (Remember to write the name of interviewee and the organization on the protocol)

Interviewee's Name:

Date:

Organization:

Interviewer:

Questions for program workers (except treatment champions)

1. Take me through the process of testing, linking, and retaining a client to HIV treatment services?
 - a. Where in the process do you see the most clients dropping out?
 - b. In your experience, what contributes to the dropouts?
2. In your experience, what does a client need to do to be considered retained (go to appointments, have Viral loads taken) in treatment services?
 - a. Do you think the services offered to key populations are effective for getting them into and retaining them in treatment?

Follow up Questions

- i. Does the age of a KPLHIV make a difference when it comes to retention in treatment?
- ii. If so, do you have specific ways, designed considering their age groups, of encouraging their retention in care?
- iii. Does disclosure of status make a difference when it comes to retention on KPLHIV in HIV treatment?

- iv. In your opinion, who do you advise they disclose to? Does who they disclose to make a difference when it comes to retention? How much of a difference?
 - v. Do you have clients who have not disclosed their status to anyone, but the nurse, and they are doing very well in their treatment?
 - vi. What do you do to encourage disclosure of status?
- b. What other general ideas do you have about ways to retain key population on treatment more effectively?
- c. How about defaulters?
- i. In your own terms, who is considered a defaulter?
 - ii. How do you do defaulter tracing?
 - iii. How do you make sure they don't default again or are not lost to follow-up after link return?
3. What is a client required to do in order to be considered as adherent (following their medication regimen religiously) to ART?
4. As a follow up to their linkage, how do you communicate with your clients?
- i. What technology do you use to communicate with them?
 - ii. Does this form of communication give the clients an opportunity to give feedback or is it just one way?

- iii. Do you do physical visits?
 - b. What is the nature of your communication with them?
 - i. What do you talk about?
 - ii. What time do you communicate with them?
 - iii. What about the language you use?
 - c. Is there a way the client can reach out to you with an issue or do you always have to communicate first? Can they come to you unexpectedly to just talk about something they are going through or to be tested for something or must they wait for their assigned appointment time?
- 5. What are the challenges that make it hard for KPLHIV to adhere to ART? How could people in your role help with this? Who else do you think can help?
- 6. What are the barriers making it hard for KPLHIV to be retained in treatment services?
 - a. To what extent do you feel issues of stigma affect linkage and retention of KPLHIV in treatment services?
 - i. In your experience how does stigma affect ART adherence? Has your facility had situations where a client defaulted or was lost to follow up because they felt stigmatized?
 - ii. Have you had clients say they feel worthless because of their status? Is self-stigma a big issue when it comes to retaining clients to treatment services

Interviewee's Name:

Date:

Organization/ facility:

Interviewer:

Questions for Healthcare Workers

1. Take me through the process of testing, linking, and retaining a client to HIV treatment services.

a. Where in the process do you see the most clients dropping out?

b. In your experience, what contributes to the dropouts?

Is there a difference in the testing, linking, and retaining process when it comes to key populations?

c. Is there a need for one to self-identify as a KP at the facility?

d. What is done different for key populations compared to the general populations?

2. In your experience, what does a client need to do to be considered retained (go to appointments, have Viral loads taken) in treatment services?

a. What are the services offered to clients to encourage retention?

i. Is there a difference in the service when it comes to KPLHIV compared to the general population? If so, what is done differently?

b. Do you think the services offered to key populations are effective for getting them into and retaining them in treatment?

- c. Does the age of a KPLHIV make a difference when it comes to retention in treatment? Is it the same with the general population?
 - i. Do you have specific ways, designed considering their age groups, of encouraging their retention in care?
- d. Does disclosure of status make a difference when it comes to retention on KPLHIV in HIV treatment?
 - i. In your opinion, who do you advise they disclose to? Does who they disclose to make a difference when it comes to retention? How much of a difference?
 - ii. Do you have clients who have not disclosed their status to anyone but the nurse and they are doing very well in their treatment?
 - iii. What do you do to encourage disclosure of status?
- e. What other general ideas do you have about ways to retain key population on treatment more effectively?
- f. How about defaulters?
 - i. In your own terms, who is considered a defaulter?
 - ii. How do you do defaulter tracing?
- g. How do you make sure they do not default again or are not lost to follow-up after link return?

3. What is a client required to do in order to be considered as adherent to ART?
4. What have you done to help non-adherent clients to start adhering?
 - a. Is this process done differently for someone who is inconsistent in their medication timing compared to someone who misses to take their medication entirely for days?
 - b. Has what you've done been effective? If not do you have an idea of what else could be done?
5. As a follow up to their linkage, how do you communicate with your clients?
 - a. What technology do you use to communicate with them?
 - i. Does this form of communication give the clients an opportunity to give feedback or is it just one way?
 - ii. Do you do physical visits?
 - b. What is the nature of your communication with them?
 - i. What do you talk about?
 - ii. What time do you communicate with them?
 - iii. What about the language you use?
 - c. Is there a way the client can reach out to health care workers with an issue or must the communication always begin with the health care workers? Can they

come to you unexpectedly to just talk about something they are going through or to be tested for something or must they wait for their assigned appointment time?

6. Stigma questions: Stigma scale (STRIVE STIGMA measurement)

a. In the past 12 months, how often have you observed the following in your health facility?

- i. Healthcare workers unwilling to care for a client living with or thought to be living with HIV
- ii. Healthcare workers providing poorer quality of care to a client living with or thought to be living with HIV, relative to other patients
- iii. Healthcare workers having negative attitudes towards clients living with or thought to be living with HIV

b. In the past 12 months, how often have you:

- i. Experienced people having negative attitudes toward you because you care for patients living with HIV
- ii. Been avoided by friends and family because you care for patients living with HIV
- iii. Been avoided by colleagues because of your work caring for patients living with HIV

c. In the past 12 months, how often have you observed the following in your health facility?

- i. Healthcare workers confronting or educating someone who was mistreating or speaking badly about people living with HIV
- d. To what extent do you feel issues of stigma affect your facility's ability to link and retain HIV patients in treatment? Is it worse or similar for KPLHIV compared to general populations?
 - i. In your experience how does stigma affect ART adherence? Has your facility had situations where a client defaulted or was lost to follow up because they felt stigmatized? (a lot/a few)
 - ii. Have you had clients say they feel worthless because of their status? Is self-stigma a big issue when it comes to retaining clients to treatment services

Interviewee's Name:

Date:

Organization:

Interviewer:

Questions for treatment champions/ peer navigators (address them with the title they are given at the organization)

1. What is your role in the organization?
2. Tell us your experience as a person living with HIV who is also a KP
3. Do you take your medication? (do you take it every day? at the required time?)
4. What have you done to ensure that you take your medication every day and at the required time?
5. Talk to us about your experiences with other program workers and your relationship with them
6. Talk to us about your experiences at the Health facilities and your relationship with health care workers
 - a. How do they communicate with you? What technology do they use (phone? Message? Call?) What language do they use? What language do you prefer?
 - b. Do you have a chance of reaching out to them whenever you need assistance or counselling? Or do you just meet with them when you have an appointment?
7. As a treatment champion, what do you do to help other KPLHIV to adhere to ART?

8. What are some of the reasons they say make them non-adherent? (disclosure issues, stigma, violence, faith, other KPLHIV)
9. When a KPLHIV defaults what do you do to bring them back?
10. What do you think should be done more to help KPLHIV take their medication every day and on time and remain in treatment?
11. Do you often feel judged for being a KP?
12. Do you feel judged for being a KP who is also HIV positive?
13. Have you at any moment felt bad about yourself because you are HIV positive and a KP?
14. How do you cope with the feelings?
15. How do you help other KPLHIV cope with the feelings?
16. Does disclosure of status make a difference when it comes to retention on KPLHIV in HIV treatment?
 - a. Did it make a difference for you?
 - b. In your opinion, who do you advise they disclose to? Does who they disclose to make a difference when it comes to retention? How much of a difference?
 - c. Do you have clients who have not disclosed their status to anyone, but the nurse and they are doing very well in their treatment?
 - d. What do you do to encourage disclosure of status?

APPENDIX B

Research Participant Information and Consent Form

Study Title: Understanding gaps in the retention of KPLHIV in the HIV treatment continuum

Researcher and Title: Ruth Osoro, Graduate student / Dr. Nancy Rhodes, Associate Professor

Department and Institution: Advertising and Public Relations, Michigan State University

Contact Information: rhodesn3@msu.edu

BRIEF SUMMARY (*This is a general informed consent requirement*)

You are being asked to participate in a research study. We are required to tell you about the research study, to tell you that it is your choice to participate or not, to explain the risks and benefits of being in the study, and to empower you to make an informed decision. You should feel free to discuss and ask the researchers any questions you may have.

You are being asked to participate in a research study about Retention of key populations living with HIV(KPLHIV) in HIV treatment. Your participation in this study will take about one hour.

You will be asked to answer questions pertaining KPLHIV retention in HIV treatment by the interviewer.

The most likely risks of participating in this study are revealing sensitive information.

You will not directly benefit from being in this study. However, by answering our questions you may help us understand the barriers to treatment for KPLHIV. This will help us find better ways to serve KPLHIV, so they will get better care.

PURPOSE OF RESEARCH

This research aims to understand how KPLHIV are currently being served, and to find areas that could be improved.

WHAT YOU WILL BE ASKED TO DO

You will be asked to answer questions about your work with KPLHIV, and what you see as the barriers to some KPLHIV getting and staying in treatment.

PRIVACY AND CONFIDENTIALITY

With your permission, we will record your answers so we can learn from them. You will be required to go on record saying that you consent to being recorded, but you will never be personally identified with the information you give us.

YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW

You have the right to say that you will not answer any questions and you can stop answering them at any time after the interview has already started. There will be no problem if you stop and you will not be criticized.

COSTS AND COMPENSATION FOR BEING IN THE STUDY

You will receive KSH1000 for participating in this study.

RESEARCH RESULTS

We will be happy to share with you our summary of the study findings if you wish to receive it.

CONTACT INFORMATION

If you have any issues or questions about this study please contact the researcher Dr. Nancy Rhodes at +1 517 355 2314 or email rhodesn3@msu.edu, or Ruth Osoro at +254 727602280 / +1 517 575 8603 or email osororut@msu.edu.

If you have questions or issues about the part you are playing in the research, or a question about your rights as a person who is being asked questions in this research, or would like to complain about this study, you can call the Michigan State University's Human Research Protection Program at 1-517-355-2180, Fax 1-517-432-4503, or e-mail irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI 48910 USA.

DOCUMENTATION OF INFORMED CONSENT.

Your signature below means that you agree to be asked questions in this research study.

Signature

Date

You will be given a copy of this form to keep.

APPENDIX C

Code Book

Introduction

This *coding* protocol is aimed at assessing the barriers and facilitators of retention to HIV treatment for key population living with HIV(KPLHIV). It examines program workers and health care workers interviews about the retention of key population living with HIV.

The Health belief model (HBM), which was developed in early 1950s to assess why people don't embrace prevention behavior or screening behavior for the early detection of disease is one of the most widely used theory of health behavior; it has also been used to provide a framework for this study.

The HBM has five components that are proposed to influence the likelihood of a person to engage in a health behavior:

- Perceived susceptibility: perceptions of the likelihood that one will experience the outcome
 - In this case it would be the health care workers and program workers perceptions of KPLHIV vulnerability to experience HIV related opportunistic infections, malignancies and ultimately death if they are not retained in HIV treatment.
- Perceived severity: perceptions of the seriousness of the consequences associated with the outcome
 - Health care workers and program workers perceived severity of outcomes if KPLHIV are not retained in HIV treatment.
- Perceived benefits: potential advantages of engaging in the health behavior, including the behavior's perceived efficacy in preventing the undesired outcome

- benefits of being retained in HIV treatment
- Perceived barriers: perceived obstacles to engaging in the health behavior
 - obstacles to retention in HIV treatment
- Cues to action: factors that signal or remind an individual to engage in the health behavior and range from experiencing symptoms to receiving persuasive appeals from the media, family and friends, or a health care provider (factors, internal or external, that stimulate a person to engage in a health behavior)
 - Internal and external factors that stimulate a KPLHIV to be retained in care
 - For example, the phone calls that remind them they have an appointment

Definition of terms

The following definitions are important in selecting and analyzing the content under study.

Antiretroviral therapy: The use of HIV medicine to treat HIV infection.

CD4+ T cell: Cells that are meant to trigger the human body's response to external pathogens by stimulating other cells in the body to fight infection

Health care worker: Ministry of Health employees working in health facilities where key population living with HIV are linked.

HIV care continuum: The successive steps of HIV care from HIV diagnosis to viral suppression that people living with HIV go through.

Key populations: sex workers (SWs), men who have sex with men (MSMs), transgender people, and people who inject drugs (PWID) among others

Linkage to care: The completion of a first medical clinic visit after HIV diagnosis.

Program worker: A person working in a key population led organization that implements a key population HIV program

Retention in care: “A patient's regular engagement with medical care at a health care facility after initial entry into the system.”

Viral load: Term used to describe the amount of HIV in the blood of a person living with HIV.

Viral suppression: When the viral loads of a person living with HIV have been made undetectable by ART

Defaulter: PLHIV that have missed appointment between 4 days and 3months

Lost to follow-up: PLHIV that have missed appointment by more than 3months

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CCC	Comprehensive care center
PMTCT	Prevention of mother-to-child HIV transmission
FSW	Female Sex Worker
GF	Global Fund
HIV	Human Immunodeficiency Virus
KASF	Kenya AIDS Strategic Framework
KP	Key Populations

KPLHIV	Key populations Living with HIV
LDL	Low detectable levels
MSM	Men who have sex with Men
NACC	National AIDS Control Council
NASCOP	National AIDS and STI Control Program
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief
PWID	People who Inject drugs
PLHIV	People Living with HIV
STI	Sexually Transmitted Infection
STF	Soluble Mycobacterium tuberculosis factor
SW	Sex workers
TCA	To come again
UNAIDS	The Joint United Nations Programme on HIV/AIDS
VCT	voluntary counselling and testing
WHO	World Health Organization

Table 5: Coding scheme for the HBM components

Code Name	Conceptual Definition	Operational Definition	Decision/Coding Rules	Examples
HBM – perceived susceptibility	health care workers and program workers perceptions of KPLHIV vulnerability to experience HIV related opportunistic infections, malignancies and ultimately death if they are not retained in HIV treatment.	Comments regarding individual perceptions that KPLHIV are susceptible to opportunistic infections, malignancies and ultimately death if they drop out of care and also comments showing that program workers/healthcare workers remind KPLHIV that they are susceptible all those outcomes if they drop out of treatment	Code even when it is implied	“you know I can talk from the context of key population, this is a sex worker, you have tested her, tested positive but maybe she has not gotten enough counselling that taking these drugs is important but now you tell her to come to the clinic for treatment”
HBM – perceived severity	Health care workers and program workers perceived severity of outcomes if KPLHIV are not retained in HIV treatment.	Comments regarding individual perceptions that KPLHIV dropping out of care has severe consequences and also comments showing that program workers/healthcare workers remind KPLHIV that they will face severe outcomes if they drop out of treatment	Code even when it is implied	“So, I was imagining when I pictured other HIV positive people, their shoulders looked this way (crunched shoulders), and at that time an organization was providing them with porridge. I imagined

Table 5 (cont'd)

				myself getting to that point and it scared me”
HBM – perceived benefits	The perception of health care workers and program workers that it is beneficial for KPLHIV to be retained in HIV treatment	Comments regarding individual perceptions that retention in care is beneficial to KPLHIV and also comments showing that program workers/healthcare workers express to KPLHIV that they it is beneficial to stay in treatment	Code in terms of its benefits to the KPLHIV, but also to the society at large and to public health initiatives	“you know I can talk from the context of key population, this is a sex worker, you have tested her, tested positive but maybe she has not gotten enough counselling that taking these drugs is important but now you tell her to come to the clinic for treatment”
HBM – perceived barriers	The perception of health care workers and program workers of obstacles that lead to poor retention of KPLHIV in HIV treatment	Comments regarding individual perceptions on what barriers KPLHIV face that lead to not being retained and barriers organizations and health care facilities face that prevent them from facilitating KPLHIV retention.	Code in terms of whether the barrier is an individual barrier or an organization/facility level barrier	<p>Alcoholism: “you see like I have said I also mentioned that most of them are depending on alcohol, so they do not check their nutritional supplies.”</p> <p>Lack of disclosure:</p> <p>“now for instance that client who is always keeping appointments and they are not adhering</p>

Table 5 (cont'd)

				<p>to medication, you need to find out what is happening to their life,, what is making them not to take their drugs everyday despite the fact that they come for their drugs every day, you find out the reason why so that you can sort out after you have known the reason why and most of the times I have realized it's because of disclosure probably they have not disclosed to the person they are living with and when the time to take medication comes it's a bit difficult for them to go take their drugs and come, so we encourage them a lot on disclosure issues and always doing for them adherence counselling.”</p>
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Table 5 (cont'd)

HBM – cues to action	Internal and external factors that stimulate a KPLHIV to be retained in care	Comments made about the innovative ways that the health care workers and program workers have come up with to keep reminding KPLHIV engaging with treatment.		<p>“Constant reminder. Like two days to TCA[to call back] you can give me call or text telling me”</p> <p>“for the timing what we do currently, we encourage the clients so they can set alarms for themselves, what happens, we decide together when you are able to take your medication?”</p>
Facilitators of retention	What program workers and healthcare workers think are facilitators of retention	Comments about interventions that increase the likelihood of KPLHIV to be retained in HIV treatment		<p>Disclosure: “so when they disclose their status it's easy for them, for one there is a burden that is lifted because they can share their issues, another thing, whenever they are in problem, so they have, especially</p>

Table 5 (cont'd)

				they are sick, it's easy for us to get the treatment support especially the one who has been disclosed to, to get in to try and give them medication unlike one who has not disclosed to anyone because for us we can't do disclosure, so even if you look for a treatment supporter, he won't be able to call this person and tell them that you need to come for drugs for this particular person, so if someone is sick at home or in another facility it's very hard for us to reach them and we consider them lost"
Suggestions for improvement	What program workers and health care worker think should be implemented or	Comments about what should be implemented or strengthened in order to increase KPLHIV retention rates		Make drop-in centers ART sites: "maybe the government or the donor could fund KP programs

Table 5 (cont'd)

	strengthened in order to increase KPLHIV retention rates			to make them ART sites it could be different. Because these programs specifically target KPs so they will not discriminate on them. They have been sensitized. The program workers have been sensitized so they know needs of the sex workers. So if at all the DICs could be made ARTS there would be a very big difference.”
Other		<p>Comments that do not relate to any of the HBM attributes but are important in describing the context within which the KP-led organizations and healthcare facilities operate</p> <p>This includes:</p> <ul style="list-style-type: none"> • The HIV care continuum steps 		Attrition point: “after they are linked. for those who accept to be linked, because most of them accepts to be linked, they go start their ART and then after some time, 1-3 months, they get lost.”

Table 5 (cont'd)

		<ul style="list-style-type: none"> • Attrition point of KPLHIV from the HIV care continuum • Anything that you feel is important but does not fit in the other codes 		
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REFERENCES

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