The Association Between HIV Status Acceptance and Antiretroviral Adherence Among Recently Diagnosed Individuals in Coastal Kenya

By

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Abstract

Poor adherence to antiretroviral therapy (ART) is a key factor that determines low viral suppression, poor health, and potential ART resistance among people living with HIV (PLHIV). Proper uptake of care is especially important in low-resource settings where the impact of ART non-adherence can be profound. One theoretical factor that can potentially enhance uptake of care and ART adherence is the extent to which newly diagnosed PLHIV accept their HIV status. This mixed methods study analyzes the relationship between HIV status acceptance and ART adherence in Kilifi, Kenya, the country with the 4th largest HIV epidemic in the world. This study involved n=16 newly diagnosed PLHIV participants who participated in a longitudinal qualitative study as part of the Tambua Mapema Early Screening Programme. As part of the programme, newly diagnosed PLHIV were enrolled in care and their seronegative partners enrolled in PrEP. Four one-on-one in-depth interviews were conducted with PLHIV participants. The first interviews were conducted approximately 2 weeks after HIV diagnosis, with subsequent interviews taking place at 3, 6, 9, and 12 months during the participants' medical follow-up visits. Viral loads were collected two weeks post diagnosis and at the 6-month mark. The final sample size of 16 was chosen purposively to include only recently diagnosed individuals who had their viral loads collected. The study analyzed interviews conducted during the 2nd week and 6th month assessments, to examine the relationship between status acceptance and uptake of medication. We found that a positive shift in acceptance of HIV-status was associated with decreased viral loads. The participants described multiple factors that helped them process their diagnosis. An encouraging support system, dependency of family, availability of effective medicine, increased knowledge, and spirituality enabled participants to move away from internalized stigma to developing positive outlooks on their HIV-status and complying with

their ART regimen. These preliminary findings suggest that there is a necessity for further research to understand how HIV status accommodation influences the way individuals respond to treatment. An improved understanding will enable healthcare workers to provide more targeted, individualized support and counseling in the care of HIV.

Introduction

Poor adherence to antiretroviral therapy (ART) is the main influencing factor in treatment failure for individuals living with HIV globally [1-5]. Poor adherence is associated with low viral suppression, poor health, and potential permanent resistance to certain ART medication regimens. Studies have found transmissible drug resistance strains in Sub-Saharan Africa post-initiation of care [2,6]. Proper uptake of care is especially important in low-resource settings where the impact of non-adherence can be detrimental to the goal of reducing transmission. A 2016 systematic analysis found that the average adherence rate in Sub-Saharan Africa was 52.5% (adherence 100%) and 72.9% (adherence 95%). These recent estimates reveal the imperativeness of continuous adherence promotion in this region [7]. In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and partners created the 90–90–90 targets which delineated targets to achieve by the year 2020: 90% of people living with HIV (PLHIV) will know their status; 90% of PLHIV will receive continuous antiretroviral therapy; and 90% of people on antiretroviral therapy will achieve viral suppression. In 2018, increases in the number of people who knew their status and were on treatment in Eastern and Southern Africa reflected in improvement in viral load suppression among all PLHIV - from 43% (37–50%) in 2015 to 58% (50–64%) in 2018 [8]. Despite major strides, the 90-90-90 targets were not achieved by 2020 [9]. The linear dose–response relationship between level of adherence and virological success has been established, and therefore it is important to identify factors that influence ART adherence [10,11].

There are many intersectional factors that serve as barriers to ART adherence. Previous research has indicated that these adherence-related factors include lack of access to healthcare services, lack of social support, miseducation and mistrust of treatment and healthcare systems, mental illness, difficulty with daily regimen, financial constraints, stigma, and substance abuse [2,12-14]. An additional factor that can contribute to ART adherence among PLHIV is acceptance of one's HIV status. This factor refers to the extent to which an individual acknowledges their positive status, accepts linkage to care, seeks care and understands the necessity and value of HIV care. Research has shown that acceptance of HIV status is central to an individual's knowledge and attitude towards diagnosis, access to social support, healthcare practices, and engagement with care and counselling [20,23]. A recent qualitative study from coastal Kenya described the role of HIV-status acceptance among newly diagnosed PLHIV [22]. This qualitative study indicated variability in the degree to which newly diagnosed PLHIV either accept or deny their HIV status and called for further research to understand the factors that promote status acceptance and the potential consequences of status acceptance.

Kenya has an estimated 1.5 million PLHIV [15]. In 2015, Kenya adopted the World Health Organization's guideline to immediately offer ART therapy to individual's post-diagnosis. In 2017, the Government of Kenya and the global initiative to prevent, diagnose and treat major diseases in developing countries, Unitaid, reached an agreement to introduce a generic version of Dolutegravir (DTG). DTG is a first-line drug with an easier regimen (one pill daily), less side effects, and a lower likelihood of resistance within the public sector compared with efavirenz, the first-line HIV drug currently used in Kenya. In a bid to make the pricing more affordable, various nonprofits including the Bill & Melinda Gates Foundation, Unitaid, USAID, PEPFAR agreed to a pricing agreement of $75 per person annually in the public sector [16].

The Kenya AIDS Indicator Survey 2012 found that less than 10% of Kenyans between the ages of 15 and 64 were not adhering to their ARTs. The study found that adolescents and youth and individuals living in rural areas were more likely to be non-adherent. Adolescents had a 50% less likelihood of being adherent in comparison to adults. Key social, economic, cultural, individual level and treatment related barriers to adherence for youth included struggles with disclosure, mental illness, discrimination, poverty, and difficulty with medication regimen and side effects. Additionally, the correlation between rural residence and poor adherence may have reflected lack of access to health services, suggesting a need for more research and regional evaluation [17]. The study stated that the results were a highlight of the success of the Kenyan national ART program. However, 2019 data reveal a gap between individuals on ART and individuals who have suppressed viral load with 74% (65-86) on antiretroviral therapy and 68% (60-79) with suppressed viral loads [15,17]. The difference between the percent of those on ART and the percent of those with suppressed viral load is modest but the sociodemographic, psychosocial, and treatment-related determinants of ART adherence are interconnected and must be addressed to optimize adherence.

The objective of the study is to use data from a longitudinal cohort study that included qualitative interviews with newly diagnosed PLHIV in coastal Kenya to analyze the relationship between narratives about HIV status acceptance and ART adherence, measured by viral load. We aim to examine how participants cope with and accommodate their new HIV-positive status, and whether there are patterns between HIV status acceptance and uptake of care. Analysis of qualitative interviews also allowed for exploration of socio-cultural and psychosocial factors that influence adherence among newly diagnosed PLHIV in coastal Kenya.

Methods

Overview: Study setting, Participants, and Procedure

This study analyzed data from qualitative interviews conducted with newly diagnosed individuals participating in the Tambua Mapema Plus Screening Programme and explored patterns between qualitative themes and viral load data collected as part of this cohort study. The overarching goal of the Tambua Mapema Plus Screening Programme is to diagnose people with acute HIV infections (AHI) or prevalent HIV infection and enroll those individuals into an observational cohort following enrollment in HIV care and ART services. Tambua Mapema utilized point-of-care HIV-1 RNA testing in conjunction with standard rapid antibody tests to diagnose AHI and prevalent HIV infections. Additionally, Tambua Mapema incorporated HIV partner notification services to identify potential AHI and prevalent HIV cases linked with index participants. All individuals enrolled in the Tambua Mapema cohort were followed for 12 months to examine clinical outcomes, including linkage to care, ART initiation and viral suppression in HIV-infected patients.

Eligibility criteria for participation in Tambua Mapema included (1) aged 18 to 39 years; (2) never been diagnosed with HIV infection; and (3) a score of 2 or higher on a risk score algorithm used to identify persons at higher risk for AHI (additional detail on the AHI scoring algorithm provided elsewhere) [18].

Tambua Mapema screened 2,874 patients seeking care at 6 facilities (4 private and 2 government) beginning December 2017. Screening took place in Kilifi and Mombasa County and the Mtwapa and Bamburi regions of coastal Kenya. Verbal consent was obtained prior to screening for eligibility. Individuals who consented to participation in screening were shown a 2-minute, IRB–approved video explaining the purpose of the study in Kiswahili or English followed by obtained consent by the research staff. Individuals then went through the HIV testing intervention, which included HIV-1 RNA testing and 2 rapid antibody tests for individuals who tested positive. Overall, 50 patients tested HIV positive (2 were acute HIV cases) and enrolled as participants in the 12-month longitudinal cohort, and were linked to HIV care including ART, and offered assisted partner notification services. Individuals enrolled in the cohort were invited to participate in qualitative interviews. Baseline in-depth interview data was collected approximately 2 weeks after HIV diagnosis and at 3, 6, 9 and 12-month follow-ups. Interviews were held during the participants' medical visits in a private room at the KEMRI office in Kilifi. The interviews were conducted in Kiswahili and later transcribed and translated. All the interviews have been de-identified to protect patient confidentiality [18]. All interviews were conducted by a trained research assistant, supervised by investigators Dr. Eduard Sanders (ES), Dr. Susan Graham (SG), and Dr. Elise Vanderelst (EV), and project manager Dr. Clara Agutu (CA).

Measures

Data was derived from a total of 22 participants enrolled in the longitudinal qualitative study. Of those, we analyzed data from 16 participants based on the following eligibility criteria: interviews were completed at baseline and 6 months and viral loads collected at baseline and at 6 months. Study participants completed a short computer-assisted personal interview (CAPI) or computer-assisted self-interview (CASI) on an electronic tablet. Data collected from the quantitative questionnaire included demographic information, beginning of illness, history and patterns of sexual behavior including number of partners, detailed inquiry of sexual behavior with last 3 partners, timing (concurrent vs sequential) of sexual history, transactional sex, and same-sex relations; these quantitative data were not analyzed as part of this thesis.

Qualitative in-depth interviews were conducted to gain insight on barriers and facilitators to ART in the study population. The subject matter of the interviews included knowledge and experiences regarding: HIV transmission risk and reduction, acute vs. prevalent HIV, ART, health maintenance, and self-advocacy and perceptions of assisted partner notification and disclosure to partners. The interviews also covered HIV acceptance and participant perceptions and experiences with their diagnosis. Questions explored the effects of receiving an HIV diagnosis and potential challenges faced by recently diagnosed HIV patients, including with partners, sexual behaviors, reproductive health, access to care, initiating and adhering to treatment. One of the main objectives of the interview for newly diagnosed individuals was identifying necessities and gaps in facilitators and barriers to and experiences with ART treatment challenges such as acceptance, coping with ARTs, finding healthy coping mechanisms for physical and mental health [18].

Data Analysis

For the purpose of this study, we will not distinguish between AHI or prevalent HIV due to sample size limitations; both groups will be classified as recently diagnosed individuals. The study utilized NVivo version 12 to identify and categorize the attitudinal and contextual factors that affect HIV status acceptance and treatment uptake among this demographic. Data was examined through qualitative data analysis methods including open coding, axial coding, and comparisons. The study utilized a grounded theory approach as concepts and categories were formed during data analysis. All transcripts were analyzed in complete form in the primary stage of open coding to create a total of 21 codes. The next stage involved rereading the transcripts and merging 21 preliminary codes into 5 final codes (see Table 1). The following codes were examined to identify factors associated with ART adherence: HIV diagnosis experience and emotional impact; Immediate treatment; Treatment adherence. The final stage of axial coding involved connecting open codes and examining the relationships between different themes. The final stage of analysis involved a trajectory approach to examine the longitudinal data for individual changes in perceptions of status, experiences, and viral load over time. This trajectory approach included a focus on how participants explained acceptance and reoccurring themes related to acceptance in the codes.

Once coded, a matrix was generated to depict individual participants' experiences with regard to HIV status acceptance over time, based on their 2-week and 6-month interviews (see Table 3). Individual participant viral load data (collected at 2-weeks and 6 months) were included in this matrix to provide insight into patterns between HIV status acceptance and clinical outcomes. Using a chronological matrix facilitated the search for patterns or positive relationships between HIV status acceptance and viral load.

Ethical Considerations

Tambua Mapema Screening Programme was approved by the KEMRI Scientific and Ethics Review Unit (No. 3280), the University of Washington Human Subjects Division (STUDY00001808) and the Oxford Tropical Research Ethics Committee (Protocol 46-16). Written informed consent was obtained from all participant through all phases of the study. Patients were reimbursed for their participation based on local norms in Kenya (KSh 350-500, or US $3.26-$4.68); the variation in amount was based on time and type of visit.

Results

Patient results and characteristics

Sixteen participants who were interviewed and whose viral loads were collected at baseline and at 6 months are included in the final sample. Table 2 presents characteristics of the sample. A total of 32 interviews with 16 participants were conducted, and included nine females, with a mean age of 26, and seven males, with a mean age of 30. All participants were religious, with the majority identifying with Christian religions. About 75 percent of the participants had below or had completed primary education. All participants but two (one woman and one man) were virally suppressed at month 6.

Overall, qualitative narratives revealed that the majority (n=13) of participants had strong negative psychological reactions to their initial diagnosis. By the 6-month interview, however, all but one participant described improved acceptance of their HIV status. Three factors promoting HIV status acceptance were described: (i) Social support and community, (ii) religious faith, and (iii) biomedicine (each theme is elaborated upon below). In addition, a fourth theme suggested that the positive shift in increased HIV status acceptance factors was linked to adherence behaviors and was also reflected in increased viral load (VL) over time. Where relevant, improved trends in participant VL between 2-week and 6-month assessments are reported in text below. Based on participant responses, there was no pattern of adherence according to participants' sex, age, or place of residence.

Identifying a support system and community contribute to HIV status acceptance

The recognition of a support system or a sense of community was central to participants' HIV-status acceptance and improved adherence.

> "During the beginning of the process when I was a bit depressed, I wanted to get the best. I was constantly looking for advice like everywhere, my friends, even if I would ask indirectly. But I would take the thing they would say into consideration - my family, sometimes even on YouTube channels, social gatherings. So, I think it has been helpful to open up my eyes to the world at large." (Study no.6, 20-year-old male, recently diagnosed prevalent HIV, month 6).

The participant initially responded to their diagnosis through shock, thoughts of death, and a sense of defeat in continuing with his life plans. The identification of support groups helped to widen his perspective and find purpose.

> "I picked that the aspect of helping people is very important in life, helping people is very important in life to the extent that maybe it is one of my … right now… it was not in my mind but right now I have an aspiration to help to change people life, to make people happier from people who are maybe depressed to people who are … maybe make them better." (Study no.6, 20-year-old male, recently diagnosed prevalent HIV, month 6).

The support systems had a vital role to play in fostering a sense of purpose. The participant abandoned the perspective of giving up on life and instead chose a new course of life revolving around helping people who may be experiencing mental health challenges. In addition to a shift in perspective, this person experienced a decrease of VL from 4.74 copies/ml at baseline to less than 1.60 copies/ml at 6 months.

Other participants noted how gaining a sense of solidarity with others in their community minimized the sense of isolation and encouraged the use of HIV medications and a commitment to life:

> "I remember being very sad at the beginning and after knowing that I am not alone and there are other people who are suffering from the same disease even within my community, that gave me a sign of relief. And since discovering that, I decided to take my medication and continue to live my life." (Study no.7, 23-year-old female, week 2)

The availability to connect with other members in the community who were coping with the disease transmitted a feeling of hope to newly diagnosed individuals and a sense that they can also continue with their regular life if they followed the regimen. Notably, for the participant noted above, their VL declined from 4.74 copies/ml at 2-week assessment to less than 1.60 copies/ml at 6-month assessment.

Religious faith and HIV status acceptance

Religion was a recurring theme throughout participant's narratives. Patients' belief in a higher power assisted with the psychological toll of receiving an HIV diagnosis. One man who relied on faith explained:

> "I left home to come to the hospital, and I prayed to God that I will accept whatever outcome. After the outcome, I accepted and was satisfied, it cleansed my soul and to continue with medication." (Study no.3, 30-year-old male, recently diagnosed prevalent HIV, week 2)

The concept of soul cleansing implies that the participant had his worries mitigated through prayer. Through the reliance on God, the participant was able to accept his status and continue with proper uptake of care. As shown in Table 2, this participant's VL decreased from 4.9 copies/ml to undetectable.

Participants who had strong faith systems described the belief that God ultimately decides everything, which relieved them of the psychological and internalized burdens related to their status. One participant noted that his faith in God led to not just an acceptance of his diagnosis but self-acceptance, as he believed that it was not in his own power to judge himself or decide his fate. This worldview led the participant to cast aside negative emotions that were self-deprecating. The participant describes below this process of realizing his faith and its impact on self-acceptance:

> "It is like I had told you, that there was some difficulty at the beginning but you

> must slowly … you have to take caution, have self-acceptance, you wait for God’s days when they are due. Because there is no one who can pass judgement for themselves, for me to say I will die tomorrow or the day after tomorrow. On my side, I was feeling a certain bitterness. However, later I came to think about it and told myself even if I am bitter to myself it is not good. God is the one who knows … although I keep thinking of how I might have gotten it. I obviously had to accept myself.” (Study no.4, 24-year-old male, recently diagnosed prevalent HIV, week 2)

Despite the strong declaration of faith and acceptance, the participant above had minimal change in VL, from 4.5 copies/ml at 2-weeks to 4.47 copies/l at 6-months. However, this persistent VL may have been due to a host of reasons that are not documented in this research including different biological response to the ARTs or resistance to the medication.

Individuals who turned to faith after diagnosis began to take ARTs in the hopes that God would increase the effectiveness of the medication. One participant combined his belief and trust in biomedicine and God and held out faith that he could be cured from HIV. Christianity gave him purpose, alleviated feelings of being *“sentenced”* and relieved him of internalized stigma through the perspective that his diagnosis was ultimately God’s plan for a greater good.

> “Yeah, I am taking my medication because you know when… I came to know about my HIV status you know it pushed me closer to God you know, so I have a lot of hope in God more than in myself, so for this I can say I trust in God most.
>
> You know I have no problem taking the drugs and you know on my spiritual side, I am prime so I do believe God will eventually pay me so I will take my drugs till that time and if there is no cure that can be found with the doctors and the research and everything, I do believe God will eventually heal and take me out of this situation, yes that is hope on

> mind, that is where my trust is." (Study no.5, 36-year-old male, recently diagnosed prevalent HIV, month 6).

Biomedicine and improved quality of life and health

Participants noted many self-stigmatizing attitudes after initially receiving their HIV diagnosis, including not feeling human, feeling embarrassed and condemned. Counseling and the availability of medication provided a strong motivation for individuals to accept their status and begin care. Participants who were breadwinners in their family described an amplified motivation to remain healthy, in order to provide for the family. Another driving factor related to the use of ART medications was the desire to be and appear healthy to minimize worry about experiencing severe symptoms among family members.

> "What made me accept is the pain I was in and the fear of getting sick to the extent that it will affect my family where they will not have peace for how weak I am … basically having the bad symptoms that HIV people have during the late stages of the disease. Generally, the medication has had a positive effect on me, especially health wise. It also has made my mind relax in some way.
>
> Because when I was tested and was told I have the virus if it were not for using the drugs, I would have killed myself because since I was in school, I had said at the moment I will have the virus … once I know I have the virus, that will be my last day, I will kill myself. In whichever way, I would have killed myself. But the way I got information there I said it is okay let me continue." (Study no.1, 24-year-old male, recently diagnosed prevalent case, month 6).

The relationship between level of acceptance and self-stigmatization on adherence

Factors associated with HIV status acceptance were linked to medication adherence. Participants who moved towards accepting their status developed a new perspective on being HIV-positive. Individuals who were able to develop a new outlook of HIV explained that when faced with stigma, they were able to perceive HIV as a "normal" disease that need not convey a sense of shame or stigma and that is not necessarily a fatal condition. One patient noted *"doctors say HIV is just a condition and it's manageable, but cancer is different."* Additionally, they avoided internalizing negative stereotypes by distancing themselves from individuals who express stigma and by adhering to their medication regimen. These mechanisms protected them from the internal negative effects of discrimination and were reflected in achieving a non-detectable viral load:

> I: "Okay, and when you were telling your friend HIV is a condition and it's not as bad as cancer how does it make you feel? How does it encourage you?" (interviewer)
>
> R: "It encourages me because with HIV, if you are taking your meds properly and the way you are taking them you can live as long as God has planned for you." (Study no.13, 32-year-old single mother, newly diagnosed chronic HIV, month 6).

Another participant exhibited attitudes of self-acceptance immediately after diagnosis. He shared a similar perspective of HIV being a normal disease.

> "I have not been worried at all. This is normal for all human beings and this disease is not affecting dogs or anything of that sort, this is our disease and so I am not worried at all." (Study no.9, 39-year-old male, recently diagnosed prevalent HIV, month 6).

The participant revealed no attitude of self-stigmatization. The high level of self-acceptance and a perspective of HIV as a normal disease facilitated a positive attitude towards diagnosis and was concomitant with a VL decrease from 4.14 copies/ml at 2-weeks to less than 1.60 copies/ml at 6-months.

On the contrary, one participant combated internalized stigma by refusing to succumb to the role of someone who is sick. In this specific case, the participant was able to develop a positive relationship with her ARTs by not giving in to the idea of being “sick”. This participant reported feeling *“disturbed”* and *“angry”* and experiencing regret at getting infected but hiding her reaction upon diagnosis. The wide range of negative emotions impacted the participants’ mental well-being which led to the development of this mindset a coping mechanism:

> “when you have it in your mind that you are not sick, then it gives you an easy time, you will not find it difficult to take medication. I tell myself, in order for me to have peace and for me to adhere well to mediation, I have to set my mind.” (Study no.15, 26-year-old female, newly diagnosed acute HIV, month 6).

This form of coping might have produced a sense of self-efficacy to adherence to ART. Indeed, this participant showed a decrease of VL from 6.91 copies/ml at 2-weeks to below 1.60 copies/ml at 6-months.

Discussion

This study provides support for the role of HIV-status acceptance as an important part of the pathway from learning one’s HIV status to managing adherence to ART. Themes that were linked with HIV status acceptance included presence of a supportive community, perceived solidarity with other PLHIV, biomedicine and religion and faith. Narrative findings underscored the importance of connection with individuals who share and understand the burden and reality of living with HIV, which could facilitate improved knowledge on ARTs and increased adherence among those who are newly diagnosed. The positive shift in status acceptance allowed participants to move away from internalized stigma and feelings of condemnation and develop a more positive attitude of themselves and their relationship with their treatment. Additionally, the availability of counseling services created a safe space for participants and created an environment that encouraged and enabled adherence. Future research can analyze the ways in which internalized stigma and its psychological effects including fear and anxiety can impede adherence to antiretrovirals and further demonstrate the linkage between support systems, HIV status acceptance and positive adherence.

Research has found that stigma is an obstacle to finding social support [21]. Lack of social support has been shown to be a barrier to ART adherence. Identifying a source of social support signified that individuals felt less isolated, and the sharing of experiences made it difficult to be in denial of one's status [20,24]. A study in Botswana found that having a confidante was vital in developing a positive outlook and adapting lifestyle changes such as adherence that were beneficial to health. Additionally, being a part of a social network such as church, sports teams, or a support group indirectly improved ART adherence [20]. Previous studies have found that the psychological toll of diagnosis and mental illness can impede adherence [24,25].

Findings from this study supports previous research that found that internalized stigmatizing attitudes were a significant barrier to proper treatment uptake [20,21]. The Tambua Mapema study incorporated counseling, an enabling factor in educating participants on the importance and benefits of ART adherence. Counseling normalized HIV in the perspective of participants. In post-counseling assessments, several respondents noted that HIV was like any other disease and when ARTs are adhered to, individuals can live a normal and healthy life. Participants in the study described how support systems in the form of counseling, religion, church networks and present partners helped them continue their uptake of counseling and ARTs.

The findings demonstrate the need for HIV care guidelines to focus on mental health among newly diagnosed people. Diagnostic, preventive, and treatment guidelines must be culturally tailored to meet the needs of the target population. Immediately offering ARTs to individuals' post-diagnosis is important in increasing ART uptake but there needs to be a focus on health systems strengthening to enhance support/counseling interventions for newly diagnosed PLHIV in this region. Health systems strengthening can ensure retention of healthcare workers and increased training for healthcare workers to provide holistic care to PLHIV.

Limitations

There are limitations to the study. The sample size of 16 limits the generalizability of the findings. Furthermore, due to the sensitive nature of the interviews, there is a risk of biases in the form of underreporting of stigma and discrimination. Qualitative interviews were conducted in the context of participation in a longitudinal cohort study, in which access to trained medical services and provision/monitoring of medication was ensured, which does not reflect general availability and quality of services for PLHIV in this region.

Reflection and Positionality

The data was collected by the research team led by Dr. Eduard Sanders, Dr. Susan Graham and Dr. Elise Vanderelst at KEMRI – Wellcome Trust in Kilifi, Kenya. I was not involved in the data collection process due to my position as a full-time student. Originally, I was supposed to travel to Kilifi to assist with the NVivo qualitative data analysis however due to COVID-19, all analysis was conducted remotely in New Jersey. My analysis concentrated on four different sectors: barriers and facilitators to ART adherence, barriers, and facilitators to

PrEP uptake and adherence, the evolution of relationships among sero-concordant and sero-dicscordant couples and my primary thesis focus of HIV status acceptance.

Although I had no direct contact with the research participants, the depth and quality of responses have enabled me to gain a better understanding of one the most crucial patient-related factors to ART adherence. Prior to the research, I had a limited understanding of the psychosocial factors that affect adherence and my contribution to the Tambua Mapema research has expanded my knowledge on the role of stigma, self-stigmatization, support systems and religious faith on adherence. I hope that my contribution adds to the growing body of work on individualized support in HIV-management and care.

Conclusion and Future Directions

This study demonstrated the association between HIV status acceptance and ART adherence. The identification of a support system and community assisted individuals in shifting their perspectives and fostered a new sense of purpose that facilitated with coping and accommodating HIV status. Having a support system reduced feelings of isolation and internalized stigma and facilitated a healthy relationship with ARTs. Furthermore, being in a supportive environment enabled participants to feel like they could live a normal life if they follow their regimen. Another major enabling factor in HIV status acceptance was faith and spirituality. Participants reported relying on faith to deal with the psychological burden of their diagnosis. The belief that a higher power ultimately decided their fate relieved the burden of their diagnosis and aided individuals in casting aside self-stigmatizing attitudes and taking their medication. The availability of ARTs also assisted participants in accepting their status as medication can allow PLHIV to live long and healthy lives. The ability to live long and healthy was a key motivation for individuals to adhere to care especially in the case that the individual was the primary breadwinner in their family. Factors associated with HIV status acceptance were connected to ART adherence. Individuals who accepted their status displayed less self-stigmatizing attitudes and adhered to their medication.

Kenya has made significant strides in improving ART access by adopting the WHO's recommendations to immediately offer treatment to individual's post-diagnosis. However, the results of this study indicate the necessity of programs/service providers to be vigilant of individuals who have difficulty accepting their status. Research has shown that there is a relationship between denial of status and poor ART adherence. Healthcare providers must consider the role of acceptance in uptake of care. This may require a focus on health systems strengthening and increasing the number of skilled providers. A possible solution is training healthcare workers to provide holistic treatment to recently diagnosed individuals integrating ART prescription and culturally tailored counseling services. Participants in this study noted that counseling was important to their acceptance and adherence to their medication demonstrating the significance of provider support post-diagnosis. Providers can be the key to sustained ART adherence through their role in educating participants on HIV, increasing patient trust in biomedicine, giving participants hope in managing their status and overall, assisting patients in accepting their status.

These findings highlight the necessity for policy makers, research scientists and healthcare providers to implement care guidelines and identify strategies to distinguish forms of denial and coping among recently diagnosed individuals. Doing so can facilitate increased targeted and individualized support for PLHIV.

Table 1: Codebook for Data Analysis

1. Psychological Effect
1.1.Shock and denial 1.2.Feelings of condemnation/being punished 1.3.Anger and self-blame due to relationship unfaithful partner 1.4.Sadness, guilt, blame and anger 1.5.Positive mindset/perception of HIV as any other disease
2. Medication
2.1.Difficulty accepting and adhering to daily regimen 2.2.The availability of effective medication as a strategy for acceptance 2.3.Acceptance of status and initiation of ARTs to reduce symptoms and live a normal life
3. Prioritization of family
3.1. Accepting HIV status in order to adhere to medication and provide for family 3.2. Accepting HIV status in order to adhere to medication, remain physically healthy and avoid worrying family
4. Religion and Spirituality
4.1.Faith in God/believing diagnosis as part of God's bigger plan 4.2.Prayer as a coping mechanism for psychological effects
5. Support system
5.1.Feeling a part of a community

Table 2: Characteristics of interviewed participants; viral load- and partner testing outcomes, Tambua Mapema Plus Trial, coastal Kenya, 2017-2020

Study no.	Gender	Age	Religion	Education	Week 2 VL	Month 6 VL	Month 6 VL
1	Male	24	Muslim	Secondary Completed	4.76	Not detected	Suppressed
2	Female	27	Christian	Below Primary Completed	4.22	Not detected	Suppressed
3	Male	30	Catholic	Primary Completed	4.9	Not detected	Suppressed
4	Male	24	Protestant	Some secondary completed	4.5	4.47	Not suppressed
5	Male	36	Protestant	Primary	4.21	Not detected	Suppressed
6	Male	20	Muslim	Higher education	4.85	<1.60 copies/ml	Suppressed
7	Female	23	Christian	Primary	4.74	<1.60 copies/ml	Suppressed
8	Female	24	Protestant	Below primary	2.96	Not detected	Suppressed
9	Male	39	Protestant	Below primary	4.14	<1.60 copies/ml	Suppressed
10	Female	26	Muslim	Below primary	6.06	<1.60 copies/ml	Suppressed
11	Female	19	Catholic	Some secondary	Not detected	Not detected	Suppressed
12	Male	39	Muslim	Below Primary	5.47	<1.60 copies/ml	Suppressed
13	Female	32	Protestant	Primary	4.23	Not detected	Suppressed
14	Female	26	Protestant	Below primary	5.01	7.53	Not Suppressed
15	Female	26	Christian	Higher education	6.91	<1.60 copies/ml	Suppressed
16	Female	28	Catholic	Primary	6.42	<1.60 copies/ml	Suppressed

Table 3: HIV Status Acceptance and Viral Load Matrix

Themes	**Week 2**	**Month 6**
Psychological effect, biomedicine, family	Study no.1: Initial **fear** of not achieving life goal of joining the Kenya Defense Forces. **Feelings of being subhuman**. In the same interview, the participant stated they accepted their status. The participant wanted to adhere to their medication because they did not want the deterioration of their health to affect their **family.** (VL 4.76)	Participant felt more hopeful due to the availability of **medication** that will allow him to live a normal life, be healthy and **provide for and educate his child**. (VL not detected) The participant's viral load is not detected meaning there is less HIV in his body.
Psychological effect	Study no.2: The participant reported **feeling "bad" and "embarrassed"** but there was nothing more to do. (VL 4.22)	The participant reported that she did not regret her diagnosis because prior to knowing her status and **taking her medication**, she was ill and in pain. (VL not detected) The participant's viral load is not detected meaning there is less HIV in her body.
Faith	Study no. 3: The participant explained that they accepted their status because they **prayed to God** prior to testing. According to them, prayer "cleansed [their] soul" and allowed them to start their **medication**. (VL 4.9)	He reported feeling better since getting diagnosed and **regularly taking his ARTs**. (VL undetected) Less HIV in the blood.
Psychological effect, faith	Study no. 4: Initial **shock** followed by acceptance because they believed that ultimately **God** decides everything including when a person dies. The participant accepted **medication** shortly after diagnosis. (VL 4.5)	The participant reported feeling like he was "a **walking dead**" for his first two months but those feelings have faded because "only **God** knows." As a result, he stopped worrying and started taking his **medication**. (VL 4.47) His responses did not reflect in his viral load which only slightly dropped.
Psychological	Study no. 5: Initial feelings of	The participant started **praying and**

effect, faith	bitterness at ex-wife and regrets of testing positive. The participant reported feeling "**sentenced**." (VL 4.21)	**fasting** and that helped reduce his fear and motivated him to take his **medication**. (Not detected) Positive change in acceptance reflected in VL.
Faith, social support	<u>Study no. 6</u>: The immediate reaction was shock followed by thoughts of death. The participant stated that his **Muslim faith** consoled him. "There is a way our religion prepares you, that death can occur to you at any time." (VL 4.85)	According to the respondent, he was initially depressed but after receiving **support** and seeking advice indirectly from family, friends and YouTube, his **perspective** on life changed. He now wants to help people who are depressed to "get better" and feel happier. (VL <1.60 copies/ml) Positive shift led to a decrease in VL.
Psychological effect, Social support	<u>Study no. 7</u>: Feelings of **loneliness, heartbreak, and suicidal thoughts** after diagnosis. The participant then realized that **there are other people suffering from the disease** even within his own community and this gave him a **feeling of relief.** They also started taking **medication because they have children** to take care of. (VL 4.74)	Feeling like he is **not the only person suffering from HIV** helped him accept his status and take his **medication** (VL <1.60 copies/ml) Positive shift led to a decrease in VL.
Psychological effect, Counseling	<u>Study no. 8</u>: Feelings of **sadness.** (VL 2.96)	The participant revealed that prior to the Tambua Mapema Programme, she had tested positive and had not accepted her status nor did she fully understand the importance of taking medication. **Knowledge** has helped her accept and adhere to her medication. (VL not detected) Decrease in VL.
Faith	<u>Study no. 9</u>: The participant reported that he was not worried since **HIV is now normal and God is the one who decides fate**. "that disease	The participant's sentiments remained the same. He mentioned HIV is not as fatal as cancer. "I have not been worried at all. This is normal for all human

	doesn't infect animals but human beings. And sometimes you cannot compete with God's plans." (VL 4.14)	beings and **this disease is not affecting dogs or anything of that sort, this is our disease and so I am not worried at all**." (VL <1.60 copies/ml) Accepted status since diagnosis. Viral load decreased significantly.
Psychological effect	Study no. 10: Participant had mixed responses. She reported not being worried and accepting her status because she was aware of her husband's infidelities. She also reported being in **denial** when it came to taking ART's and eventually accepted because of her experience witnessing her late husband's deteriorating health. (VL 6.06)	The participant reported feeling okay and having no problems. She stated it is **better to be aware of HIV status** and taking ARTs instead of getting ill. (VL <1.60 copies/ml) Decreased viral load.
Psychological effect	Study no. 11: The participant reported feeling **disturbed** because they **did not know how they contracted HIV** but ultimately decided to take **medication**. (VL Not detected)	The participant reported fairing on well and **taking her medication**. (VL Not detected). No changes
Psychological effect, Biomedicine	Study no. 12: Initial feeling of being **"heartbroken."** The participant reported feeling hopeful that he would be in good health because of advice from healthcare providers and being a "strong man." He also cited **the availability of drugs and HIV being an illness like any other**. "But having the virus is just like having a common illness provided you take the drugs, you live well, you eat well, and you will live normally." (VL 5.47)	The participant shared sentiments that **HIV is like any other disease therefore he avoided stigmatizing himself.** He reported accepting himself, being open, social, and feeling relaxed. (VL <1.60copies/ml) Positive change. Significant decrease in VL.
Psychological effect, faith, biomedicine	Study no. 13: The participant stated **she hadn't accepted her status because she had been faithful to her**	The participant reported splitting with their partner because they had been physically abusive and isolating from

	partner who had been unfaithful on multiple occasions. She has been taking her medication however sometimes she feels like stopping because it feels like her **life has been a waste.** There had been a huge psychological effect on the participant as **she reported crying regularly**. She tried to remember she is not the only one, but it will take time. Her partner had been encouraging her to continue treatment. (VL 4.23)	most of her friends because they unknowingly negatively discussed HIV around her. Despite this, the participant had a positive shift in attitude as she felt encouraged to t**ake her medication and live a long life.** The participant stated that HIV was not fatal like cancer*. She has also been relying on **prayers and the bible** to cope with her diagnosis. (VL Not Detected) Positive shift in acceptance and viral load.
Psychological effect	Study no. 14: The participant was **stressed** about being **alone** however she did not struggle with acceptance; she knew she was positive because her husband had died of the virus. (VL 5.01)	The participant **blamed** herself for getting infected. She stated that her status was an impediment to finding a partner however she had **accepted her status as long as she was in good health** (VL 7.53) Increase in VL.
Psychological effect, faith	Study no. 15: The participant reported feeling **"disturbed,"** especially when in isolation. She expressed **regret** at getting infected but ultimately only **God knows**. The participant chose to take the medication for the sake of her health. The participant's response encompassed a mixture of emotions ranging from **blaming her partner, anger, and feeling disturbed**. (VL 6.91)	The participant expressed that her **denial of her status allows her to take her medication**. The participant stated that starting her medication early has allowed her not to face any challenges as she is physically healthy. (VL <1.60 copies/ml) Viral load decreased significantly.

Psychological effect	<u>Study no. 16</u>: Post-diagnosis, the participant reported feeling **afraid** and like it was the **end of the world**. (VL 6.42)	She reports sometimes feeling **regret for acquiring HIV**, but she has realized that she could live without worry. (VL <1.60 copies/ml)

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Appendix: Interview Schedule

IMPACT OF A NOVEL HIV-1 RNA TESTING INTERVENTION TO DETECT ACUTE AND PREVALENT HIV INFECTION AND REDUCE HIV TRANSMISSION –

TAMBUA MAPEMA PLUS

Individual In-depth Interview Topic Guide for HIV-Positive Index Patients

(Newly Diagnosed with AHI or Prevalent HIV Infection)

Study number :___________________________________

Interviewer :___________________________________

Site :___________________________________

Date :___________________________________

Start :___________________________________

End :___________________________________

1. Introduction:

In this interview we would like to ask your understanding of how you came to be diagnosed with HIV and how you have been coping with the HIV infection since the day you received your HIV test results. We would appreciate to learn from your experiences regarding possible challenges, needs and gaps, especially in relation to starting and adhering to immediate treatment, and notifying your partner(s). At the same time, we would like to ensure that you have adequate understanding of key information and provision of necessary support.

With your permission, we would like to digitally record the interview for later transcription and translation to English for analysis. All information will be kept strictly confidential, and, as respondent, you will never be identified with any comment you make.

2. HIV diagnosis experience and emotional impact (Climate setting)

- How are you feeling? How have you been from diagnosis? How did you get through it? Are you comfortable talking about your experiences? Any fears /challenges?
- Please can you tell me whether you had been tested for HIV before being tested during the implementation of *Tambua Mapema* study? And if so, why, where, and how often?
- Generally speaking how has your life changed since you were diagnosed?

3. Study experiences

- How did you end up being enrolled in the study?

  (*Probe for the approach; how participant felt being told he/she may have HIV because of the presenting symptoms; how did he/she interpret the testing invitation extended*)

- What made you to accept to get tested for HIV?

  (*Probe for motivating factors; ever suspected he/she might be HIV positive*)

- What information were you given when you were being asked to take a HIV test?

(*Probe for: how were you told; how did you take it; how did you interpret it; what was the impact?)*

- How did the enrolment process go?

  (Probe for sufficient preparedness; information given and how received; the impact of information given)

- How did you get your test results, and what was that experience like?
- Do you have any suggestions to change?

4. General knowledge of HIV infection

- What do you know about HIV in general?

  (Probe for HIV-transmission – HIV progression – source of information)

For those diagnosed with AHI

The very initial phase of HIV infection is called Acute HIV Infection Phase. People often experience symptoms during this period. Symptoms of acute HIV infection can include fever, body aches, fatigue, sore throat, diarrhea, and genital ulcers, swollen lymph notes. Not all these symptoms may be present, and many people with acute HIV infection don't have any symptoms. However, if a person does experience symptoms, they may last for a few days or up to four weeks, then disappear without treatment. Given this, and reflecting on your own experience [where you were diagnosed with these kinds of symptoms and acute HIV infection OR where you were diagnosed after you had already developed antibodies so probably after the acute infection period], how best do you think we can inform people about the strong association between HIV acquisition and flu-like symptoms.

- What did you feel when you were told you have been diagnosed with AHI?

  (*How did you understand that? What was your reaction? What first came to your mind?)*

- What is your experience of the acute HIV infection?

  (Probe for symptoms and symptom recognition; had having an acute HIV infection crossed your mind?

- What have you learned about acute HIV infection? *(Probe for HIV transmission; change of sexual behaviour – source of information)*
- What have you understood about how infectious AHI is?

  (Probe for health significance; elevated infectiousness; comprehension of being acutely infected; what is the source of information?)

- How best, do you think, can we inform people that these kinds of symptoms could be related to HIV?

  (Probe for awareness raising strategies; how different should the information be communicated)

For those diagnosed with prevalent HIV

- What is your experience with HIV infection?

  (Probe for symptoms and symptom recognition if were ever experienced prior to diagnosis; had having HIV infection ever crossed your mind?

- Had you ever tested before for HIV?

  What were the results?

- In most cases, people when they test for HIV and test positive they are likely to keep the results to themselves and not disclose to anyone or get enrolled into care. Might you have known your status earlier but probably you were afraid to accept or disclose the results?

  What actions did you take? How long ago was that? Why did you not link into care at that time?

- What do you know about HIV infection generally? *(Probe for HIV transmission; change of sexual behaviour – source of information)*

- You ended up being diagnosed with HIV because of symptoms that you had presented at the health facility and you were enrolled in Tambua Mapema plus study. What did you understand about the importance of early diagnosis?

  (Probe for AHI infectiousness, public health significance; comprehension of AHI; what is the source of information?)

5. **Sexual behaviou**r

HIV diagnosis is a big shock and people deal with it differently. It is common to experience feelings of blame, and anger. These are completely natural and understandable.

- Can you tell me about your experience with being diagnosed with HIV infection?

What were your feelings (your gut level feelings) when you found out that you had HIV infection? *(Probe for any experiences that really stood out)*

- What action do you think put you at risk getting the infection?

  (Probe for unprotected sex – also other risky behaviours including, the use of drugs and/or alcohol -assuming your partner is not infected based on appearance; multiple sex partners; anal sex;)

- Who do you think might have infected you? Why?

  (Probe for: did you think having sex with them at the time was risky in any way? man or woman; steady or casual sexual partner;)

- Do you know his/her HIV status?
- Do you think he/she know his/her HIV status?
- Now that you've been diagnosed with HIV infection, will you change your behavior in any way? *(If so, probe for how it will change; if not, probe for why it will not change)*
- If female: Do you use any family planning method? Do you want to get pregnant? How has that changed since your diagnosis?

6. Sex partners and partner notification

- Will you tell the person you think infected you that you have just been diagnosed with HIV?
- If you do tell this person, how do you think it might affect your relationship?
- If this person is not already aware he or she is HIV-infected, do you think he/she will be willing to get tested? To start medications? *(Probe for options for contact tracing, if there are any) or*

- *(If already partner notification done)* How was your partner notified of the possibility of him/her having had a risk exposure with an infected partner?
- How did he/take it? Did he/she accept to get tested and what was the outcome?
- Have you shared with anyone else the fact that were recently diagnosed with HIV infection?
- Have you shared your HIV status with any other sex partner(s)?
- If so, whom have you told, or if not, whom do you want to tell and why do you want them to know? How much have you shared / are you ready to share. How much are they ready to hear?
- Would you require any assistance in notifying your partner(s) about the need for them to test for HIV?
    - *Clarify that assistance can be given without revealing the patient's identity*
- How has / will disclosing your HIV status affect you, and how has / will it affect the people you tell? (challenges)
- Could you tell us some ways that helped (or can help) you disclose / invite your partner(s) for testing?
    - *Probe on the perception of assisted partner notification, including barriers and facilitators*

7. **Immediate treatment**

- What do you know about HIV medication?

  (Probe for expressions/opinions, including misconceptions of ARVs; Insights on ART-adherence)

- Have you had any experience with ARVs like PEP (medication taken after a high-risk exposure), PrEP (medication taken to prevent HIV), or in relation to PMTC (medication taken to prevent transmission from mother to child)? If so, can you tell me more about it?
- How do you think HIV treatment is fitting/will fit into your life?

  (Probe for fears; any foreseen challenges to ART-uptake / adherence; what are the current facilitators to support ART uptake)

- What are your goals for taking HIV treatment? Why are you taking HIV meds? (If not taking, probe why not?)

  (If on treatment) why did you accept to start treatment?

  (Probe for impact of HIV treatment, desire for children/pregnancies, prevention etc.)

- What do you understand about putting someone on treatment immediately after diagnosis ("immediate treatment"). Why is this done? What are the advantages? What are the disadvantages?
- What has changed since you were put on treatment?

(Probe for: disclosure of status; relationship with partner(s); social support; perceived stigma; mental health status; gender based violence)

- What would you say are the risks and benefits of starting treatment early?

- What are your own benefits/risks so far?

8. Treatment adherence

- How do you find the treatment?

  (Probe for ART-beliefs such as 'effectiveness'; transmission risk; need for protection; etc.)
- What reminds you to take your medicine every day?
- How hard or how easy is it to take your medication every day, without missing a dose?
- What would be helpful for you? (facilitators for optimal adherence)
- What challenges have you encountered? Have you had side effects? Any other problems?
- What would you say are the reasons for some individuals with HIV in the community who are hesitant to start ART?
  - What about reasons that some individuals with HIV in the community give for not continuing with ARVs or failing to take their medicines everyday as is required? (*probe about: financial barriers, socio-cultural factors, experience at ART centre, patients' beliefs, attitude and behaviour, stigma and discrimination*)
- Generally, what would you say has been the impact of immediate treatment on your life? Do you feel you can maintain it -taking the medicines every day for the rest of your life?

  (Probe for employment, household welfare, relationships)

9. Support

- What has been the most challenging for you since you learned about your HIV status?
- Have you been thinking of what can be helpful to do for your health?

  (Probe for previous ways of coping with a crisis – changes in lifestyle)
- How do you get what you need in terms of support?

  (Probe for emotional and social supports that people with an infection can access)
- What do you think will be helpful in overcoming these barriers?
- Do you think there are specific actions that you will take to protect your health? What actions will you take?
- Do you feel empowered to ask questions and get the information you need from your health care providers? Why or why not?
- How will you ensure commitment to the actions that you decide to take? E.g. risk reduction, treatment, disclosure
- What role can your partner (and / or family) play in helping you cope with the results?
- What role as a HCW can we play? How can we help you adjust?

10. Other comments and recommendations

- Through the *Tambua Mapema Plus* study you discovered your HIV status; is there anything you would like to share with me about the study and your experience in the study?

Kindly thank the volunteer for sharing his / her information.

END