



Flipping the Script: Description of Needs and Personality Traits of People Living with HIV in Malawi and Zimbabwe

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ABSTRACT

Effective HIV prevention programs require a combination of behavioral, biomedical and structural interventions. Behavior interventions address the cultural contexts within which risk behaviors occur and aim to stimulate uptake of HIV prevention services. This research seeks to understand the relationship between the underlying needs people living with HIV (PLHIV) have from treatment, their personality traits, and how it influences treatment behavior. The overall focus is to develop the most successful campaign across sub-Saharan Africa, but primarily in Malawi and Zimbabwe. This was a cross-sectional quantitative study where interviews with 786 adult PLHIV and 504 healthcare workers (HCWs) were conducted via Computer Assisted Telephone Interviewing (CATI) in Malawi and Zimbabwe. PLHIV in Malawi and Zimbabwe are typically adherent to their medication. For PLHIV the power of the pill is scary and controlling but also liberating. Early associations with HIV tend to derive from negative comments being made about PLHIV, which fosters a sense that PLHIV are not accepted by the wider community. HCWs in Malawi and Zimbabwe do prioritize emotional support but have limited capacity to provide wider pastoral care. PLHIV, and HCWs, have good awareness of what viral suppression is, but do not always understand what it truly means. Utilization of communication channels that are acceptable and trusted will be key to successful HIV literacy treatment campaigns.

Keywords: PLHIV, healthcare workers, campaign, viral suppression, communication channels.

INTRODUCTION

HIV remains a global health crisis, in 2020, there were 37.7 million people living with HIV, including 10.2 million who were not on treatment, 1.5 million new HIV infections and 680 000 AIDS-related deaths (1). Effective HIV prevention programs require a combination of behavioral, biomedical and structural interventions (2). Four key issues that are holding back progress in a holistic approach are gaps in political leadership, legal and policy barriers, gaps in prevention financing, and a lack of systematic implementation of combination prevention programs at scale (3). The process of developing a combined package of coordinated holistic approach requires that programmers and policy makers understand the epidemic by identifying geographic variations in HIV prevalence and identifying and understand structural factors that might fuel HIV prevalence (1-3). Behavioral interventions seek to reduce the risk of HIV transmission by addressing risky behaviors (4). As such, behavior change communication forms a basic component of combination prevention (4, 5). High-risk health behavior may result in HIV transmission to HIV-negative persons (4, 6). Effective behavior interventions address the cultural contexts within which risk behaviors occur and aim to stimulate uptake of HIV prevention services (often referred to as 'demand generation'). These programs often feature intensive approaches involving a combination of activities to address multiple outcomes, including knowledge, risk perception, norms, skills, sexual behaviors and HIV service demand (3, 5, and 7). This research seeks to understand how anti-retroviral therapy (ART) is perceived by certain populations, as well as what the potential motivators could be for them to remain on treatment. Furthermore, it seeks to understand how the motivations and benefits of ART can be strengthened, shifting this balance away from the obstacles and towards adherence. In a literature review and qualitative study conducted prior to the research, where treatment adherence and the challenges associated with it were investigated (Paper in press-

Gumede-Moyo et al.) The authors came to a consensus treatment adherence is more than simply remembering to take medication, and it is more than simply understanding the importance of treatment. It is about the people as individuals, and the daily choices they make in terms of the broader context of their lives and priorities. The overall focus is to develop the most successful campaign across sub-Saharan Africa, but primarily Malawi and Zimbabwe. The findings of the research will assist to unravel how personality traits of PLHIV influence beliefs and resonance with anti-retroviral therapy (ART). The potential campaign is envisaged to tackle social death by ensuring that PLHIV feel accepted as part of the community and not isolated because of their HIV status. By ensuring PLHIV know to continue taking pills even when feeling well, is expected to tackle pill burden. The campaign should also tackle uncertainty by ensuring that PLHIV feel like they can still fulfil their hopes and dreams and that ART is the vehicle for taking them through uncertain times.

MATERIALS AND METHODS

Study Design

This was a cross-sectional quantitative study where interviews with 786 adult PLHIV and 504 HCW were conducted via Computer Assisted Telephone Interviewing (CATI) in Malawi and Zimbabwe (Figure 1).

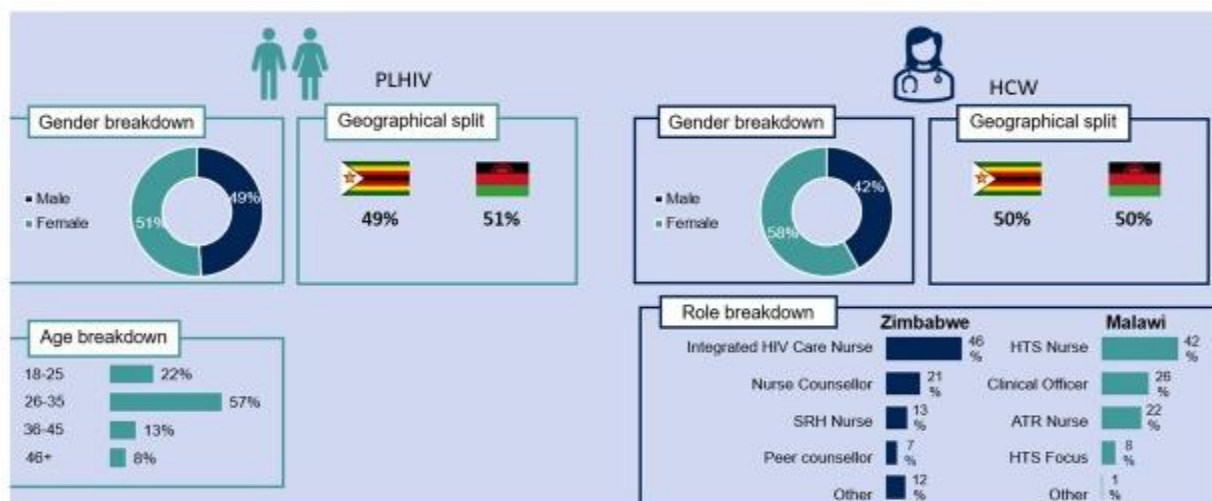


Figure 1: Demographic characteristics

Participant Recruitment

The PLHIVs were recruited from health facilities providing ART treatment services and HIV community-based organizations. Healthcare workers (HCWs) were invited to take part through health facility management. Eligibility criteria for HCW recruitment included having at least 3 years' experience and interacting with at least 5 PLHIV each day, HCWs worked at a variety of sites including public and private facilities. The recruiters provided the study participants with details about the study and the prospective participants were also told that they are under no obligation to take part in the study. The contacts details of PLHIV were forwarded to the Principal investigator (PI) in Zimbabwe and Research coordinator in Malawi. The participants were each assigned a unique numerical study identifier. The PI and Study coordinator only shared the personally identifiable information (such as telephone number and first name of

participants) to a specific moderator who was responsible to interview the study participant. Informed consent was verbally acquired over the phone.

Sample Size Determination

Recruitment was done in both rural and urban settings to ensure geographic diversity in our sample. The sample size was calculated considering the prevalence of the variables of interest, the desired level of confidence, the acceptable margin of error, design effect, contingency, the distribution of observations and the analysis requirements. The base sample size was calculated according to the following formula:

$$n = t^2 \times p(1-p) / m^2$$

Where:

n= the required sample size. t= confidence level at 95% (standard value of 2.575).

p= estimated prevalence. In this case set at 50% (0.5) to maximize sample size given; there was no prevalence hypothesis underpinning the study rationale.

m= margin of error at 5% (standard value of 0.05).

As the survey was not a simple random sample, but a clustered random sample, the design effect was taken into consideration. The standard formula for doing so was:

$$DEFF = 1 + \delta(n-1)$$

Where:

DEFF= design effect.

δ = intercluster correlation for the statistic.

n= average size of the cluster

Taking into consideration the need for a robust sample size whilst also ensuring that data collection fits within budget.

Data Collection

The questionnaires' design utilized a framework based on Integrated Behavior Model IBM (8). The formative qualitative study and literature review was used to design the structured questionnaires which were used to collect data. The survey was administered between April and May 2021. For PLHIV the following data was collected: self-reported adherence behavior; treatment literacy; psychographics (pro-activity, optimism bias); self-acceptance; community acceptance of HIV. The areas to inform communication tactic explored were channel reach; trusted sources of information; prioritization of opportunities and barriers. The HWC questionnaire was designed to collect data on motivations and responsibilities; treatment literacy; perception of PLHIV and HIV and frustrations with role. The areas to inform communication tactics concentrated mainly on prioritizations of opportunities and barrier

Reliability and Validity

The questionnaires were produced in English, and then translated to Chichewa for Malawi, and into Ndebele and Shona for Zimbabwe. Study participants were asked before beginning the interview their language preference. Pretesting of the guides was done according to procedure.

Prior to the start of fieldwork, an intensive training program was undertaken by all supervisors and interviewers, led by the local research lead. The training program ensured that all participants are completely familiar with the telephone etiquette, survey questionnaire and the sampling framework. Whilst using multiple interviewers in different regions and countries, a consistent approach was undertaken to ensure validity and quality of data was comparable. The time that was spent with each respondent before respondent fatigue sets in was capped to a maximum of one and a half hours.

Data Analysis

The data was processed and cleaned in Stata 14. The review of data at a base level was done and then analysis of individual data points for each question was conducted. The identification of core areas of distinction or differentiation was noted. The quantitative data was processed into data tables, which included statistics (including standard deviation, standard error and confidence intervals).

Ethics

The Ethical approval was obtained from the College of Medicine Research & Ethics Committee (COMREC) and Medical Research Council of Zimbabwe (MRCZ/A/2683). All participants gave verbal consent over the phone.

RESULTS

Adherence Profile

PLHIV in Malawi and Zimbabwe are typically adherent to their medication as illustrated in Figure 2, although in Zimbabwe a higher proportion reported to have taken their treatment on 10 or less days compared with the total sample.

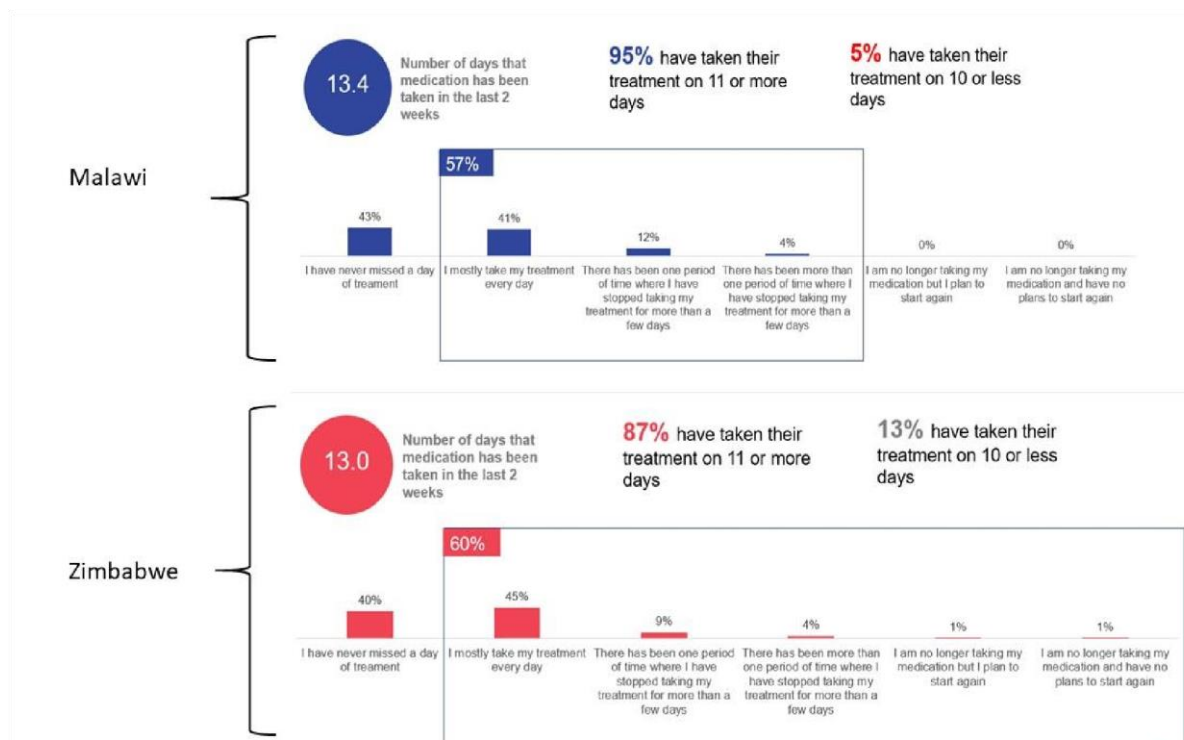


Figure 2: Adherence profile

Community Acceptance

48% of PLHIV in Malawi agree that the way they feel about having HIV is influenced by the community that they live in. Whilst PLHIV in Malawi mostly state that they feel at home in their community, and accepted by their close friends any family, 61% feel that people in the community say bad things about PLHIV, 63% believe that HIV is still a taboo topic, and 37% feel that people may want to harm them because they have HIV. Negative comments about PLHIV primarily driven by mothers (42%) and neighbours (37%). On the other hand, PLHIV in Zimbabwe feel accepted by their families, but have significant concerns about wider community perception. 46% of PLHIV in Zimbabwe agree that the way they feel about having HIV is influenced by the community that they live in. There is widespread agreement that people have biases towards PLHIV (85%) and that HIV- people think that PLHIV have done something bad (81%). While PLHIV in Zimbabwe do feel they will have the support of their family no matter what (78%), only 59% say that they feel at home in their community, and half feel that people in their community are not accepting of everybody.

Acceptance After Disclosure

PLHIV in Malawi feel particularly well supported after disclosure, which connects to high scores in this country for feeling supported and accepted by their family. However, there are still high levels of fear of disclosure, particularly with family and a partner, which do not correlate to the support received. Also, whilst the percentage is high, there are still 8% of PLHIV who do not feel well supported by their partner or spouse after disclosure. PLHIV in Zimbabwe show higher levels of fear about disclosing their status and are slightly less likely to feel supported. There is an indication of a generational influence, with younger people (children, siblings and friends) most likely to be supportive (90%). PLHIV most likely to be concerned about telling their parents, who are usually supportive (86%). However, there is less likelihood of a supportive reaction from a partner (73%) - Figure 3.

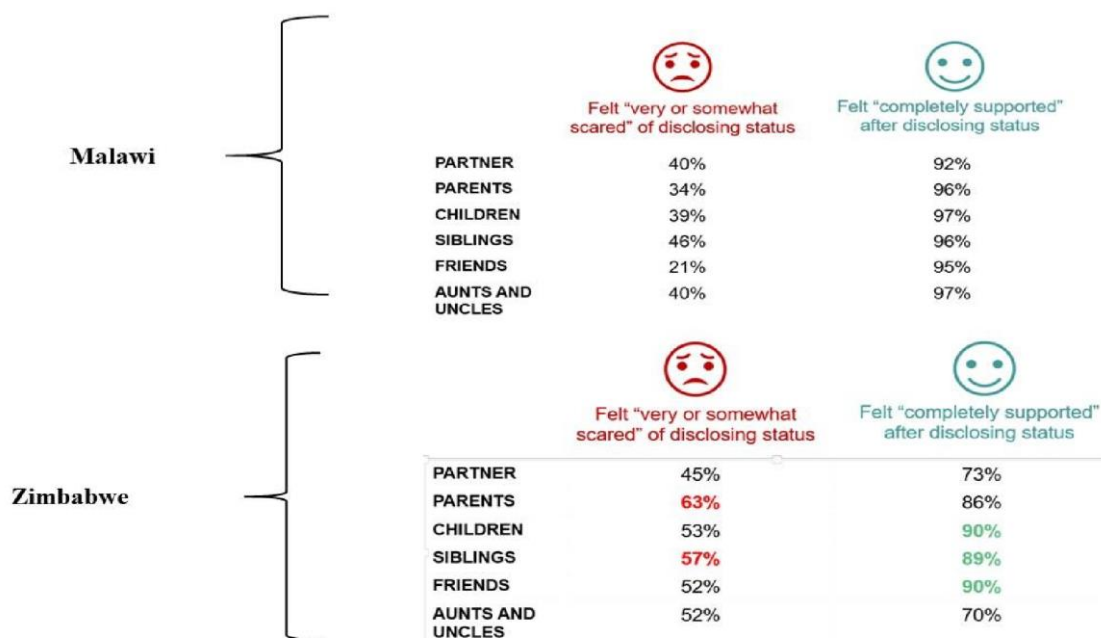


Figure 3: Reactions to disclosure

Treatment Literacy

PLHIV in Malawi are unlikely to have heard about ARVs before their diagnosis. 40% are aware of ARVs before diagnosis. They are more likely to: live in Mzimba North, Balaka, Mulanje or Phalombe; be older (aged 36-45), but have been diagnosed in the last 5 years (more opportunity to have heard about ARVs); have a higher level of education (completed form 4 and above); be working full time or be self-employed; be adherent to medication (have taken treatment on at least 11 days out of the last 14) and have disclosed to close family and/or the wider community. In Zimbabwe, PLHIV are likely to have heard about ARVs before their diagnosis. 73% are aware of ARVs before diagnosis. They are more likely to: be male; live in Mashonaland West, Masvingo, Harare or Manicaland; be in the middle age range (26-45); have completed secondary school, or for some, a higher level of education; be employed full time or self-employed; have been diagnosed less than 5 years ago and be adherent – most have taken medication every day in the last 2 weeks.

Motivation to Take Treatment

In Malawi, PLHIV say they are motivated to take treatment because they know they can live a long and healthy life, and 90% say that taking a pill every day reminds them of this. However, there is disconnect evident between understandings that you can live a long and healthy life on ARVs and adhering to medication. PLHIV in Zimbabwe say they are motivated to take treatment because they know they can live a long and healthy life, and 96% say that medication means they can live the life they want to live. However, this drops to only 69% who say that taking a pill every day reminds them of this. (Figure 4).

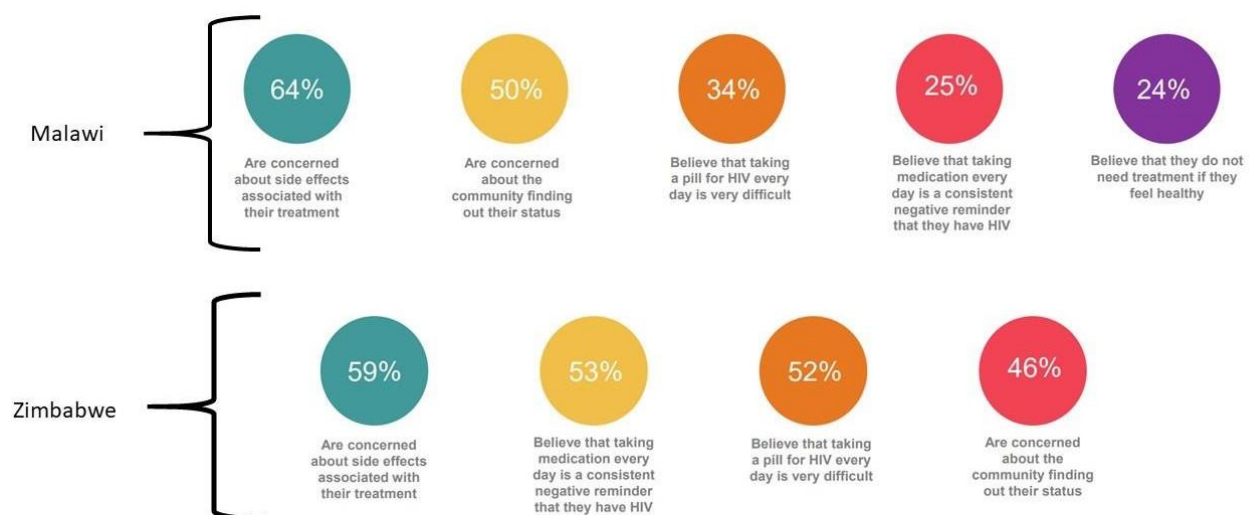


Figure 4 : Treatment Motivation

Awareness of Viral Suppression

PLHIV, and HCWs in Malawi, have good awareness of what viral suppression is, but do not always understand what it truly means. 92% PLHIV understand that viral load is the term used to describe the amount of HIV in your blood, and 76% understand that viral load determines how sick or healthy you feel. However, only 32% believe that PLHIV who take treatment every day will not pass on HIV to other people who they have sex with without a condom. 17% believe

that once you have achieved low viral load, you no longer need medicine. 34% believe that if you take your treatment every day you will be cured. 96% HCWs understand that viral load is the term used to describe the amount of HIV in your blood, and 91% know that it is possible for a PLHIV to have an undetectable viral load. However, only 21% believe that it is possible for PLHIV to have sex without a condom when they are virally suppressed. 18% do not believe that it is possible for a person to be untransmittable. 12% do not believe that PLHIV who are virally suppressed are less likely to pass on HIV to their sexual partners. 9% believe that PLHIV can stop taking their medication when they achieve viral suppression. In Zimbabwe, 95% of PLHIV understand that viral load is the term used to describe the amount of HIV in your blood, and 90% understand that viral load determines how sick or healthy you feel. However, 47% believe that if you take your treatment every day you will be cured. Likewise, only 12% believe that PLHIV who take treatment every day will not pass on HIV to other people who they have sex with without a condom. 18% believe that once you have achieved low viral load, you no longer need medicine and 14% believe that it is fine to wait to go onto treatment if you feel well.

Barriers to Adherence

In both countries there is clearly strong motivation to take treatment and good overall adherence. However, 73% of PLHIV from Malawi say that they often feel overwhelmed by life's challenges, which can lead to forgetting to take medication (32% of PLHIV in Malawi say that they sometimes forget to take pills) and 56% say that they have other responsibilities that take priority over their health. Similarly, in Zimbabwe, 81% of PLHIV say that they often feel overwhelmed by life's challenges, which can lead to forgetting to take medication (17% of PLHIV in Zimbabwe say that they sometimes forget to take pills). Likewise, 29% of PLHIV in Zimbabwe sometimes struggle to take their medication due to a lack of food. There are also clinic-based challenges in Zimbabwe as 23% of PLHIV state that they have sometimes gone to the clinic for medication and they have run out, and 24% cite this as the main reason for a period where they have stopped taking their treatment

HCWs Motivation

HCWs in both countries are motivated to help PLHIV and are passionate about their role, but they feel that the daily challenges of their work make it difficult to fully support patients. 96% of nurses in Malawi feel proud to be a nurse and find their role rewarding. In Zimbabwe 96% of nurses feel proud to be a nurse, and they feel respected by their patients, fellow HCWs and members of the community (all over 90%). However, only just over half (56%) find the job rewarding.

Prioritization of Emotional Support

HCWs in Malawi and Zimbabwe do prioritize emotional support but have limited capacity to provide wider pastoral care. In Malawi 99% of HCWs believe that part of their role is to help PLHIV to accept their status; 95% feel that the most important thing is to listen to how a PLHIV feels and 91% ask PLHIV how they are feeling when counselling and educating them. HCWs in Zimbabwe do recognize that patients have mental health needs that are not currently being addressed, but do not have the capacity to respond to this in their role. 98% of HCWs believe that part of their role is to help PLHIV to accept their status, 97% ask PLHIV how they are feeling when counselling and educating them and 91% feel that the most important thing is to listen to how PLHIV feel.

DISCUSSION

A primary focus of our research was to determine the most appropriate forum for communications as illustrated in Figure 5. We had an intention to understand the relationship between the underlying needs PLHIV have from treatment, their personality traits, and how it influences treatment behavior.



Figure 5: Communication channels

Whilst there are positive voices advocating for ARVs in Malawi, there are also more negative associations. There are HIV negative people advocating for ARVs and say positive things about PLHIV, at the same time there are also some who say negative things. Hearing negative comments from a wide range of people creates a feeling of collective community negativity towards PLHIV, which is driving PLHIV to feel less comfortable in their communities and heighten fear and stigma. Stigma has an over-arching barrier, on rationalities regarding treatment and HIV status which is also exacerbated negative community religious perceptions (9-11). Horter et al, (2017) concluded that the process of HIV status acceptance or denial is greatly influenced by the accounts of patients' health seeking and linkage to care (12). However, PLHV have concerns about segregated HIV clinical services (9). Hence there is a need to offer these services in an integrated manner which must be respectful, convenient and efficient (13-15).

There is disconnect evident between understandings that PLHIV live a long and healthy life on ARVs and adhering to medication. For many PLHIV, there is a difference between leading a long and healthy life and leading the life that you want to live. This is perpetuated in Zimbabwe where over half of PLHIV have significant challenges with taking a pill every day. The hypothesis that PLHIV may be saying that medication means they can have a long and healthy life as this is the message that has been instilled in them from HCWs, but taking a pill every day does not make them feel fulfilled. Perceptions of disease seriousness or expectation of outcome may influence long-term adherence to management; if patients are convinced that management

will improve quality of life adherence will be better (16). However, some patients require ongoing support, while others develop their own coping and acute management strategies (17). In addition, this also varies between individuals, and with cultural background and age (16). Systematic reviews show that patient-centred care results in increased adherence to management protocols, reduced morbidity and improved quality of life for patients (16, 18). This type of care requires a thorough explanation of disease to patients and exploration of their feelings, beliefs and expectations (patient “affect and cognition”) (19). Our study further segmented PLHIV into parsimonious groups that are relatively homogenous in terms of their healthcare needs helps to optimally meet their healthcare needs as recommended by other researchers (20-22).

In Malawi HCWs do recognize that there is an overwhelming amount of information for PLHIV to receive and digest at one time. This is likely to influence the level of information that is presented and means that HCWs are aware that PLHIV may not take on board everything at one time, which can impact adherence. Despite that withholding such information violates medical ethics, perpetuates health inequities, and infringes on the sexual health and human rights of people with HIV (23).

There is also disconnect between the perception of stigma by PLHIV and HCWs in Malawi. Only 26% of HCWs feel that there is a lot of discrimination towards PLHIV in the community, while PLHIV feel that it is much more significant than this. Therefore, HCWs probably play less of a role focusing on HIV acceptance, and how PLHIV feel about disclosing, as they do not see it as a major challenge. Similarly, in Zimbabwe, the understanding of the stigma faced by PLHIV does not necessarily translate to an increased focus on their pastoral care or support. HCWs do see their role as helping patients to accept their condition, but they have limited capacity to provide support to those patients who require more help to accept their diagnosis and disclose their status to others. Healthcare providers need to be supported to better equip patients to cope with the issues associated with ART (24).

PLHIV are primarily driven to take treatment by intrinsic motivations, particularly to live a long and healthy life, to be able to work and support children, and to feel strong to conquer HIV and its challenges. PLHIV are rewarded by good adherence by seeing a decline in their viral load. However, extrinsic motivations also play a role. PLHIV are also widely motivated to take treatment to look healthy to others, and because they want to follow the advice of their HCW. PLHIV in Zimbabwe also seem to have a particularly strong support network in place with 94% saying that a key motivation to take treatment is because the people close to them encourage them to. Negative comments about PLHIV tend to be driven by neighbors, which perpetuates the feeling that the community in Zimbabwe may not be accepting of HIV. PLHIV in Zimbabwe are also encouraged to have a strong support network around them and it may be that HCWs see it as the role of friends and family to consider the emotional wellbeing of PLHIV.

Study Limitations

Despite that the topic of conversation was sensitive for some respondents. There could have been some inherent differences in those who chose to partake in the study compared to those who could have been less comfortable and opt out from doing the study. This was mitigated by the large quantitative sample which is distributed across the two countries. Whilst using multiple interviewers in different regions and countries, a consistent approach was undertaken

to ensure validity and quality of data was comparable. The time that was spent with each respondent before respondent fatigue set in was capped to a maximum of one and a half hours. Therefore, there are likely new questions which arose from the research that could not be answered at the time.

However, our knowledge base was increased dramatically from conducting the study.

CONCLUSIONS

Early associations with HIV tend to derive from negative comments being made about PLHIV, which fosters a sense that PLHIV are not accepted by the wider community. Having a positive experience disclosing to some people does not give PLHIV the confidence to tell more people their status. PLHIV may be saying that medication means they can have a long and healthy life as this is the message that has been instilled in them from HCWs, but taking a pill every day does not make them feel fulfilled. HCWs do recognize that patients have mental health needs that are not currently being addressed, but do not have the capacity to respond to this in their role. The understanding of the HCWs that stigma faced by PLHIV does not necessarily translate to an increased focus on their pastoral care or support. Utilization of communication channels that are acceptable and trusted will be key to successful HIV literacy treatment campaigns.

Author Contributions:

SGM, SS, ML and AI- conceptualization, resources, data curation, software, formal analysis, supervision, funding acquisition, validation, investigation, writing the original draft. CG, EP and VN - resources, investigation, and project administration, NH, PM and KC - conceptualization, resources, funding acquisition, project administration. All authors read and approved the final manuscript.

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Informed Consent Statement:

Informed consent was obtained from all subjects involved in the study

Data Availability Statement:

This study used data obtained from human participants. The dataset (anonymized survey responses) is owned by the governments of Malawi and Zimbabwe.

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Conflicts of Interest:

The authors declare no conflict of interest.

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