



EXPERIENCES OF ART ADHERENCE AND VIRAL LOAD TESTING IN ESWATINI

A qualitative master thesis

This thesis has been written as a study assignment under the supervision of an Utrecht University teacher. Ethical permission has been granted for this thesis project by the ethics board of the Faculty of Social and Behavioral Sciences, Utrecht University, and the thesis has been assessed by two university teachers. However, the thesis has not undergone a thorough peer-review process so conclusions and findings should be read as such.

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Abstract

eSwatini is the country with the largest HIV infection rate worldwide. In order to lower this rate, it is necessary to reach the 95-95-95 goals from the Joint United Nations Programme. The accomplishment of these goals will be more realistic by concentrating on rising the number of HIV-infected individuals having a suppressed viral load. According to earlier research, a behavioural and social approach will be effective in addressing this. Since there is a gap in published research regarding experiences with ART adherence and (the implementation of) viral load testing in eSwatini this thesis studies the existing gap using the concepts of medicalisation and biopower. The following research question is formulated: How do people with HIV and health providers experience and practice HIV treatment adherence and HIV viral load testing in the context of an implementation study in eSwatini?

This research question is answered by using a qualitative research design, using in-depth and semi-structured interviews. Initially, sensitising concepts were established, which supported coding of the transcribed interviews.

It was expected that people living with HIV would feel empowered because of the use of viral load tests. Nevertheless, due to power dynamics between health providers and people living with HIV this was not the case. In the context of the MaxART study in eSwatini, people with HIV did not feel empowered because their HIV treatment adherence was medicalised, and they explained that they felt criticised.

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1. Introduction

1.1 Problem description

HIV is viewed as a global public health threat. Therefore, the Joint United Nations Programme on HIV/Aids (UNAIDS) established the 95-95-95 targets. These targets signify that 95% of individuals living with HIV know their HIV status, from which 95% are on antiretroviral therapy (ART), and 95% of those will experience viral suppression by 2030. With these targets, UNAIDS aims to stimulate and accelerate public health interventions with the final goal of ending the AIDS epidemic by 2030 (UNAIDS, 2014;2015b).

ART is the medication used to treat people living with HIV¹ in order to achieve viral load reduction to an undetectable level, called viral suppression (UNAIDS, 2016). Viral load tests are used to monitor how HIV treatment is helping to reduce the amount of HIV virus in the body of people with HIV. Besides that, these tests may enable health providers to change HIV treatment regimens in case the treatment is not working well for people living with HIV (UNAIDS, 2016; Drain et al., 2019; Lecher et al., 2016). Although viral load tests in high-resource countries are widespread and frequently applied, scaling-up those tests in low-resource countries such as Sub-Saharan African countries is scarce because of, among other things, the expense and complexity of viral load tests (Roberts et al., 2016). In recent years, there has been a development in the number of implementation studies using this new technology (Lecher et al., 2016; Lubega et al., 2022). However, limited data is available about health providers and people living with HIV's experiences with viral load. Therefore, this study focuses on their experiences with viral load testing in eSwatini.

Low-resource countries such as eSwatini are most impacted by the HIV pandemic. eSwatini is the country with the highest HIV prevalence rate globally, namely 27.9% (Newman & Hardie, 2021; UNAIDS, 2021). ART was introduced in eSwatini in 2001 and currently 91% of people living with HIV are on this medication (Ntshakala et al., 2012; UNAIDS, 2021). The amount of people living with HIV receiving ART² is rising in Africa. However, only 89% of inhabitants of eSwatini living with HIV have achieved viral suppression (UNAIDS, 2021). This shows that the 95-95-95 goals are not reached yet.

According to several studies, viral suppression leads to biomedical, public health and social benefits (Bavinton et al., 2018; Cohen et al., 2011; Rodger et al., 2019). These benefits include that people living with HIV having a consistently suppressed viral load have zero risk of transmitting HIV to their HIV-negative partner during condom-less sex acts. This global consensus statement is communicated with the message 'Undetectable = Untransmittable (U=U)' and is used by HIV activists to advocate for improved access to viral load testing which then determines whether the virus is detectable (Keogh & Dodds, 2021). Persson (2016) has suggested that knowing that one's HIV is untransmittable may lead to the option to have sexual intercourse without a condom, feeling empowered which helps building a positive self-image, and feeling liberated from internalised stigma. However, there is limited insight in social consequences in the specific health system and cultural context of eSwatini because only a few studies about this have been conducted in Sub-Saharan Africa (UNAIDS, 2018; Keogh & Dodds, 2021). This study contributes to this literature by focusing on the experiences of health providers and people with HIV with the implementation of HIV viral load technologies and HIV treatment adherence in the context of a multidisciplinary research project in eSwatini.

¹ According to the UNAIDS (2015a) the right terminology in this situation is "people living with HIV".

Abbreviations for population groups should only be used in charts or graphs where conciseness is necessary.

² Hereafter being called HIV treatment, as the UNAIDS (2015a) recommends not using an abbreviation and HIV treatment is most close to the reader.

1.2 Literature review

The literature review focuses on the political economic context of HIV, the health system of eSwatini, and the social context of ART adherence and viral load testing. Since data about ART adherence and viral load testing in eSwatini is limited, there are some references to studies from other countries in Sub-Saharan Africa and/or other age groups.

1.2.1 The political economic context of HIV in eSwatini

The first HIV infection in eSwatini was reported in 1986 and a period followed in which 7000 people died annually from it, and thousands more contracted this disease (Mabuza & Dlamini, 2017; Belle & Gamedze, 2019). Over ten years later, His Majesty the King Mswati III announced the spread of HIV and AIDS as a national emergency and since then it has been prominent on the national public health agenda (The Government of the Kingdom of eSwatini, 2018). Part of the HIV and AIDS strategy of eSwatini has been to introduce and scale-up HIV treatment and viral load testing, hence contributing to achieving the UNAIDS goals (The Government of the Kingdom of eSwatini, 2018; the Government of Swaziland, 2016).

Low-resource countries in Sub-Saharan Africa face several economic and structural challenges. With 58.9% of residents living below the national poverty line, eSwatini can be considered one of those low-resource countries (World Food Programme, 2022). Economic shortages affect the delivery of healthcare services, including HIV treatment (Gitome et al., 2014). Firstly, eSwatini often deals with a shortage of HIV medication in healthcare facilities (Magagula & Hofisi, 2018). Secondly, travelling to institutions for HIV care is expensive and time-consuming for people living with HIV because of poor road networks. The consequence is that it is hard to enrol and remain in HIV care (Pinto et al., 2013; Siedner et al., 2013; Gitome et al., 2014). Thirdly, food insecurity plays a role in the health of people living with HIV since HIV treatment must be taken after a meal and that is not feasible for everyone (Lim et al., 2009; Nagata et al., 2014; Biadgilign et al., 2012). Lastly, eSwatini faces a critical shortage of health workers to tackle the high HIV infection rate. Effective service delivery requires 23 health workers per 1000 citizens, and eSwatini is far below this minimum (Mavhandu-Mudzusi et al., 2017; Magagula & Hofisi, 2018; Stilwell & Mthethwa, 2004; Interagency Task Team on Human Resources for Health, 2012).

1.2.2 HIV health system of eSwatini

As elaborated on in paragraph 1.2.1, the HIV healthcare system of eSwatini struggles with some economic difficulties including a shortage of staff for HIV care. Community health workers, called rural health motivators (RHMs), were established as a way to enhance the access to social services including HIV services (Geldsetzer et al., 2017). They visit rural communities, examine their health issues, offer primary care, inform them about illness prevention, and persuade residents to seek medical (HIV) care. Whereas RHMs offer primary care, as well as the government, non-profits, and private clinics, secondary care is offered at health clinics with in-patient facilities, and tertiary care is delivered through a number of government and mission institutions (Vernooij, 2022a). This study has been performed within the context of fourteen health clinics and neighbouring communities in eSwatini's Hhohho region during the Maximizing ART for Better Health and Zero new HIV infections (MaxART) programme. This programme was launched by a multidisciplinary consortium, including the Ministry of Health of the Kingdom of eSwatini (MaxART consortium, 2018). This is discussed more comprehensively in chapter 2.

The interaction between health providers and people living with HIV is an important aspect of initiating and remaining in HIV services. Research conducted among women living with HIV in eSwatini shows that women were being maltreated by health providers at the facilities because of

arriving late, missing an appointment or when it was presumed that they did not take their medication properly (Becker et al., 2020). Besides that, a qualitative study suggested that specifically in Uganda (Sub-Saharan Africa) youth feel pressured to adhere to HIV treatment. They feel like they have to deserve their medication and have to gain respect from the health providers by adhering to their medication (Bernays et al., 2017; Mattes, 2014).

Wiginton et al. (2022) indicated that there is a lack of knowledge among people living with HIV in eSwatini about viral load, which is partly due to poor communication with health providers. This includes knowledge about the status of their viral load, testing history, and the risk of transmitting HIV to their sexual partner(s). Constant and clear communication is essential for a good relationship between health providers and people living with HIV and consequently for the introduction of new diagnostic technologies such as viral load testing (Magagula & Hofisi, 2018).

1.2.3 The social context of HIV treatment and viral load testing

Experiences with HIV treatment adherence

As elaborated on earlier in this chapter, eSwatini struggles with a shortage of HIV healthcare personnel. Therefore, community support is especially important (WHO, 2003; Gitome et al., 2014). Men living with HIV in Malawi (Sub-Saharan Africa) attended support groups that focused on, among other things, adherence support. This was showed to be effective for HIV treatment adherence. However, there is limited data about the effectiveness of adherence support from these groups in eSwatini (Wiginton et al., 2022). Besides that, the social support of family, partners, and/or friends facilitate engaging in HIV care, including HIV treatment initiation and adherence, and retaining in care (Wiginton et al., 2022; Brown et al., 2019; Muhamadi et al., 2011). Becker et al. (2020) concluded that women in eSwatini experience difficulties with disclosing their status to people in their social environment and that they are afraid people in the community will discover that they attend HIV clinics.

Experiences with viral load testing

Studies conducted on viral load testing in Sub-Saharan African countries that focus on implementation success or on effectiveness, i.e., Lecher et al. (2016) and Lubega et al. (2022), lack knowledge about social experiences with viral load testing in this context.

Literature about how health providers tackled the implementation of viral load testing in eSwatini and other Sub-Saharan African countries is scarce. Besides that, little qualitative research has been done on the experiences of ART adherence and viral load testing in the context of eSwatini. This study can contribute to the existing literature. As already mentioned in the first section, a suitable application of HIV treatment could be life-changing for people living with HIV. They will establish reclamation of their quality of life, reintegrate in the working life, and enjoy a hopeful future (UNAIDS, 2018). Reintegration would also contribute to the economy of eSwatini (Magagula & Hofisi, 2018). Gaist & Stirratt (2017), Goodenow & Gaist (2019), and Odokonyero et al. (2022) suggest that it is essential to increase focus on behavioural and social approach instead of the biomedical approach: this addresses the gaps in ART adherence and viral suppression in eSwatini. For this reason, this study focuses on social experiences regarding ART adherence and viral load testing.

1.3 Theoretical framework

This study can be seen from the perspective of a social ecological model (figure 1). This framework identifies the interaction between the individual, interpersonal/network, community, and institutional/health system level, and it promotes health-related behavioural change. The framework emphasises that particular changes in the social environment will result in changes within individuals, and that the support of the population is required for environmental changes (Wiginton

et al., 2022; McLeroy et al., 1988). The main focus of the data analysis is on the individual (person living with HIV) and institutional/health system level (relationship between health provider and people living with HIV). This thesis also touches upon the interpersonal/network (cultural norms and social environment) and the community level (social support) in order to get a comprehensive understanding of the data.

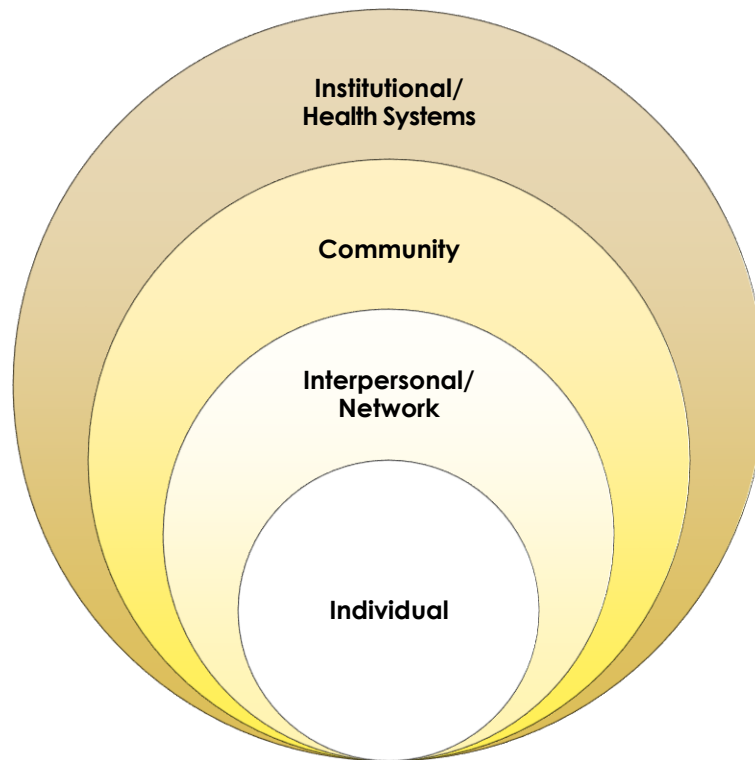


Figure 1 Socioecological framework, after Wiginton et al. (2022), promoting health-related behavioural change.

A theoretical concept that can be applied is the biopower approach from Foucault. It describes how people or institutions in a dominant position use their power on individuals in the name of the social good (Zaidi et al., 2021). Biopower involves eliminating the differentiation between individuals and social groups and approach them as a unity. On the contrary, it requires distinguishing certain high-risk groups in society (Foucault & Macey, 2003; Beck, 1992; Sorensen & Christiansen, 2014). Biopower creates “truths” which residents obediently adopt (Hutchens, 2021). The biopower approach is mostly mentioned in terms of the government exercising power over its citizens. An example is the COVID-19 pandemic in which vulnerable individuals were isolated because of protective government regulations in name of the social good. However, this resulted in inequities and risks for these groups regarding medical care and social support (Rangel et al., 2022). Biopower can also be exerted on the micro-level, including in a health provider-patient relationship (Zaidi et al., 2021). Another example is Crisis Pregnancy Centres in the US where (mis)information is disseminated about abortion and practical services are used by healthcare providers to persuade women to “choose life”, taking a religious perspective in name of the social good (Hutchens, 2021).

The concept of medicalisation is related to the biopower approach, since they both have been applied to examine and comprehend how power, society, and medicine interact. The medicalisation of HIV in Sub-Saharan Africa has contributed to the management of the disease since it helped launch HIV treatment (UNICEF, 2009; Patton, 2007; Giami & Perrey, 2012). Medicalisation implies

the transition of non-medical human issues being specified and treated as medical issues (Conrad & Bergey, 2015). The medicalisation of a problem can result in recognising and thereby treating an illness, which improves an individual's quality of life. However, medicalisation can also function as a form of social control and it can specifically focus on biomedical aspects, whereas the socio-political, cultural, psychological, relational, and economic context may lack attention (Gitome et al., 2014; Conrad & Bergey, 2015; Tiefer 2012). Therefore, it is also necessary to consider the social factors influencing HIV treatment.

1.4 Research questions

Since there is a gap in the insights about HIV treatment adherence and viral load testing in eSwatini this thesis studies social factors influencing them. The following research question will be studied during this thesis:

- How do people with HIV and health providers experience and practice HIV treatment adherence and HIV viral load testing in the context of an implementation study in eSwatini?

Apart from the main question, the following sub-questions are formulated:

- How do power dynamics between health providers and people living with HIV shape the implementation of viral load testing in the health facilities?
- How does the social and political-economic context affect people with HIV's experiences of HIV treatment and viral load testing?

1.5 Interdisciplinarity

An interdisciplinary view is taken by integrating the concept of medicalisation, the biopower approach and socioecological framework. The socioecological framework takes a public health perspective and a social behaviour perspective since it studies interactions within individuals (people with HIV), between individuals (people with HIV, people in their social environment and health providers) and between the (public) health system and people with HIV and the influence of this on the individuals' behaviour (Wiginton et al., 2022; McLeroy et al., 1988). The concept of medicalisation originated from sociological and anthropological literature hence it implies the development of the behaviour of individuals and their attitude regarding (non)medical issues and the consequences of this (Conrad & Bergey, 2015). Moreover, the biopower approach focuses on both the biological and the sociological perspective as it concerns the behaviour of people from a position of power and the control they exert over other people's bodies (Sabina, 2018). This conceptual framework is essential hence it is recommended to consider the context of viral load testing and ART-adherence with a social and behavioural approach and those concepts focus on that.

2. Methodology

2.1 Design and procedures

Data from the MaxART programme was used for answering the research questions. The purpose of the MaxART Programme was “to improve the lives of people living with HIV and prevent new HIV infections in eSwatini by dramatically improving the uptake of HIV testing, care, and treatment services and demonstrating that early access and initiation on ART can significantly improve clinical outcomes for people living with HIV and reduce new infections.”. This programme supported the implementation of viral load tests between 2014 and 2017 (MaxART consortium, 2018).

A qualitative research design was used for this study. This study elaborated on datasets from the MaxART project, specifically their field research in the form of in-depth and semi-structured interviews. The in-depth interviews were conducted in SiSwati, one of the two official languages spoken in eSwatini. They were audio-recorded and transcribed. Thereafter, the interviews were translated to English. Besides that, the semi-structured interviews were conducted in English, audio-recorded and transcribed (MaxART consortium, 2018).

2.2 Participants and recruitment

The social science research team contacted previously consented people living with HIV, introduced themselves and asked for written consent for taking part in an interview. Eight in-depth interviews were conducted with people living with HIV, aged 18 years and older. Only people living with HIV, with an unsuppressed viral load six months after participating in the EAAA study, were able to participate in those interviews. The qualitative interview guide (Appendix 1a) used for the in-depth interviews with people living with HIV who had an unsuppressed viral load, includes questions about their structural and social environment. These questions are asked to understand their situated experiences of HIV testing, following treatment, and being enrolled in the EAAA implementation study. The interviews generally lasted half an hour, and the transcripts (including translation) are about thirty pages per interview.

Health providers from these health organisations were approached using a diversity sampling approach. Ten semi-structured interviews with these health providers are used for this thesis (Vernooij, 2022b). The qualitative tool for the semi-structured interviews (Appendix 1b) comprises questions about their knowledge of the MaxART study and how the health providers explained HIV testing and counselling, HIV treatment initiation and adherence, and viral load testing to people living with HIV. Based on notes of the interviewer and transcripts itself, it can be concluded that quality of the interviews differs. The duration of the interviews varied between 8 and 40 minutes and the length of the transcription is 5 pages in general.

While analysing the interviews, I specifically focused on data about the relationship between health providers and people living with HIV and experiences with HIV treatment adherence and viral load testing as other data from these interviews regarding experiences of implementing EAAA is already published (Pell et al., 2019; MaxART consortium, 2018).

2.3 Variables of interest and operationalisation

The concepts of biopower and medicalisation have been operationalised based on paragraph 1.3 by formulating the following sensitising concepts:

- Trust between health provider and client
- Information provision by health providers
- Perceived relationship between health providers and people living with HIV
- Authority of health provider
- Socioeconomic factors influencing HIV treatment adherence
- Perceived ART adherence
- Feelings towards viral load results
- Purpose of viral load tests
- Causes for high viral load.

Initially, these codes were used for the coding process. Considering that this data analysis is an iterative process, the codes were changed later on for better analysis of the data (see Appendix 2).

2.4 Data analysis

A combination between deductive and inductive coding is used while analysing the interview data. This research approach is called grounded theory, which has the ability to recognize and describe social processes (Bowen, 2006). The sensitising concepts as described in paragraph 2.3 can serve as a form of guidance and as a starting point for data analysis while being open to emerging codes appearing from the data. At first, the transcripts and observations were summarised to get a good understanding of what information in the data is useful. After that, English transcripts were coded in NVivo to categorise data using attribute, index, and analytic codes (Morling et al., 2018; Bowen, 2006). The code tree can be retrieved from Appendix 2.

2.5 Ethical aspects

Since I analysed an existing dataset collected during the MaxART project, I had no influence on data collection or participant recruitment. However, ethical conflicts can occur during analysis. Beforehand, I did not have experience with HIV-related issues in low-income countries and there was a possibility I developed bias towards the participants or misinterpret the translated data. Therefore, it was necessary to obtain feedback from my supervisor who collaborated on the study and to frequently discuss the social context of the MaxART project and the interpretation of the interview results with her. An evaluation of these ethical aspects is provided in the discussion.

All informed consent forms are signed by the interviewed people living with HIV and health providers. In those forms there was not explicitly asked for permission to share the data with third parties (outside the MaxART project). However, there was no mention that the data will not be shared with third parties. It is a grey area whether I, as a student researcher at Utrecht University, was allowed to analyse this data. In the informed consent forms, there is stated that the data will be anonymised, just as I received them. Also, the data is not traceable to certain health facilities, so the confidentiality of the data is protected.

3. Results

The results of this thesis are differentiated based on the experiences of health providers and people living with HIV and structured according to themes that emerged from the literature and data analysis.

3.1 Experiences of health providers

3.1.1 Information management

Information management regarding HIV treatment

At the clinics, health providers measured adherence by counting the pills people living with HIV have left. A health provider working as a doctor at one of the clinics mentioned that people living with HIV throw away pills and therefore cannot be trusted regarding adherence.

When people living with HIV do not take medication correctly a health provider mentioned that “you have to go on giving them the information about the dangers” (interview 9). Several healthcare professionals said that people living with HIV are concerned that the government or healthcare facilities are out to get them because they are offering them free medicine.

However, a few health providers emphasized that it is crucial to be honest with patients about HIV treatment and that they should be empowered to make their own decisions. A health provider stated the following:

They [people living with HIV] have to make their choice because that person is the one who's going to take the medication. You cannot force the person because the person can take the medication and go and throw it away, it's better that the person says yes, I do need the tablet (Female, working as an expert client, interview 9).

Information management regarding condom usage

Another theme that emerges from the data is information management regarding condom usage.

They rarely use condoms, so starting ART early will really help because we don't know what they are doing in their rooms (Female, working as an expert client, interview 17).

As indicated by this health provider, most health providers assume that people living with HIV barely use condoms. They lie about using condoms because they are aware that health professionals want to hear that they do use them. As indicated earlier, when people living with HIV have a suppressed (i.e., undetectable) viral load they are untransmittable, and it will not be necessary for them to use a condom against HIV transmission. A few health providers mentioned that while some people living with HIV might be trusted with this information because they understand it, others might not. This could lead to the (re)infection of other individuals. This seems to be the reason for not (always) wanting to communicate this information.

Information management regarding viral load testing

From the data, it becomes clear that viral load testing can be used as a tool to gain information about adherence.

Yet he was taking a tablet every day and throw it there. Another day he takes another tablet, throws it away and he brings you the correct number, they are clever. But measuring the

viral load can be a very good indicator (Male, working as a doctor at one of the clinic, interview 12).

This health provider signified that he does not trust clients regarding adherence since he presumes that they are not being honest during their pill count. Therefore, the viral load tests can be a good indicator of measuring their adherence.

Health providers said that telling people living with HIV they have an unsuppressed viral load as well as telling them they are undetectable might function as a motivation to start with and/or adhere to their medication.

3.1.2 Authority of the health provider

Health providers mentioned that rural dynamics have an impact on the extent clients listen to them.

Ntfontjeni (location of health facility) is still a rural area so those people can't even ask so many questions they just upgrade to anything you tell them especially if it's a health provider who is saying the message to them (Female, working as a lay counsellor, interview 15)

As shown by this quote, this health provider mentioned that clients in rural areas will listen to anything health providers tell them. This was endorsed by other health providers interviewed who added that HIV infected individuals in urban areas will have more questions about HIV treatment because of their educational level.

3.1.3 Medical factors influencing HIV treatment adherence

Health providers mentioned experiencing side effects might have an effect on HIV treatment adherence.

So, I think they are just scared. So many people there, those myths and conceptions which they hear from the people around so that's why they are so scared (Female, working as a lay counsellor, interview 15).

This health provider appointed that many people living with HIV are afraid of the side effects because of misconceptions they hear from their social environment.

3.2 Experiences of people living with HIV

3.2.1 Information management

Information management regarding HIV treatment

A person living with HIV said she observes the health providers doing the pill count and "tells them that they have not counted her pills properly" (interview 6). In this situation, the health providers deny making mistakes.

The reasons they [health providers] mentioned were that it is possible I am not taking my treatment properly, but I told them that I am taking my treatment, even my wife assured them that she also reminds me to take the pills (Male, 57 years old, interview 5).

As illustrated by this quote, many healthcare professionals appear to believe that the high viral loads of people living with HIV are the consequence of improper use of HIV treatment.

They said you drink the pills [taking medication] no matter what even if they make you

vomit, rinse the pill and drink it again (Male, 36 years old, interview 8).

As this person living with HIV indicated, health providers tell him it is very important to take the medication and it should never be forgotten. In addition, health providers tell people living with HIV it is necessary to start treatment early. As a health provider stated: “it helps boost you other than coming to the hospital in a wheelbarrow” (interview 2).

Information management regarding condom use

The majority of people living with HIV appointed that health providers told them to always use a condom during sexual intercourse, like elaborated on by this person living with HIV:

When initiating on ART, they encouraged us to use condoms always and we complied (Male, 36 years old, interview 8)

Information management regarding viral load (testing)

About half of the people living with HIV mentioned they have been told about viral load by the health provider, but most do not remember well what was told to them.

Interviewee: They said the viral load had risen.

Interviewer: What does that mean?

Interviewee: They said I don't drink the pills [taking medication] accordingly (Female, 45 years old, interview 3).

Hereby, this person living with HIV appointed that health providers tell her she is not taking her medication correctly. This shows that health providers are sometimes interpreting high viral load results as an indication of not taking HIV treatment properly. Although, it is also possible that the medication is not functioning effectively. The other interviewees do not recall the health providers informing them about viral load. However, only a few of them have limited understanding of what viral load signifies.

Another person living with HIV says the purpose of a viral load test is being “able to tell if someone is taking her treatment properly” (interview 2).

3.2.2 Authority of the health provider

Several clients mentioned in interviews that they changed their behaviour as a result of health providers' statements.

Interviewer: You do not miss doses anymore.... what made you realise it is better [...]?

Interviewee: It is because the nurse mentioned that I am not taking the pills correctly and the viral load is unsuppressed (Female, 48 years old, interview 1)

As this person living with HIV indicated, they stopped using alternative medication, started using condoms or adhered to HIV treatment because nurses mentioned that a client was not following their treatment correctly.

3.2.3 Perceived relationship between health providers and people living with HIV

A perceived relationship is explained as how both people living with HIV and health providers view their mutual relationship when specifically asked about it. People living with HIV were asked about how health providers treat them. Nearly all people living with HIV mentioned that the medical staff treats them well. Only one person living with HIV says he "isn't treated with dignity". Because of that he found himself irritated and walked away from the clinic.

Paragraphs 3.2.4 and 3.2.5 explain factors influencing HIV treatment adherence according to health providers and people living with HIV. Based on the concept of medicalisation, a differentiation is made between medical and non-medical (socioeconomic) factors. Paragraph 3.2.3 focuses on experiences with viral load testing.

3.2.4 Medical factors influencing HIV treatment adherence

Perceived HIV treatment adherence

Perceived HIV treatment adherence says something about how people living with HIV assess their own HIV treatment adherence. All participants do have an unsuppressed viral load; hence they were questioned by the researchers regarding the causes of this. Most of them do not know what causes this high viral load. Moreover, almost all respondents recalled that they are taking their medications as prescribed. Each individual has a method for being reminded to take their prescription on time. A person living with HIV declared the following:

Most of the time I'm friends with the TV, I like watching generations, so I take my pills at 8 pm. I don't miss generations and most of the time I'm indoors (Male, 31 years old, interview 4).

Only a few people living with HIV mentioned that they occasionally take their medication somewhat later than they should, but never more than an hour later.

Experiencing side effects

The majority of people living with HIV mentioned they felt better after starting HIV treatment. However, a number of them reported several temporary side effects, shortly after initiating HIV treatment such as dizziness, changing weight, and itchiness.

As described in paragraphs 3.1.1 and 3.2.1, health providers believe the main reason for an unsuppressed viral load is just an improper application of HIV treatment. However, given the fact that clients report almost always taking their medication correctly there could also be non-medical factors influencing HIV treatment adherence and resulting in an unsuppressed viral load. The following paragraph elaborates on these socioeconomic factors.

3.2.5 Socioeconomic factors influencing HIV treatment adherence

Food insecurity

One of the main factors that influences HIV treatment adherence is that several people living with HIV mentioned they do not have good access to food. This is hampering their ability to take their HIV treatment since they are aware that ARVs have to be taken after a meal.

Interviewer: Does it happen that you miss your doses on some days or do you miss your doses regularly?

Interviewee: It does not happen, sometimes I don't have food, so I do not take the pills (ARVs).

Interviewer: On how many occasions has that happened, situations where there is not enough food?

Interviewee: It has happened for three months (Female, 48 years old, interview 1).

This person living with HIV did not take her medication for a long time because she did not have access to food. One of the interviewers questioned one of the interviewees about how the nurses had explained the high viral load results to him. This respondent put it:

[...] they asked me if I have problems taking my treatment in time. They suspected that maybe I was stressed or maybe I wasn't eating well (Male, 31 years old, interview 4).

Apparently, this quote indicates that there was one health provider who thought that the unsuppressed viral load could have been caused by food insecurity in addition to inappropriate ARV use and experiencing stress.

Limited education

All respondents confirm they had limited education. This might affect their ability to take medication and use other HIV services properly, thereby making them rely on their social environment or health workers.

Interviewee: My cousin reminds me when I am due for a visit at the clinic by telling me the date.

Interviewer: Your cousin reminds you because you are illiterate?

Interviewee: yes (Male, 36 years old, interview 8)

This person living with HIV tends to forget his return dates because of being illiterate.

Social support

As elaborated on in previous paragraphs, some people living with HIV rely on their social environment for reminding them about their return dates or following their treatment. Also, most of them talk to at least one person about HIV issues but seem to have difficulty trusting more people about their status and taking HIV treatment in general. Only one respondent revealed that she attends an HIV support group where she learns about HIV-related topics. The other respondents are not aware that such support groups exist or do not attend them. However, a few of them would like to participate in those groups.

Obstacles with coming to the facility

Most people living with HIV appear to experience no issues with remembering to come to the facility on a return date to receive their medication. As mentioned earlier, there is one respondent who is being reminded by his family member. Besides that, respondents mentioned forgetting the return date a few times, but some still received their medication. Moreover, they might experience issues when coming by public transport or have to travel by foot because of lack of money. This might have an effect on picking up their medication on time or receiving information about HIV.

Intrinsic motivation for initiating and continuing HIV treatment

I saw that if I don't start taking the treatment, I will then get sick and be bedridden and I won't be able to help my children (Female, 45 years old, interview 3)

People living with HIV frequently recalled that the reason for initiating and continuing treatment is keep caring for their children and to stay a healthy person. They express their concerns about dying if they do not follow HIV treatment correctly.

Obstacles at the facility

A theme emerging from the analysis was the increasing work pressure at facilities. An increasing number of clients are initiating HIV treatment since the MaxART program; hence health providers mentioned the EAA has added a lot of work for them. Consequently, several people living with HIV complained about the waiting times at the facility, which depend on the queue to get in and the staff capacity.

That is the one thing I mostly complain about: I don't know what can be done because you find that when we are seated in the queue, you hear someone saying he is leaving without getting the services. Then you imagine that any other person can be

tempted to leave as well, so I really don't know how we can address this queue issue (Male, 31 years old, interview 4).

This person living with HIV appoints the possibility of people living with HIV leaving without receiving their services, because of the long waiting time at the clinic. A health provider mentioned another consequence of the work pressure and long waiting times:

You find yourself skipping some important information to give to the client, maybe because of the long queue because you are exhausted, that's the problem (Female, working as a manager, interview 6).

3.2.6 Experiences with viral load testing

Changing behaviour because of viral load results

As elaborated on in paragraph 3.1.1, knowing the viral load might motivate people living with HIV to get HIV treatment and/or adhere to it. This corresponds with how a respondent, who did not take her medication for three months, explained it:

Interviewer: It felt bad... okay. Did you make any changes after hearing that the virus is resistant in your body? What were the changes?

Interviewee: I am now taking my pills correctly and on time, I do not miss doses (Female, 48 years old, interview 1)

Another respondent also confirms taking her medication on time while being aware of her unsuppressed viral load.

Negative feelings towards viral load testing

Several people living with HIV assigned feeling very stressed after being informed about their viral load results.

I realised I will end up dead so I listened carefully to what I can do in order to lower the level of the virus in my body; I fixed my mistakes that I am able to take the treatment correctly (Female, 44 years old, interview 6)

People living with HIV feel shocked about these results and feel like they have to calm themselves down.

4. Discussion

This qualitative research set out to answer the following research question: How do people with HIV and health providers experience and practice HIV treatment adherence and HIV viral load testing in the context of an implementation study in eSwatini?

How health providers practice HIV adherence and HIV viral load testing

During adherence counselling, it appeared that health providers were very conscious about the information they disseminate about the viral load test results out of fear that it might lead to a decrease in condom use. Interestingly, this appears to be in direct contrast to the global *Undetectable = Untransmittable (U=U)* discourse, the notion that an undetectable HIV virus, as measured through the use of HIV viral load tests, means the person with HIV is uninfecious and thus unable to spread HIV (Bavinton et al., 2018; Cohen et al., 2011; Rodger et al., 2019; Keogh & Dodds, 2021).

Social scientists studying the social effects of new biomedical technologies proclaim that new biomedical technologies may affect how people act in our world. For example, Persson (2016) states that viral load tests empower Australians living with HIV giving them control over their own life. Health providers appear to manage information from viral load testing in adherence counselling pragmatically, strengthening the discourse on the importance of condom use. The reason for this appears that they are not confident that people living with HIV can handle this information properly, resulting in the risk of transmitting HIV. Looking at these findings through the lens of biopower, one could argue that health providers are using their ability to have access to more information in order to prevent people living with HIV from mishandling this information and infecting more people with HIV. During the period the MaxART project took place (2014-2017) the U=U discourse was not as widespread in many African countries, as compared to high-income countries where viral load tests have been more widely accessible (Bor et al., 2021). This possibly explains why health providers may have not been communicating the U=U message. In recent times, it appears that this message is receiving more traction also from social science researchers who stress that communicating the U=U message can create empowerment among people living with HIV (Keogh & Dodds, 2021): it fulfils their desires of having a family and possibly becoming less stigmatised than before.

According to health providers, there are concerns among people living with HIV regarding the government's intention of their attempts to provide free HIV medication. This fear might affect people living with HIV's feeling of control. Nonetheless, health providers do feel that people living with HIV should be empowered in making their own decisions regarding HIV treatment. Besides that, health providers admit that sharing information about viral load testing might motivate adherence.

How people with HIV experience viral load testing

This is one of the first qualitative studies assessing the experiences of people with HIV with viral load testing, which was first introduced as part of routine care in eSwatini in the context of the MaxART implementation study (Vernooij, 2022). It appears from my analysis of interview data that most of the people living with HIV do not recall being told about viral load testing. Some people living with HIV acknowledge changing their behaviour, this means taking medication properly, because of their viral load results. It seems that this is mostly due to the negative emotions they experience like fear and stress.

It also emerged that health providers assumed that when the viral load test showed that people with HIV had a detectable viral load, they interpreted this as a sign that people with HIV were not taking medication correctly. However, people living with HIV emphasized almost always taking their medication properly. People living with HIV attributed the result of their viral load test to suffering from stress or a lack of food. Instead of paying attention to social and economic-political factors affecting the effects of HIV treatment on people's bodies, viral load tests are seemingly leading to

medicalisation of HIV treatment adherence. As a result, a detectable viral load is perceived as a medical problem rather than a social one. In addition, food insecurity in African countries negatively affects treatment adherence. This insecurity is a strong indicator of non-adherence (Young et al., 2014).

Work pressure-based obstacles in the facility also affect HIV treatment adherence: long waiting times might result in people living with HIV leaving the facility without getting their HIV services. Moreover, health providers might inform them less comprehensively because of time management.

Based on research from WHO (2003) and Gitome et al. (2014), adherence support from the community is especially important in low-resource countries as there often is a shortage of healthcare personnel, like in eSwatini. And while it appears that most people living with HIV participating in this study are not involved in support groups, they do receive support from their immediate environment (mostly family) which helps them adhere to their HIV treatment.

Furthermore, literature suggests that limited education, and thereby low health literacy, can not only influence follow-ups but also proper intake of medication (Azia et al., 2016). All people with HIV who participated in the study have had limited education, however it is not evident how this affects their adherence in general. One person living with HIV experienced forgetting appointments because of being illiterate. However, it is discussed with the supervisor to not state an argument about limited education and ART adherence in Sub-Saharan Africa. This argument is seen as a racist argument because it was used during the release of HIV medication as a reason not to introduce HIV medication in Sub-Saharan Africa.

Lastly, a few people living with HIV report experiencing obstacles with coming to the facility, mostly due to the transport they can use. This is consistent with research that shows that financial constraints are an obstruction when travelling to facilities and thereby negatively influencing ART adherence (Azia, et al., 2016; Kagee, 2008).

Discussion of the strengths and limitations of the study

Limited data was available from the MaxART project to use for this specific study. People with HIV's experiences with viral load testing were scarce since health providers did not inform them sufficiently and those who were informed did not always comprehend the given information. Besides that, only eight interviews with people with HIV, with an unsuppressed viral load, were available for this thesis. The number of interviews and the fact that they were not very in-depth was a limitation for this study. For that reason, I applied ten interviews with health providers which did not only elaborate on viral load testing, but also on health providers' involvement in practising global health interventions. However, this dataset was also limited.

Another limitation is that the interviews with health providers were less structured than the ones with people living with HIV, making implementation harder for this study based on a secondary data analysis. Besides that, I have limited knowledge of biomedical HIV technologies in the field of social science and anthropology. Therefore, it was challenging to relate the analysed datasets to existing critical studies.

A strength of this study is that this bridges the knowledge gap on implementing viral load testing in Sub-Saharan African countries.

To reflect on paragraph 2.5., I did not experience misinterpreting the interview results. However, I did develop some bias regarding the argument about limited education and HIV medication adherence. I became aware of this after receiving feedback from my supervisor and decided to integrate it in this discussion.

Recommendations for further study

It is recommended for further research to study the possibilities of educating the health providers about social and political-economic factors influencing HIV treatment adherence. If there is a better understanding, staff could have more trust in people living with HIV and/or support them

in taking their medication. Healthcare personnel cannot manage this all by themselves as some factors are strongly linked to eSwatini's health system. It is suggested to conduct a nationwide and independent study on improving the (living) conditions of people living with HIV, aiming on making HIV treatment more accessible to them.

Another recommendation is studying interventions which can empower people living with HIV in their HIV treatment adherence in the context of eSwatini. A systemic review based on data in Sub-Saharan African countries (Buh, 2022) recommended, among other things, peer support for young adults, cognitive behavioural interventions or home-based nursing of people living with HIV as effective interventions. However, there is a lack of research on widespread, targeted interventions that are successful in enhancing ART adherence in Sub-Saharan Africa nations including eSwatini. It can be advised to study possibilities for using viral load tests to positively motivate people living with HIV to adhere to their HIV treatment.

Furthermore, a welcome attribution to related literature would be a study regarding the implementation of new biomedical technologies, wherein the most effective implementation strategies will be researched in the context of Sub-Saharan Africa.

Concluding statement

The implementation of biomedical technologies such as viral load testing takes place in a particular social and political-economic context. The expected empowerment of people with HIV, in terms of positive self-esteem did not happen. This seemed to be connected to particular power dynamics between health providers and people living with HIV, whereby health providers did not share all available information about condom use and viral load testing with their clients. It rather appeared that the information shared about the results of viral load tests made people living with HIV feel anxious or stressed about not taking their HIV treatment correctly. In the context of the MaxART implementation study in eSwatini it is concluded that viral load testing led to medicalisation of HIV treatment adherence, whereby individuals were reprimanded rather than empowered.

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Appendix 1a. Interview guide for interviews with clients from the MaxART project

Qualitative interview guide

EAAA clients initiated on ART above standard of care who had an unsuppressed viral load and received adherence counselling

Structural environment (explain as getting to know the person's background a bit)

1. What is your current job or what kind of activities keep you busy during an average day, whether you get money from them or not? (probe for changes before and after testing) *Ungangichazele kutsi engabe usebenta kuphi noma mhlawumbe nje yini lotiphilisa ngayo noma loyentako ngelilanga, kungaba yintfo lotfola imali kuyo noma longatfoli imali kuyo? (butisisa ngelushintjo ekucaleni nasekugcineni sewuhlolile simo se HIV).*
2. Please tell me who you currently live with (partner, children?) *ngicela ungitjele kutsi engabe uhlala nabani (ngabe ngulotsandzana naye, bantfwana ?)*
3. How old are you? *Semingakhi iminyaka yakho?*
4. What is the highest level of education attained (ask reasons for dropping out) *Ngabe esikolweni wagcina kabani? (buta kutsi kwaba yini tizatfu teku yekela sikolwa)*
5. What is your religion? *Engabe ukhonta kuphi?*
6. Accessing HIV services (How you get to the facility -where you access HIV services-, how long does it take, any difficulties in the past month to get there) *kutfola lisito ngeHIV (kutsatsa sikhatsi lesinganani kufika emtfolamphilo lapho utfola khona lusito nge HIV, futsi uhlala sikhatsi lesinganani emtfolamphilo kute usitakale, kuke kwaba khona yini bulikhuni bekufinyelela kulenyanga lendlulile?*

Experience of HIV testing/ lowendlule kiko mawutestela iHIV

7. Please tell me about the day when you were tested HIV positive, how did it go, from the time you entered the facility and when you left the facility? (probe for month, year, facility, experience of being tested, any changes in clinics) *Ngicela ungichazele mayelana nelilanga ucala kuhlola simo sakho sengati utfola kutsi sophila neligciwane leHIV, kwahamba njani, kusukela ufika emtfolamphilo lapho wahlola khona kuya lapho sohamba emtfolamphilo?(buta inyanga, umnyaka, umtfolamphilo, lwati ngekuhlolwa ingati, kushintja imitfolamphilo)*
8. Was this your first test and what was the reason for getting an HIV test? *Bocala yini kuhlola simo sakho sengati futsi yini sizatfu lesabanga kutsi ufune kwati simo sakho?*
9. How is your relationship with the health providers of the health facility you usually visit for HIV services? (probe for differences between staff, examples of how good or bad the relationship is) *Engabe kunjani budlelwane bakho netisebenti tetemphilo lapho utfola khona lusito ngeHIV? (buta ngebudlelwane netisebenti letehlukene temtfolamphilo, mhlawumbe tibonelo letinhle naletimbi kulobudlelwane)*

10. After you tested HIV positive what were the next steps taken by the health providers?
Emva kwekutsi utfolakale kutsi uphila neligciwane le HIV kwaba yini tinyatselo letalandzela lapho letatsatfwa tisebenti tetemphilo?

Social environment/ support

11. Did you talk to anyone about getting tested for HIV? (probe for family, partner, in-laws, friends) *Kukhona yini lowake wacocisana naye mayelana nekupopola simo sakho seHIV? (butisisa kungaba ngumndeni, lotsandzana naye, bekhakhakho noma mhlawumbe bangani bakho)*
12. Please tell me about who you lived with at the time of testing (how many people in the household, any changes in living situation before and after testing HIV positive, probe for who is considered the decision maker in the household) *Ngicela ungichazele kutsi bohla nabobani ekhaya ngesikhatsi upopola simo sakho? (bangakhi bantfu lobohlala nabo, kukhona lokwa shintja kulendlela benihlala ngayo ngaphambi kweku testa nangemvakweku testa, butisisa mayelana nalowenta tincumo ekhaya,)*
13. Please tell me about your marital situation at the moment of testing and after? (probe for boy/girlfriend, how many relations, how long, age, where does your partner work)? *Ngicela ungitjele ngebudlelwane bakho nalotsandzana naye ngesikhatsi uhlola simo sengati nangesikhatsi sewati ngesimo sakho sengati? (butisisa ngesingani sakhe, bangakhi lavana nabo, sikhatsi lesinganani, umnyaka nemsebenti waloyo lavananaye).*
14. Do you have children (probe for ages, children status, and whether they are living at home) *unabo yini bantfwana? (itsini iminyaka yabo, simo sengati sebantfwana, ingabe bahlala nawe ekhaya)*
15. Have you discussed your HIV status with someone? Why, why not? With your partner? How did they react? With other people, how did they react? *Engabe ukhona yini loke wacocisana naye mayelana nesimo sakho sengati? Leni? Leni ungacocisani naye? Loyu lovana naye ke? Baphatseka njani? Labanye bantfu ke? Baphatseka njani?*
16. Do you know the HIV status of your (current?) sexual partner? Is he/she on ART? (if no, do they talk about it) *Uyasati yini simo sengati salotsandzana naye nyalo? Engabe socalile yini kudla emaphilisi ekutsintibalisa ligciwane le HIV? umangabe chake niyakhulumisa yini ngako?*
17. Were there any changes or consequences that happened after you tested HIV positive (job, relationship, family, living place) *Kukhona yini lushintjo lolwaba khona emva kwekutsi utfolakale kutsi uphila neligciwane le HIV(kungaba semsebentini,ekhaya noma lapho uhlala khona?)*
18. Who do you talk or go to for support related to your health? *(ngubani loyaye ukhulume naye lokusekelako ngetindzaba tetemphilo?)*
19. Have you ever felt you are treated differently because of your HIV status by someone? If yes, what did they say? *kuke kwenteka kutsi bantfu bakuphatse kabi ngendzaba yesimo sakho se HIV? uma atsi yebo, batsini?*
20. Are you part of any support group (if they are not part of support group ask if they are interested in being part of a group and refer to support group in the area and give phone number). *Ikhona yini inhlango yebantfu labaphila neHIV loyingenele?(uma angakayingeneli buta kutsi engabe uyafuna yini kuba yincenye yalabanye bantfu*

*labaphila neligciwane leHIV/ i-support group, mutfumelele kusupport group
lesenzaweni umnikete nenombolo)*

Experience with ART/ tizatfu tekungacali emaphilisiema ARVs

- 21. Did the health provider discuss with you about benefits of starting starting ART? Engabe sisebenti setemphilo sakuchazela yini mayelana nesidzingo sekucala emaphilisi ekutsintsibalisa ligciwane?*
- 22. What did the health provider tell you about starting ART? Engabe sisebenti setemphilo sakutjela ini mayelana nekucala emaphilisi ekutsintsibalisa ligciwane?*
- 23. What was your understanding about the purpose of starting ART treatment? Ngekwati kwakho yini inhloso yekucala emaphilisi ekutsintsibalisa?*
- 24. How long after you tested HIV positive were you offered to start ART? (if client doesn't know ask for best guess, in weeks, or months or years) kwaba sikhatsi lesinganani emva kwekuhlola simo se HIV watfolakala kutsi uphila nalo ligciwane le HIV kutsi bakunikete litfuba lekucala emaphilisi ekutsintsibeta ligciwane le HIV(umangabe lobutwako akasakhumbuli buta ngekutsi kwaphela emaviki, tinyanga noma iminyaka lemingakhi?).*
- 25. Were there any barriers in starting ART? tikhona yini tingcinamba/tihibe lowabhekana nato ngekucala emaphilisi ekutsintsibalisa? (butisisa ngetihibe noma tingcinamba letaba khona Kanye netizatfu tekuphuta kucala emaphilisi ekutsintsibalisa ligciwane leHIV)*
- 26. How long after you were offered to start ART did you start ART? (if client doesn't know ask for best guess, in weeks, or months or years)(kwaphela sikhatsi lesinganani bakunikete litfuba lekucala emaphilisi ekuntsintsibeta ligciwane kutsi uwacale wabese uyawacala?)(nangabe lobutwako angasakhumbuli buta kutsi kwaphela emaviki, tinyanga noma iminyaka lemingakhi?)*
- 27. What motivated you to start ART (probe for multiple reasons) (yini lokwakukhutsata kutsi ucale emaphilisi ekutsintsibeta ligciwane le HIV?(Butisisa ngetizatfu letiningi)*
- 28. Did you experience any side effects of taking ARVs?(kukhona yini imivuka leyaba khona noma lekhona lebangwa ngemaphilisi ekutsintsibeta ligciwane?)*
- 29. Did you experience any health benefits after taking ARVs? (kukhona yini imiphumela lemihle yetemphilo lebekhona ngoba socale emaphilisi ekutsintsibeta ligciwane?)*
- 30. What do you do to remember to take your ARVs every day at the same time? Do you have anyone who supports you to take your ART? Who and why did you choose this person? (kukhona yini lokukhumbutako noma lokusitako kukhumbula kunatsa emaphilisi ekutsintsibeta ligciwane? ngubani, engabe yini sizatfu lesabanga kutsi ukhetse loyo muntfu?*
- 31. Did you manage to come on your follow up visits during the last 6 months. If not, probe e.g. what made it difficult to attend the clinic on the appointment days? (probe for reasons, did they overcome obstacle and how) tikhona yini tingcinamba/tihibe letibekhona letibange kutsi ungakhoni kubuyela emtfolamphilo etinyangeni letisitfupha letengcile? (buta kutsi kwaba yini tizatfu, nekutsi tikhona yini tingcinamba latincobile, utincobe njani?*

32. Do you ever use other types of medicine or immune boosters to stay healthy? (Probe for what kinds, probe whether they visit traditional or religious healers and changes since testing HIV positive or having started ART). *Uye utisebentise yini letinye tintfo letifaka ekhatsi imitsi leminywe noma mhlawumbe kwekunyusa emasotja ? (buta ngetinhlobo, ngaba kutsi ukutfole enyangeni noma kubathandazi nekutsi yini leseyshintjile kusukela utfole kutsi uphila neligciwane noma kusukela ucala emaphilisi ekutsintsibalisa)*
33. Did you ever miss any of your tablets? What is the longest time that you forgot to take your tablets? What were the reasons for missing your tablets? What did you do when you remembered it? (probe for reasons why?) *kuke kwenteka kutsi ukhohlwe kunatsa emaphilisi kwengce emalanga lamabili noma ngetulu(engabe kwaba yini sizatfu saloko)*

Experience with EAAA

34. Please tell me what you remember about the EAAA program (if interviewee doesn't remember ask for the patient booklet and point at the EAAA sticker for them to remember by themselves) *ngicela ungitjele konkhe lokukhumbulako mayelana neluhlelo lwekusheshe ucale emaARVs labatsi pheceleti iEAAA/ sheshe? (buka bhukwana mangabe angakhumbuli umtjengise sitikha sak EAAA)*
35. What do you remember to be the purpose of starting ART early? (EAAA program)? *nawukhumbula yini inhloso yaloluhlelo lwekusheshe ucale emaARVs.?*
36. What were the reasons you accepted to be part of the EAAA program? *Engabe yini sizatfu lesakwenta kutsi ufune kubayincenye yaloluhlelo lwekusheshe ucale ema ARVs?*
37. Did you ever have a viral load test taken after starting ART?
38. What do you know about the purpose of a viral load test? *ngekuva kwakho yini umgomo weluhlolo lwekutsi linganani ligciwane emtimbeni?*
39. Did a health provider discuss the viral load test and your results with you? (probe for understanding of the results) *Engabe sisebenti setemphilo sacocisana yini nawe mayelana neluhlolo lwekutsi ligciwane linganani emtimbeni? (butisisa ngekucondzisisa kwemiphumela yelinani leligciwane)*
40. How did you feel after receiving your viral load results? (if previously barriers to accessing clinic/ remembering ARVs were mentioned, ask if any steps were taken to remove these barriers after receiving and understanding the viral load results?)
41. Have you attended any community health event recently? Was anything discussed about starting ART early? (why, why not, please describe event, and opinion about it). *Engabe uke waba yincenye yemcimbi noma umhlangano weluhlolo lwe EAAA emmangweni?(yini sizatfu sekutsi uwungenele noma ungawungeneli, ngicela ungichazele kutsi engabe wawunjani lona mcimbi noma umhlangano nekutsi utsini umuvo wakho ngawo).*
42. In your community (umphakatsi and/or inkhundla) are there any traditional *leaders* involved in activities about HIV and the importance of starting ART early (EAAA) in particular (please give example of involvement, positive or negative influence). *Emmangweni (Emphakatsini wakho noma enkhundleni yangakini) bakhona yini bahholi bemmango labasenta tindzaba taka HIV noma taloluhlelo lolusha lokusheshe ucale*

emaphilisi ekutsintsibeta ligciwane leHIV-EAAA (nangabe bakhona ngicela ungiphe sibonelo semsebenti labawentako kungaba ngulokusekela loluhlelo noma lokulibuyisela emuva).

43. In your community (*umphakatsi or inkhundla*) religious *healers* and/or traditional *healers* involved in activities about HIV and EAAA in particular (please give example of involvement, positive or negative influence). *Emmangweni (emphakatsini wakho noma enkhundleni yangakini) bakhona yini labo labashumayelako noma baholi bemabandla labasenta tindzaba taka HIV noma taloluhlelo lolusha lokusheshe ucale emaphilisi ekutsintsibeta ligciwane leHIV-EAAA (nangabe bakhona ngicela ungiphe sibonelo semsebenti labawentako kungaba ngulokusekela loluhlelo noma lokulibuyisela emuva)*
44. In your community (*umphakatsi or inkhundla*) are there RHM's or other community health workers involved in talking about starting ART early (EAAA / "sheshe") (please give example of involvement, positive or negative influence). *Emmangweni (emphakatsini wakho noma enkhundleni yangakini) bakhona yini bagcugcuteli/banakekeli noma labanye nje labakhuluma ngetemphilo labasenta tindzaba taka HIV noma taloluhlelo lolusha lokusheshe ucale emaphilisi ekutsintsibeta ligciwane leHIV-EAAA(nangabe bakhona ngicela ungiphe sibonelo semsebenti labawentako kungaba ngulokusekela loluhlelo noma lokulibuyisela emuva*

Appendix 1b. Qualitative tool for interviews with health providers

II: Qualitative tool for semi-structured interviews with HIV service providers

Instructions prior to the interview

1. Give providers the social science information sheet and explain goal of interview: getting their views and experiences with EAAA to give them a voice to raise concerns, suggestions and feedback about EAAA. Please stress this is not an evaluation, we are not looking for 'correct' answers of what they believe we may want to hear, rather it is about getting true feedback from the way EAAA is affecting them and their work.
2. Assure that the interview will be anonymous, and their interview data will not be linked to them, nor to their facility, we will present interview data as a whole from the 9 facilities combined so it will not be traceable to their facility.
3. Ask if they have any questions, and ask for permission to tape record the interview, explain the reason for recording is for you to focus entirely on what they say whilst not having to write simultaneously, and to adequately capture what they are saying instead of summarising it. This increases the quality of the interview data.
4. If they agree and don't have further questions ask them to sign the a consent form..
5. On the consent form and when saving your files (both the recordings and written transcriptions) allocate the same code to identify the interview, for example for the first provider interview in Ntfontjeni you would name the file: PR.NT.01. the second one PR.NT.02 and for Mshingishingi the first interview you would say: PR.MS.01

Instructions during the interview

6. Introduce each topic briefly before going to the next topic and ask interviewee whether as part of their daily work they are involved in carrying out HTC, ART initiation, ART adherence/follow up activities.
7. The questions that are coloured that these are asked in several sections, please don't repeat the coloured questions if you have already asked them in a previous section. To assist I have coloured the questions yellow in ART initiation which should be skipped if the interviewee is also involved in HTC and has answered those questions already. The questions that are green in Adherence & Follow up should be skipped if the interviewee is also involved in ART initiation and you already asked the questions there. But for a person who is involved in HTC and Adherence & Follow (and not in ART initiation) you may need to skip the yellow ones in Adherence but not the green ones. Please let me know if there are any unclarities.

Topic list for semi-structured interviews with health understand their experiences of and attitudes regarding EAAA

1) Health providers including clinicians, nurses, counsellors, expert clients (select the topics of relevance according to the provider's involvement in HIV care)

A. Training (ask to all)

1. For how long have you worked at this facility?
2. Please tell me what you know about EAAA (initiating every HIV positive client on ART irrespective of CD4)
3. What is your understanding about the purpose of EAAA?
4. How did you feel about trainings provided by the EAAA team (what went well, less well, need for more training if so, which topics)

B. HIV Testing and Counseling

5. Did EAAA influence the time taken for testing and counselling? (if yes probe for how, what is taken extra time, is this an improvement or challenge, probe for any other changes in procedures. If not probe for why not)
- 6a. Do you explain EAAA during HTC (if yes, probe for what is being explained during HTC)
6. How do clients react to EAAA when you explain it (which questions are frequently asked) probe for an example question?)?
7. How did you explain the benefits of participating in the study to clients during the control phase? (please give an example, ask what they tell about the viral load and resistance testing? (probe for informing clients about starting ART early during control phase)
8. How do you explain the benefits of participating in the study to clients in the intervention phase?
9. How do you feel about offering ART to newly diagnosed clients on the same day? (Do clients accept this generally, what are possible positive or negative effects?)
10. What do you think are the motivators for clients to start ART early when they have a high CD4 counts or still in stage 1 or 2?

C. ART initiation or pre-ART counselling

11. Did EAAA influence the time taken for ART initiation? (if yes probe for how, what is taken extra time, is this an improvement or challenge, probe for any other changes in procedures. If not probe for why not)

➔ **Skip questions 12 till 15 below if interviewee is involved in HTC and answered questions 6 till 9**

12. How do clients react to EAAA when you explain it? (which questions are frequently asked, probe for an example question?)
13. How did you explain the benefits of participating in the study to clients during the control phase? (please give an example, ask what they tell about the viral load and resistance testing?)
14. How do you explain the benefits of participating in the study to clients in the intervention phase?

15. How do you feel about offering ART to newly diagnosed clients on the same day? (Do clients accept this generally, what are possible positive or negative effects?)

16. How do you know whether a client is ready to start ART? (Probe: what is the procedure, who 'decides' whether a client is ready)

17. What do you think are the motivators for clients to start ART early when they have a high CD4 counts, still in stage 1 or 2?

18. Did you have any clients who did not want to start ART early? What were the reasons? Are these reasons different from clients offered to start ART eligible to start based on CD4<350, stage 3 or 4?

19. Did you explain to clients starting ART can reduce the chances of transmission to a sexual partner? (Why, Why not?)

D. Adherence & Follow up

20. Did EAAA influence the time taken for ART monitoring (if yes probe for how, what is taken extra time, probe for any other changes in procedures, for example related to the 2 week review, refills?)

--> Skip questions 21 till 24 if interviewee is involved in HTC or ART initiation and answered the questions 6 till 9 or 12-15

21. How do clients react to EAAA when you explain it (which questions are frequently asked? probe for an example question?)

22. How did you explain the benefits of participating in the study to clients during the control phase? (please give an example, ask what they tell about the viral load and resistance testing?)

23. How do you explain the benefits of participating in the study to clients in the intervention phase?

24. How do you feel about offering ART to newly diagnosed clients on the same day? (Do clients accept this generally, what are possible positive or negative effects?)

→ Skip questions 25 till 27 if interviewee is involved in ART initiation and answered the questions 16 till 19

25. How do you know whether a client is ready to start ART? (Probe: what is the procedure, who 'decides' whether a client is ready)

26. What do you think are the motivators for clients to start ART early when they have a high CD4 counts, still in stage 1 or 2?

27. Did you have any clients who did not want to start ART early? What were the reasons? Are these reasons different from clients offered to start ART eligible to start based on CD4<350, stage 3 or 4?

28. Are you able to refer clients for other psycho-social services available? (probe for which kind of services are available, for example gender based violence, food support, why or why not are they able to refer?)

E. Opinions on EAAA (ask to all)

29. How did you feel about the study being implemented in phases?
30. Did you see clients from other facilities not included in EAAA/or who were still in control phase transferring to this facility? How did you handle those situations?
31. How do you feel about having the EAAA team in the facility (working relationship, communication, conduct, in control phase versus implementation?)

End of interview

Ask if interviewee has any questions or feedback

Appendix 2. Code tree of the data

Experiences with HIV treatment adherence	Medical factors influencing HIV treatment adherence	Perceived HIV treatment adherence
		Experiencing side effects
	Socioeconomic factors influencing HIV treatment adherence	Food insecurity
		Limited education
		Social support
		Obstacles with coming to the facility
		Intrinsic motivation
		Obstacles at the facility
	Information management regarding HIV treatment adherence	
Experiences with viral load testing	Changing behaviour because of viral load results	
	Negative feelings towards viral load results	
	Information management regarding viral load testing	
	Information management regarding condom use	
Relationship between health providers and people living with HIV	Perceived relationship	
	Authority of the health provider	