

HIV-treatment adherence: Exploring experiences of peer counsellors and young-adult clients in HIV Care centres in Eswatini

Thabo Cebolenkhosi Dlamini



Centre for International Health

Faculty of Medicine

University of Bergen, Norway

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Thabo Cebolenkhosi Dlamini

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Centre for International Health,
Department of Global Public Health and Primary Care,
Faculty of Medicine,
University of Bergen, Norway
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ABSTRACT

Achieving viral load suppression is a persistent challenge amongst young people in HIV care in Southern Africa, Eswatini in particular. Research has shown that treatment-adherence counselling has been central in the global response to HIV and is tipped as central in adherence support to increase treatment efficacy as well as help prevent drug resistance. The Ministry of Health introduced a National Expert Client programme in 2007 to shift tasks including Pre-ART counselling and preparation for ART for newly identified clients. Since then, the scope of expert clients has expanded to include ongoing counselling for clients in care to enhance adherence to care and treatment.

This study aimed at exploring experiences of peer-counsellors and young-adult clients on HIV-treatment adherence counselling in one HIV care centre in Eswatini. Data were collected over a period of 3 months and involved 6 peer counsellors who worked in the facility for at least 6 months, and 12 young-adult clients (15-24 years of age) who had at least 6 months in HIV care and treatment. This study used a combination of in-depth interviews and observation methodological approaches. Collected data was transcribed, translated and analysed using systematic text condensation.

The main findings of the study include how participants viewed living with HIV as burden; How dedicated social support played a role in treatment support and adherence as well as stigma both experienced and anticipated.

From these and using the cognitive behavioural change model underpinned by the social cognitive theory as an analytical lens, we discussed two dimensions of burden that generally were expressed from the findings which included living with HIV and the need to take ART daily to achieve optimum health. The findings also demonstrated that stigma remains a huge threat to access and actual retention in adherence, care and treatment for clients and counsellors alike in the facility and community. Young-adults accessing care did not feel as part of the decision-making process about their care but instead were dictated to and had to conform to healthcare workers' orders. These combined determined if the client would achieve adherence to care and treatment notwithstanding the prescribed standard counselling that was given.

Key words: HIV treatment-adherence, adherence-counselling, stigma, passive receipt of care, expert clients

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Glossary of terms

UNAIDS 2020 goal - The targets, as outlined by the UNAIDS underscored an ambition that: 90% of people living with HIV should know their status; 90% of those who know their status be put on treatment; 90% of those on treatment be virally suppressed (UNAIDS, 2014)

HIV drug resistance (HIVDR) is caused by one or more changes (mutation/s) in the genetic structure of HIV that affects the ability of a specific drug or combination of drugs to block replication of the virus (WHO, 2019)

Young adults-young people aged 15-24 years (SHIMS, 2017).

Abbreviations

HIV- Human Immune-deficiency Virus

ART- Anti Retroviral Therapy

NNRTIS, - Non-Nucleoside Reverse Transcriptase Inhibitors

PI- Protease Inhibitor

DTG- Dolutegravir

EFV- Efavirenz

NVP- Nevirapine

VLS- Viral load suppression

LMICs- Low-Middle Income Countries

CBT- Cognitive behavioural therapy

UN- United Nations

WHO- World Health Organization

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‘Tough times never last- but tough people do!’-Robert Harold Schuller

I would like to dedicate this work to the Almighty who against many odds kept me, restored me, recovered me and walked this journey with me.

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INTRODUCTION

This study explores HIV-treatment adherence counselling in a context of increased ART coverage and reports of poor adherence among young adults in Eswatini.

Overview of HIV burden

HIV and AIDS continue to cause substantial morbidity and mortality around the world. Of 79 million people who have been infected since the start of the HIV epidemic, approximately 38 million are living with the disease and over 36 million have died as at 2020 (2). Of these, around 0.7 million new deaths and 1.5 million new infections were reported in the same year, 2020. However, the overall death toll has been reduced by 64% since the peak in 2004 and by 47% since 2010 (2, 3). According to WHO, the drop in HIV-related mortality is especially evident in the regions with the greatest burden of HIV infection in particular the WHO African Region (4). The region recorded nearly 70% (460 000) of people dying from HIV-related causes in 2020 globally, indicating a near 48% drop in mortality since 2010 in the region.

Evidence suggests however that HIV still disproportionately affects poor regions of the world. In 2015, the UNAIDS published data suggesting that 28 of the 30 countries that make up for 89% of the global burden of HIV were Low Middle-Income Countries (5). Africa alone accounts for approximately 68% of the global burden of HIV with Southern Africa accounting for 9 of the top 10 countries with the highest HIV prevalence and 84% of young people living with HIV globally (3, 6). This means the predicted continual youth population growth in Africa is likely to increase new HIV infections and consequently the need for Anti-Retroviral Therapy (ART) (1).

Eswatini in Southern Africa has the highest HIV prevalence in the world. According to a 2019 WHO HIV data and statistics report the prevalence stands at 27% of the adult population, and 9% of young people (7). The tiny Kingdom with an estimated population of 1.1million has an annual incidence rate of 1.36% (8, 9).

UN 2030 goal to end HIV

As a crucial component of the Global United Nations Sustainable Development Goal (SDG) number 3, the ambitious target to end the HIV epidemic by 2030 inspired common will amongst nations to be more robust in providing access to effective HIV care services for all (10). Targets were set for a 15-year period divided into short term and long-term measurers to ensure healthy, non-infectious people living with HIV. The end goal was set at achieving specific quotas for

testing coverage, enrolment to treatment as well as viral load suppression (5). In the short term, the goal was set at diagnosing at least 90% of people living with HIV, have at least 90% of those on treatment and at least 90% of those on treatment achieve viral load suppression (VLS) by year 2020. The second phase was set at improving from the 90% to 95% across the spectrum by year 2030 to ensure that the response outpaces the epidemic (5).

“By accelerating the pace for available HIV prevention and treatment tools, the number of new HIV infections would be 89% lower in 2030 than in 2010, and the number of AIDS-related deaths 81% lower. Rapid scale up would avert 28 million new infections and 21 million AIDS-related deaths by 2030” - UNAIDS Fast Track Strategy (5).

After 5 years of implementation, as at the end of 2020 results showed that globally about 84% of all people living with HIV knew their HIV status (2). Among people who knew their status, 87% were accessing treatment and among people accessing treatment, 90% were virally suppressed (2, 4). This means the targets were nearly met and the focus may well be on doubling the effort towards the 2030 goal.

HIV Treatment and Drug Resistance

Despite the advent and accessibility of Anti-Retroviral Therapy (ART) especially for Low Middle-Income Countries (LMICs), new HIV infections are still recorded (2, 11). The continued absence of a cure for HIV makes ART the only available treatment option in its management. ART has been commendable in reducing new infections, morbidity and HIV related deaths over the years (3, 4). The efficacy of ART as a life-long treatment relies however on good adherence, which if disrupted, chances of treatment success are jeopardized (12). Now, as a consequence of poor treatment adherence, unachieved VLS in the presence of ART poses a high risk for the development of drug resistance, transmission of virulent virus strains, and adverse health outcomes including treatment failure, at worst death (13).

HIV drug resistance (HIVDR) is a direct consequence of failed adherence and a significant contributor to poor achievement of treatment goals. Over the years, HIV drug resistance has escalated as pre-drug resistance (in treatment naive patients) or acquired resistance due to viral replication in the presence of ART (14). This implies an increased likelihood of treatment failure. The resultant reduced effectiveness of treatment is shown to increase the risk of patients discontinuing treatment, getting sick or even dying (15). For this reason, the WHO recommends a 10% threshold for drug resistance (DR) prevalence to warrant removal of the resistant drug

from national formulary (14). It is upon this recommendation that due to increasing drug resistance the drug formulary was changed most recently in 2018 (14, 16).

If poor treatment adherence persists, even with newer robust drugs, resistance and possible treatment failure are still likely (17). The challenge for high HIV burden settings is that they are predominantly poor, making drug susceptibility testing expensive hence reserved for complicated cases. As such, treatment adherence support provides an economic preventive measure against drug resistance (18).

HIV amongst Young People

There is a general consensus about poor health seeking behaviour and treatment outcomes for young people particularly in southern Africa. A series of surveys done in numerous African countries show a trend of low HIV testing and treatment coverage with similarly poor treatment outcomes presented as low viral load suppression (8, 19-21). Labelling, stigma and discrimination associated with the disease create self-stigma and consequently poor treatment outcomes for young people (22, 23).

Many cultures identify adolescence as a unique developmental stage where the desire for autonomy is strong which consequently increases health concerns (1). Several studies in sub-Saharan Africa have shown young people as more likely to drop out of HIV care, or interrupt treatment because of stigma and disclosure issues, including long travel and waiting times at clinics (25). The additional burden of HIV diagnosis and chronic treatment enhance confusion and make coping harder. In this context, effective counselling presents an opportunity to enhance acceptance of an HIV positive status and ART adherence to achieve VLS as a goal of treatment.

Counselling

The UNAIDS defines counselling as an interpersonal, dynamic communication process between a client and a trained counsellor to resolve personal, social, or psychological problems and difficulties (26). It requires empathy, genuineness, absence of any moral or personal judgment, and the respect necessary to assist the client to explore, discover, and clarify ways of dealing with a concern (26, 27). Counselling is proven useful in shaping behaviour and enabling its recipients to better adapt to prevailing life stressors (28). Its effectiveness however rests on cultural, client and counsellor factors, environment and context.

In HIV and AIDS care, counselling has been a cornerstone for adherence support aimed at helping patients accept the diagnosis and regain the ability to manage their lives, consequently achieving compliance to treatment (29). It is important to note that it took researchers time to understand the pathophysiology of the disease and subsequent treatment, and this made HIV and AIDS infection a death sentence with unprecedented stigma and discrimination of victims in the early days (28). Decades later, such stigma is still attached to the disease. The early AIDS days coincided with Kobler Ross' then recent work on death and dying where she outlined grief in terminal illness. Her model found synergy in the mediation of AIDS related psychological distress, thereby securing the role of counselling therapy in coping, acceptance and behaviour change for people infected with HIV (28).

Counselling in adherence support

Good adherence gives ART a better chance at effectiveness in the management of HIV, hence adherence support is an important component of the basic HIV care package (30). Numerous strategies have been adopted to attend to issues on adherence to ART in both well-resourced and low-resource settings, a part of which are based on cognitive and/or behavioural principles (31, 32). Patient-based behavioural interventions targeted at those experiencing challenges with treatment have been most effective (33). By way of a systematic conversation, ongoing counselling should aim at enhancing acceptance of HIV diagnosis and help individuals on their path to reclaim control over their health aiming for adherence to care and treatment, thereby VLS as a goal of therapy. If effectively implemented, counselling can achieve positive behaviour change. In a number of LMICs especially in Africa, adherence counselling amongst other tasks is done by lay-counsellors, a cadre that has been significant as extra hands in HIV and AIDS response since the 2006 UNAIDS Universal access to ART program (11, 34).

National context of HIV response in Eswatini

Eswatini is estimated to have an HIV prevalence of 27%, the highest in the world (4). Through concerted efforts by multi-stakeholders locally and international bodies, the country was on course to achieve the UN 2020 fast track goals of 2020 by 2017 (8). The National rate stood at 87% of people living with HIV knew their status. Of these, 89% were on treatment with 91% of those on treatment having suppressed viral load.

Eswatini national AIDS Programme (ENAP)

After reporting its first case in 1987, the country committed to launching a response centre in the same year to coordinate response activities (35). Amongst a number of key programmes, ENAP implemented HIV Testing and Counselling (HTC) now HIV testing services (HTS) which have expanded massively in the country since inception in 2003 (35). HTS is the entry point for HIV prevention, treatment, care, and support in Eswatini and is offered in a dual approach. Since 2006, to reach a wider range of people, HTS has been either Client initiated, or Provider initiated. Both approaches leaned on an opt-out approach to remain observant of human rights-based care. The counselling component ensures that clients are ready for any possible outcome of the HIV test, which lays a basis for good treatment adherence in the event they are diagnosed with HIV and have to start on treatment (36).

Eswatini is amongst the earliest countries to mention HIV in its national development plans and to study the socio-economic impact of HIV and AIDS (37). A rise in HIV prevalence led to new measures. In 1998 a new HIV and AIDS policy was developed and focused on the three components: prevention, care and support, as well as impact mitigation (38). These are relevant even today and still guide the response to the epidemic. In early 1999, the government declared HIV and AIDS a national disaster and in 2001 the National Emergency Response Committee on HIV and AIDS (NERCHA) was established to coordinate and mobilize resources for an expanded, scaled up and coordinated response in the country (37). By year 2003, the HIV incidence rate was 4.7% and 1 in 3 adults were living with HIV (39). In 2004 HIV and AIDS related deaths stood at over 50% of all deaths in the country (9, 40). This period was before the United Nations declared Universal and free access to treatment in 2006.

Universal access to ART in Eswatini

Eswatini faced two significant health challenges at the height of implementing universal ART coverage. In 2011 it had the highest HIV prevalence in the world (26%) and a critical shortage of health care workers; with 1.7 physicians/10,000 population and 16.0 nurses/10,000 population (9). These challenges hampered the provision of HIV care and treatment. Alternatively, the ministry of health introduced and implemented a Nurse-led ART initiation program to rapidly decentralize and scale-up access to HIV services (35). Training of nurses in ART initiation helped improve accessibility of ART services for people in the rural areas, who attend clinics run only by nurses (35). This reduced the need for patients to travel to hospital and wait for the doctor to initiate ART thereby cutting costs and time constraints and ultimately

enhanced practical scale-up of treatment coverage. By June 2013, the proportion of eligible patients who had initiated ART was 81 percent, up from 63 percent in July 2012 (36).

Working with a number of international partners, in year 2015 the country adopted WHO updated guidelines on HIV management which introduced an even more robust programme to scale up access to HIV care and treatment (35). Unlike the 2010 guidelines which prioritised immune-compromised HIV clients with a CD4 cell count of 350 and below for ART initiation (41), the 2015 guidelines emphasised on ART for all who test positive for HIV as early as possible (30). This programme helped the country achieve HIV prevalence stagnation and nearly the 2020 UNAIDS 90/90/90 targets by 2017.

The national rate however masks differences between sectors of the population. According to an HIV incidence measurement survey in 2017, the country still falls short of achieving treatment goals for young people, in particular viral load suppression (8). Of 54% of young people diagnosed and on treatment, 72% had viral suppression, making just 50% of all young people living with HIV (8). The trend of poor viral suppression among this age group has been shown to exist in a number of developing countries including Zimbabwe, Zambia and Lesotho. Uniform amongst recommended actions in these countries is the strengthening of adherence support (9-11).

[HIV Expert Clients as adherence counsellors](#)

In Eswatini, adherence support through peer counsellors or lay counsellors also known as ‘Expert clients’ is widely practiced and forms part of the basic package of HIV care (30, 41). The counsellors are recruited amongst HIV positive and adherent to ART patients with some minimal education requirements who are then trained on a basic HIV care package (42).

The national HIV Expert Client Program was established by the Ministry of Health in 2007 following a significant shortage of healthcare workers. Today, this cadre has since grown significantly in size and scope (36). Expert clients have become a valued cadre within Eswatini’s national health system, and more than 450 expert clients currently work as part of multidisciplinary health care teams throughout the country (43).

Expert clients’ role is to support pre-ART and ART patients. Facility based expert clients have assumed responsibility for counselling, linkage, and adherence monitoring services, enabling nurses to focus on clinical services (36). At the community level, meanwhile, they trace patients

who have been interrupted in treatment and provide counselling support to help these clients return to care.

In a study done on the effects of task shifting in Eswatini in 2016, it was found that expansion of access to care and introduction of expert clients was strenuous; It resulted in longer processes and many hands before patients could access ART (42). Poor performance of facilities on given targets threatened these counsellors' jobs (42), as such the quality of counselling work would come second to meeting set targets. Another South African study looking into lay-counsellor perspectives on their sexual reproductive health (SRH) work with adolescents cited poor training and rigid operating procedures in working with adolescent-specific issues as major barriers (44). Counsellors felt that their clients default counselling because of trust issues. They would have to refer complicated cases because their scope limits them and this compromised the overall therapy outcomes (44). 'Information-fatigue' is another issue the study described, that young people are privy to HIV facts thus giving counsel on the same information becomes repetition and they do not concentrate, making reaching out to them difficult.

Despite such challenges with the work of counsellors, significant improvements have been noted in HIV response since their introduction. Lay counsellors have been found to provide quality services and relieve the workload of overstretched health care workers in Zambia (34). Actually, major improvement in treatment outcomes has been noted since their introduction in 2006, despite emergent issues of drug resistance and persistently poor VLS among young people in the region (14, 25).

Numerous studies have described negative findings concerning HIV-treatment adherence counselling outcomes in young people. Adherence counselling was found less effective in achieving viral suppression in young people compared to adults with a history of poor adherence in a 2015 study in Eswatini (45). Viral load suppression rates were also low (23%) among adolescents and children with virological failure that completed recommended intensified adherence counselling sessions in Tanzania (46). Adherence counselling that is applied early in treatment and continuously in ongoing care has been shown to be essential for early diagnosis of indicators of negative treatment outcomes and consequently corrective action (47). However, adherence counselling is somewhat shown to be less effective as an interventional strategy in virologically defined treatment failure. A recent study in Uganda confirms this (48), suggesting that adherence counselling is more effective as a preventive strategy for potential drug resistance even in the advent of highly potent drugs (18). This

evidence brings the importance of proactively applying treatment adherence counselling as a standard of care for greater results.

Study Justification

Research shows that robust scaling-up of ART led to near global success in reaching the UN 90/90/90 goal of 2020 to outpace the HIV epidemic (2). This is also true at national level for Eswatini who had managed 87/89/91 as at 2017 (8). Even with this national-level success, young people remain further from the goal of viral load suppression (8). Numerous other studies conducted in Sub-Saharan Africa show a cross-cutting trend of unmet VLS among young people despite intensified adherence counselling (42, 45, 46, 48). In fact, poor viral load suppression's share of the collective HIV response gap grew from 18% in 2015 to 21% in 2017 (25). Amongst other reasons for the unmet viral load suppression has been drug resistance to which the WHO offered guidance to replace the no longer effective drugs in 2017 (15).

The introduction of Dolutegravir (DTG) has offered a new opportunity in mitigating drug resistance and achieving VLS. Occurrence of viral load surge now should likely be a result of poor adherence, meaning that its management should concern improving adherence support, which will consequently preserve the robustness of the drugs (18, 49). In 2018 the UNAIDS noted that the sustainability of scaled up treatment programmes ahead shall be dependent on newer antiretroviral medications (25). The WHO also further tipped viral load suppression and adherence support as crucial to maintaining the strength of new regimens, preserving current drugs against resistance as well as moving towards ending HIV in 2030 (16).

Even 3 years before the drug resistance concerns in 2014, the UNAIDS had already realised a delay in young people's treatment outcomes (5). As a response, it launched an 'All in' campaign aimed at improving efforts in response to poor HIV response outcomes for young in 2014 (50). Even then, there has not been any significant improvement in a number of African countries and this potentially impairs attainment of the 2030 Sustainable Development Goal of ending HIV (5).

In early HIV and AIDS days, counselling was used as a tool to help HIV positive people cope with the diagnosis and has been consistently practised in treatment adherence support thereon (28, 29). Despite its application as a part of the basic HIV care package, young people continuously fail to achieve VLS.

Counselling provides an opportunity to enhance positive behaviour change to improve adherence thereby treatment success. Its application on young people has been extensive, however, its effectiveness has not been adequately understood and documented for this age group. Understanding how the counselling is perceived and experienced by both givers and consumers could be crucial for improving on best practices and strengthening on gaps to enhance the goal of viral load suppression and ultimately contribute to the 2030 goal of ending HIV. This study therefore aims to add to the limited understanding of treatment adherence counselling perceptions and experiences held by both Expert clients as counsellors and young adult clients interacting in HIV care in Eswatini.

Research Objectives

The main aim of the study was to explore experiences of peer-counsellors and young-adult clients on HIV-treatment adherence counselling in one HIV care centre in Eswatini. The Specific objectives were:

- To describe peer counsellors' HIV treatment-adherence counselling practices
- To explore the perceptions and experiences of peer counsellors of their role in HIV treatment adherence counselling
- To explore perceptions and experiences of young-adult clients receiving ongoing HIV-treatment adherence counselling

Theoretical concept

To explore the phenomenon of HIV—treatment adherence counselling, this study used the cognitive behavioural change model based on the social cognitive theory as a lens. In the social cognitive theory, Bandura posited that human behaviour is a learned concept, a construct of culture, socialization and interaction (51). He explained how the most essential aspect of behaviour is that acquired information serves as a guide for action, making behaviour change in humans possible through the influence of thought. Therefore, through the re-presentation of foreseeable outcomes, future consequences would be transformed into current motivators of desired behaviour (52). This process is applied as cognitive behavioural therapy (CBT) in healthcare.

Cognitive Behavioural Therapy is a client-centred method for enhancing intrinsic motivation by exploring and resolving uncertainty and barriers to behaviour change using empathy to support self-efficacy of clients (53). According to Dobson and Dobson (2009), CBT is founded

on three fundamental assumptions (27); the first being that cognitive processes and content are accessible and can be known using counselling to help individuals who cannot figure these out by themselves. The second assumption is that human response to environments is not haphazard, but products of how we think. The third fundamental assumption is that perceptions can be targeted, modified, or changed, and, when the change is a product of rational, realistic, and balanced thinking, then the individual's symptoms will be relieved, increasing adaptability and functionality.

The application of Cognitive Behavioural Therapy based on the social cognitive theory uses a set of core concepts whose emphasis is the full involvement of the client in their own plan of care. These include the client being a fully informed active participant who is capable to work with the counsellor to develop goals for therapy focusing on current observable behaviour. Secondly, it is also important that therapy is relatively brief and action-oriented where the client applies themselves practically and own the process (27, 51).

Cognitive behavioural therapy is used widely for emotional and behavioural challenges. In this study it will be used an extension of the social cognitive theory to help illuminate how HIV treatment adherence counselling is carried out, experienced and perceived by peer counsellors and their clients in the Eswatini context.

METHODOLOGY

Study Design

A qualitative research design was used in this study. This approach was best fitted to help in exploring the subjective perceptions and experiences informants held on HIV-treatment adherence counselling, observing practice and interaction all which are largely experienced in unique social domains (55).

To get in-depth accounts of perceptions, this study explores HIV-treatment adherence counselling in a context of increased ART coverage and reports of poor adherence among young adults in ESwatini.

To understand the counselling process the study used a mix of two qualitative research methods: semi-structured interviews and participant observation. The theoretical framework used in the study laid the basis for the interview guide used for exploring perceptions and experiences of both peer counsellors and young-adult clients with HIV-treatment adherence counselling. Participant observation was used to understand the counselling process as it unfolded giving more understanding of the counsellor-client dynamics and how the outcomes of the counselling process could be influenced by diverse factors in the study setting.

Study setting

The study setting was chosen by the researcher based on knowledge of the area, availability of possible informants, ease of entry, and feasibility of travel.

Eswatini is a landlocked country in Southern Africa bordered largely by South Africa and Mozambique only to the East (56). It has a population of 1.2 million people and is divided into four administrative regions, namely: Lubombo, Manzini, Hhohho and Shiselweni. The study was conducted in the Hhohho region, the second most populous region, accounting for 28% of the population. The region has the second highest poor HIV viral load suppression, higher levels of early sexual debut and young-adult female HIV prevalence which is triple that of their male counterparts (8). It has the National referral hospital, a secondary care hospital and one health centre among a number of clinics and public health units.

This study took place in a healthcare facility where I interviewed both HIV peer counsellors (expert clients) and young-adult clients, as well as did participant observation. All data collection was done in this healthcare facility located in the outskirts of Mbabane, the capital

city of Eswatini. The facility is one of the high-volume clinics in the region serving approximately 2000 clients in HIV care and treatment. It is a baby clinic to Mbabane Government Hospital, the only national referral hospital in Eswatini, and services areas including about six residential zones in its surroundings with a population totalling around 13000 people (BSRCS, 2013).

Characteristics of informants and recruitment Characteristics of informants

There were two types of informants in the study: providers of treatment adherence counselling (peer counsellors) and receivers (young-adult clients) in active care. A total of 18 informants were recruited to participate in the study; 6 peer counsellors and 12 clients. All Informants including both peer counsellors and young-adult clients were met in the facility for both interviews and participant observation. Nearly all informants came from within the area except for three who came from urban Mbabane and one from a rural area beyond the clinic's catchment area.

All 6 peer counsellors (HIV expert clients) working with the facility; two facility-based and four based in the community were recruited into the study. These were all female. The facility based counsellors serviced every client who visited the clinic for HIV services while community-based counsellors followed up on pregnant women, both HIV positive and negative until the child reached two years of age working on prevention of mother to child transmission of HIV.

The other 12 informants were young-adult clients (9 girls and 3 boys) ranging from between 18 and 22 years of age in active HIV care. From the 9 girls 2 had a child each. Ten (10) of the young adults were at least a single orphan, with the late parent's death allegedly associated with an HIV related cause.

Recruitment

Purposive sampling was used in this study. It is common that sampling in qualitative design studies is deliberately targeted at groups or individuals considered to be rich in experience and information that can help answer the research question (55). I interviewed peer counsellors who gave consent to being interviewed and observed. Community based counsellors were somewhat difficult to invite for participation due to their alternating schedule for reporting in the facility. Ordinarily each one reported to the facility once a week but due to COVID-19 mitigation measures, the four of them reported in alternating weeks, two per week.

With assistance from the facility-based peer counsellors we identified young-adult informants who met the criteria for inclusion. The first step involved getting a database of clients who had at least six months on treatment and scheduled for HIV treatment refill within a space of four weeks from 12 November to 12 December 2020 initially. However, due to strict COVID-19 measures, the timeline was eventually opened until March 2021. We separated the chronic care files from the others in the file cabinet, retrieved the client contact numbers and targeted them for recruitment. After the first week of recruitment, we experienced several clients we had targeted who did not honour their appointment dates which made the recruitment process slower. This prompted us to not only mark their return dates and rely on their clinic attendance but to also call and remind them of their appointments.

Due to COVID-19 second wave in late December 2020 extending into 2021, as well as the facility closing for two weeks for festive holidays from the 24th of December, recruitment was further disturbed. When the clinic resumed its services in January 2021, recruitment continued alongside data collection until we reached a level of data saturation in March 2021 where there were no new emerging themes from the data collected. Other challenges included clients who were not reachable on their mobile phones such that we had to go back and find others from the clinic database.

Each invited young adult gave consent for either interview, participant observation or both. Those who were eligible to partake in the study but could not give consent either because they were below the consenting age, were doubtful or out-rightly declined participation were not included in the study.

Inclusion criteria

Criterion for inclusion in a study refers to qualities and characteristics that potential participants should meet to be considered for enrolment (55). This study involved two sets of participant categories; peer counsellors and young-adult clients who met the different inclusion criteria defined in the table below.

Peer counsellors	Young-adult clients
<ul style="list-style-type: none"> • Having worked for at least six months in counselling. 	<ul style="list-style-type: none"> • Age 15-24 years old • HIV positive on ART • Active on care at-least three months

<ul style="list-style-type: none"> • Willing to participate and give informed consent 	<ul style="list-style-type: none"> • Of sound mind, capable to give informed consent • Receiving ongoing counselling or received some in the past three months
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Data collection

Data collection was conducted from 18th of December 2020 – 23rd March 2021. However, I stayed in the field from August 2020- March 2021. Pre-data collection activities included planning of the fieldwork, entry into the facility and obtaining ethical approval. I then conducted data collection, transcription, translation and basic level data analysis with ongoing data collection which continued well after data collection had ended.

For data collection, I used a standard checklist for participant observation. Semi-structured interview guides were used for interviews and all of these were audio recorded. The interview guide evolved as data collection continued as informed by responses from informants. As the researcher, I was the one asking the questions in siSwati, the local language. With each interview, I would listen to the audio recording and check for areas where my questioning needed modification so that the questions are asked better on the next informant for more elaborate responses.

To get the informants to be comfortable and open, each interview started with general questions like asking them about how they are, the weather and the likes. Being a local and knowing the language as well as my familiarity with the HIV care system made it easier for me to ask relevant questions and to understand deeper meanings to words and expressions used during the interview. As the interviews continued, I grew familiar with the interview process and it became easier to manoeuvre around the interview guide in a manner that all questions got addressed though without having to follow the guide in the written sequence. Most of the interviews ranged between 35 and 60 minutes while the shortest was about 30 minutes long.

Data collection was done within the facility. All interviews were held in a designated office in the clinic. However, there are times where the room would be in use by the clinic, and we would use an alternative one assigned by the clinic manager. For each interview I conducted, I had to make sure the audio recorder worked and also took notes for non-verbal cues, observed surroundings and sometimes, where consent was given, took photos of the surroundings to illustrate crucial points.

For every participant observation session, I went into the counselling room and the counsellor would formally introduce me to their client. I would only greet the client and then observe for several predetermined aspects in the checklist during the session. My observations were not only specific to counselling sessions but also daily routine. Patient flow and the structure of services provided in the facility are some key processes I observed and took interest in. These were useful in expanding my understanding of the entire environment under which treatment adherence counselling was provided and experienced in the facility.

Ethical considerations

Permission to conduct the study was sought from the Norwegian REK Vest which gave an exemption for ethical approval. Locally, permission was granted by the Eswatini Human and Health Research Review Board (EHHRB) before field work was initiated. Informed consent was sourced from all informants as a mandatory requirement to participate in the study. There were three different informed consent forms; one for peer counsellors which provided for both interviews and participant observation. The other two were for young-adult clients; a separate one for interviews and another for participant observation. These, unlike the form for peer counsellors were separated because counselling was not routinely given especially for clients who were doing well on care and treatment; therefore, some would be available for interviews but have no indication for counselling, hence the need to recruit separately for each aspect. The informed consent forms were translated from English to siSwati and were given to all potential informants to read where after they were given a chance to ask questions and given answers. All informants were able to read and to sign the informed consent form. I emphasized to each and every informant that participation was completely voluntary and they reserved the right to withdraw at any time without any prejudice. All informants gave consent to be interviewed and audio recorded. All signed informed consent forms were kept confidential in a lockable cabinet with the researcher.

All audio recordings were securely transferred to a password protected computer immediately after each interview. As a backup, I also kept copies of the audios in the audio recorder throughout data analysis which were deleted as soon as data analysis was completed. Transcription and translation as well as all data handling was done by the researcher. On the interview transcripts and participant observation checklists the names of clients were replaced with unique patient identifiers made up of four characters: two letters and two numbers. All names used in this thesis are made up to protect the confidentiality of informants.

Data Analysis

Data analysis for this study was a continuous process throughout the course of data collection and writing of findings. During fieldwork, I did some preliminary analysis and added some questions to the interview guide based on responses so that I could get more quality understanding of the subject under discussion. After all the data was transcribed and translated, a more systematic and thorough analysis was done.

Transcription and Translation

Each interview was recorded and kept as an audio file before being transcribed in siSwati and translated into English. Each document transcribed was fully translated before starting on the next one. All interviews were done by the researcher, including note taking and transcribing. The final transcribed and translated transcripts were kept as word documents in a password protected folder and computer for analysis.

Analysis

I began by going through all the transcripts organized by counsellors and clients respectively. I read through the data numerous times trying to find the sense and direction of the details provided by the informants. Broad topics covered in the data included: the subjective experience of living with HIV and taking lifelong treatment; how counselling is delivered as well as dynamics involved in achieving adherence to HIV care and treatment. From reading the transcripts, responses by counsellors were not mutually exclusive from those of clients therefore the analysis was not separated and the was not treated separately. A general profile of the informants was made including age at HIV diagnosis, experience with poor treatment outcomes and subsequent counselling, as well as demographics. All the transcripts were then printed out for manual hand coding.

Data analysis was an ongoing, continuous back and forth process throughout data collection, transcription, and translation. A more systematic analysis was done after all data was translated. The study data analysis used systematic text condensation. According to Malterud (2012), systematic text condensation is a method for thematic analysis of different types of qualitative data that is both descriptive and explorative and represents a pragmatic approach. It includes a stepwise approach; getting the total impression of the data; identifying and sorting meaning units condensation; and synthesizing from condensation to descriptions and concepts. Using a pragmatic approach, I deducted themes using the theoretical framework as a viewpoint and emerging themes from the data were also used in an inductive approach (55). The entire analyses process was done by the researcher manually. From the collected data the researcher

coded and grouped similar codes into categories. From the categorized chunks of data, relevant themes were drawn that captured in reduced form, the main findings of the study. *Analysis process example,*

Meaning Unit	Condensed text	Code	Category	Theme
“It is difficult to work with this age group because all we talk about is abstract and they have never felt sick of HIV. They have not seen an AIDS infected person as such ART to them is a by the way, they are ok...”	Offering pretreatment adherence counselling to Adolescents who have been diagnosed of HIV but never been sick	Achieving adherence	A mixed burden	The deception of no symptoms

Table 1. Shows one example of how systematic text condensation was done in the analysis of data

FINDINGS

In this section I will present findings from the research study. The findings are presented with a sense of both perceptions and lived experiences of Counsellors and Clients. Clients' perspectives are based on experiences living with HIV and receiving care and treatment. Counsellors on the other hand have additional experience including being clients living with HIV and receiving as well as giving counselling. Even though the informants were interviewed separately, the findings show that their views somewhat complement each other in many ways and as such the findings are not separated into the two groups of informants.

The findings will discuss four major themes. These are: The burden of living with HIV; Dedicated social support, as well as stigma. Each of these are illustrated with some sub-themes and quotes.

From the interviews it was evident that both clients and counsellors have both objective and subjective understanding of HIV, its treatment and how it is seen in the society. Counsellors have the added experience of having been clients and recipients of care and counselling before they became peer counsellors. They doubled as counsellors whilst also remaining clients in the same facility. The interviews also showed how both cadres experience the counselling interaction, feelings from these experiences and how they believe it can be improved to assist people living with HIV accept their status and lifelong ART. The informants also shared numerous issues which they believed were impediments in the successful implementation of the counselling process, retention in care and the general outlook of HIV care in the facility. All informants were given pseudonyms in the description of the findings.

The burden of living with HIV

All informants shared their own experience of living with HIV. From battling how they got the disease, having to live on treatment every day, to dealing with the sensitivity and stigma society has attached to HIV and being different. How clients acquired, know and perceive HIV including how society perceive the disease influences how they experience and perceive the condition and treatment, live and cope with it, how they feel about themselves and go about seeking care and treatment.

Having passively acquired HIV

Some informants had struggled with coming to terms with their HIV diagnosis because they were victims of vertical transmission. For the fact that they did not get the disease of their own making, they were aggrieved. *Nosisa*, one of the peer counsellors explained,

"...it's hard for these young people to understand what is happening. Say their older sibling does not have HIV and the younger one is also HIV negative, meaning they are the only one living with HIV, it causes further confusion as to what did they do wrong to deserve this! They are resentful" [Nosisa]

Rather than feeling angry, being the only child with HIV at home made *Esihle* feel isolated. She said,

"It has been six years since I got to know of my status. I believe I was born with HIV; my mother is on treatment too. At home I am the only child who is on treatment and that has been hard. My younger siblings do not have HIV. I feel different from others." [Elihle]

In an effort to avoid the emotional rollercoaster they knew discovering one's positive HIV status brought, according to *Velile*, her caregiver deliberately delayed disclosure. She said,

"It was painful learning that I have HIV. I was 12 and didn't understand then what this was all about. Yes, I was taking medication but they did not tell me, I only knew I was sick. Well, I was sickly! I was always sick and I only knew that the medication was for helping me deal with that. My grandmother only broke it to me when I was around 15 years old: that's three years of curiosity. She took longer to tell me and she justified that, she was waiting for me to be old enough to handle it..." [Velile]

Mandla on the other hand chose to not discuss his HIV status with his mother. He would not imagine accusing her for giving him this disease. He explained,

"I only started to living with her three years ago when I was 16. I am not comfortable discussing sensitive stuff like HIV with her because I think she would feel like I am laying blame on her for my status. She is on treatment too I know even though I discovered this when I came to stay with her. She kept this from me all that time and I feel like she too was never comfortable talking about it." [Mandla]

Starting and staying on treatment is the hardest part

Informants experienced a range of difficulties with treatment. Initiating ART was one thing, and the actual daily drug administration was another. It was hard to accept that his health and life relied on this daily routine. *Sandile* explained,

“I think it was starting them. That was the hardest for me. The thought that your life borders on them and you are told you have to take them for life. Me thinking ‘I have to drink medication till my last day’ I even thought of giving up” [Sandile]

For *Velile*, on the other hand, the literal drug administration was the hardest part. Even though she had full understanding of repercussions that came with not taking the drugs according to the prescription, she would skip doses nevertheless.

“Taking the medication, as in the literal taking of the drugs is quite difficult for me and that’s why sometimes I cheat. Oh, not necessarily cheat but I forget...It’s giving me a real problem because sometimes I get scared when I remember what we are taught here that if we don’t take the drugs, we will have weak immunity and get sick and that really freaks me out.” [Velile]

Sebe narrated how exhausting it was to take medication; how she tried but failed and defaulted at some point. It complicated her treatment regime even.

“...Oftentimes I would just feel like not taking them at all. I would be tired but knowing that stopping has terrible consequences I had no choice but to continue. I had a tough time; I was failing and I stopped at some point. I got very sick and even had to switch to second line.” [Sebe]

Even *Tibu* echoed that *“Taking medication daily without a break is difficult...”* She suggested reducing the dosing frequency to make this work and said *“...maybe if we took a pill once a month I would like it better, otherwise it is tiring!” [Tibu]*

Dealing with a mixed burden

Most peer counsellors shared quite similar accounts of how complex giving care to young people with significant multiple challenges at once had been. Often the complexities were associated with female clients. *Mbali* regularly saw HIV as a co-diagnosis with unplanned pregnancy and this created a number of challenges for the young women she reckoned.

“...I work with newly diagnosed pregnant women. I often have to call them daily to remind them since they are not yet used to the treatment routine. That they are also pregnant is a challenge. ‘I wasn’t thinking of having a baby just yet, at the same time I need to start on this medication, what will my parents say?’ They are stressed, and we have to help them cope and accept both conditions simultaneously. It is an unplanned

pregnancy, HIV, initiation to treatment and the thought that if they don't take the medication they may pass the HIV to the unborn child, it is too much." [Mbali]

Owe also noted the challenges with young mothers and how she believed the fact that they are still dependants themselves made them feel bad about bringing shame to the family hence did not disclose to the parents.

"We have young mothers and most of them default easily. I think they do not disclose to their parents that they have started ART in the first place. I believe they face difficulty on how they can disclose considering that they feel by being pregnant they have brought shame and added responsibility to their parents. I say this because when I do home visits others say 'please do not visit me at home, lets meet at the clinic instead'" [Owe]

She continued to narrate how one client decided to conceal her status and not disclose despite being a child and staying in her parents' house. Without activating familial support, this led to challenges in her adherence and also made any subsequent follow-up even more difficult ...

"...she said to me 'I do not want my parents to know,' and that made it harder to establish parental support because without consent I could not visit her at home. She kept her medication with her friends and at home nobody knew they are living with HIV." [Owe]

Nosisa felt that dealing with females in this developmental stage was difficult. They had unpredictable behaviour patterns with a lot of disruptive emotional changes leading to challenges in achieving treatment success.

"...It is not good. This age group is difficult because we are dealing with a 'stage' instead. It's hard because others get pregnant. Even worse others still say they stay with their boyfriends who got them pregnant. Now when the boy leaves them, they get frustrated and default treatment in the process. This way it is hard to deal with them." [Nosisa]

The deception of no symptoms

Some counsellors believed that previous direct or indirect experience with HIV had a bearing on the level of seriousness with which clients viewed the disease and their attitudes towards treatment. Absence of this exposure was believed to lead to a casual approach towards treatment and the easy decision to skip doses in some days without regard for the consequences.

"...They often find out they have HIV but feel healthy and without symptoms. From what I have seen, this makes treatment a huge discomfort. Adults on the other hand accept their diagnosis and treatment much easily because either they present late with opportunistic infections such as TB, or they have seen or cared for an AIDS stage relative which this makes their adaptation quicker compared young people. The time they are having fun, it's then that they default. Say they went to visit boyfriend; they don't bring medication along." [Mbali]

Mbali shared her own story on how she discovered she had HIV but because she felt fine, did not take medication for a long time and the complications she faced thereon:

"I tested in 2006 but didn't start treatment then, I was fine. In 2008 I got pregnant and was somehow forced to start treatment. I think my not starting treatment then allowed HIV to progress a lot such that when I started, I developed active TB. I had to add TB treatment now on top of my HIV medication and I won't lie it was too much medication and side effects. Two years after curing TB my immunity was not recovering, I had TB again and had to re- take treatment. I don't remember anything as difficult as taking so much medication, at one time. I felt like stopping ART, but thankfully I had ample support at home. From there I never looked back, being sick and that pill burden I swore to myself to never skip treatment" [Mbali]

Another counsellor echoed how seeing the devastating effects of AIDS in a close relative made her commit to treatment.

"I decided to start treatment because I had seen AIDS on my own cousin before it killed him. I was in shock at first but later I was able to take my medication. If I hadn't known or seen the devastating effects of AIDS, I don't think I would have turned out this way because the treatment is exhausting." [Nompe]

Care routines

Informants gave varying accounts of their experience of service delivery. These experiences included the positive platform that counselling is, but also encompass care encounters that were perceived as instructional and rigid, providing limited space for either clients to contribute to their care plan, or counsellors to contribute to shaping their roles.

Based on lived experiences, counsellors described their outlook on counselling. They gave accounts of how the concept and approach itself, themselves as counsellors, the clients and the

local context altogether influenced the counselling process, the outcome and the effect this interplay had on the client's treatment outcomes.

Client on ART

Nosisa who worked as a facility-based adherence counsellor explained how the primary responsibility of preparing newly diagnosed clients for lifelong ART rested with counsellors, with nurses coming in on the last part to initiate a ready-for-ART clients. She described this as laying a foundation for continuity in care.

“After the client has been diagnosed with HIV, they come to us where, above opening a care file, our main focus is addressing all pertinent questions and concerns towards anchoring long term ART adherence in the mind of the client. We do this understanding that acceptance is central to good adherence and work actively to achieve it. We then refer to ART Nurse who will only initiate the client” [Nosisa]

Bandile who is also a counsellor added client monitoring as one of his primary responsibilities. He discussed the importance of treating and viewing his clients as equals as a way of creating a supportive atmosphere.

“I do counselling, pill count, viral load monitoring and so on. When the clients come here they start in outpatient then for HIV testing then for those reactive, my task is to enroll and register. Most importantly I give counselling with a view to encourage the newly diagnosed peer through disclosing my own status so they may feel they are not alone and work towards accepting this new reality.” [Bandile]

Resilience coaching

Community based counsellors described their job as mentorship. They described that their work revolved around empowering all young mothers on safe motherhood through inspiring them towards outliving daily challenges at home that would otherwise compromise their adherence to treatment.

“...we visit all pregnant women, positive or negative at home. We seek to understand their socioeconomic environment and how this may impact their response to care and treatment. After all I should be able to assist the client explore possible avenues towards outliving such challenges with an aim to prevent mother to child transmission by empowering the negative to stay negative and the positive to adhere to treatment” [Mbali]

Counsellor *Mbali* believed that motherly instincts were crucial to invoke so to encourage treatment adherence particularly for first time mothers. By triggering these and fixing the discussion on the ‘innocent child,’ she was able to encourage a single mother who had lost all hope to remain on treatment.

"...She said 'He has abandoned me and the child, so if I'm dead I won't go through this torture.' Knowing motherly instincts, since I am a mother myself and cannot just leave my child, I carried for nine months to suffer alone, I leveraged on that and talked of the welfare of the child to say if he has abandoned the child whilst you are here, how much more when you are gone!" [PC3 Mbali]

The Marginal position of counsellors providing care Heavy work load

Fulfilling the expectations of being a counsellor included a number of tasks. Primarily, the job entailed giving counselling to clients but the depth, context and accompanying tasks were different for both facility and community-based counsellors.

Mbali, a community-based counsellor discussed her typical day. She highlighted how they went about particularly strengthening family support for their clients and referring for antenatal care those pregnant women not presenting to the health facility. Despite visiting a handful of clients in a day, *Mbali* found her work more demanding physically.

"We see at least 4 clients per counsellor in a day. We work in six zones and we have to walk to visit our patients. Beyond visiting and assessing client living conditions and giving tailored adherence support, counselling and helping integrate family into the care of the client, we also have a responsibility to ensure that along the way people who need help related to our work are attended to. This is how we generally recruit new clients from the community, most of which are pregnant mothers. Then there is the daunting task of documentation; we carry heavy registers to fill and some referral books." [PC3 Mbali]

Speaking of tasks, *Bandile* believed that despite counselling being her primary task, it formed a small component of her daily tasks in the facility. In describing the work she does, *Bandile* believed she was more of a stretched clerk.

"We see at least 40 clients each day for pill count, re-appointment and ongoing counselling. We are just two and some days it's one. In between seeing clients for treatment refills, we see newly diagnosed clients that need to be prepared for ART

initiation and that is a long process. We also file, reconcile the appointment register to see who has not come and make appointment reminders as well as retrieve files for clients coming the next day. We have monthly teen club meetings which involve a separate load of clerical work. It's crazy!" [PC5 Bandile]

Client resistance of counselling

Most counsellors shared their experience with young people in counselling. Not only did the counsellors encounter what they described as 'active avoidance' of each encounter, they were also confronted with overt lack of enthusiasm if the session took place. These attitudes as described by Mbali, could not deter their efforts to offer help.

"They are not paying attention and instead remain glued to their phones during the session. I think they are longing for the time you finish. We call before visiting them, and they either say they are not around or just do it for the record. Sometimes we visit without calling, and they just say 'I am on my way somewhere right now,' just to avoid counselling. Unfortunately, we cannot impose ourselves or disturb their routine so we reschedule. The patience we have to have sometimes is unimaginable but then again, we can't abandon them, we have a duty to help them" [PC3 Mbali]

There was no exception for clients who were attended in the facility, counselling was not entirely acceptable either. Nosisa described varying levels of rebellion meted by her clients towards herself and the exercise. Not only did they defy the counselling, they were also rude, which made the work event more difficult she said.

"They don't respond positively to counselling. Amongst the young adults, some have become pregnant, something we actively discourage but they don't listen or care. In one instance I was giving counselling, and the young lady pointed to her watch literally and said 'please hurry up, I have somewhere to be,' with an attitude. It is unfortunate what we encounter, but we try again over and again." [Nosisa]

Passive receipt of care and instructions

Most clients had experienced a counsellor that had answers and never asked during counselling. While sharing her experience with a counselling encounter she had after being diagnosed with high viral load, Esihle summarized the session as one-sided. She narrated how her counsellor had no intentions of finding out from her of possible clues or issues that may have led to the elevated viral load, but instead told her to practice safer sex. This was supposed to be a solution

to her problem, which according to her, was never there in the first place. According to Esihle, the counselling was misplaced.

“Early on the year I had high viral load. I was too stressed, had switched medication and administration time so I would forget. I received stepped-up adherence counselling. See, I am generally an open person but what I didn’t like is assumptions made on what led to my high viral load; ‘you need to use a condom!’ I mean who said I’m having sex to begin with! Secondly, I know for sure how being sick from HIV feels so why would I not use a condom? ‘That counsellor talked about what she wanted and not my issues.’”
[YAI Esihle]

Mandla for one believed that the art of counselling had to be based on active inquiry into the source of the challenges facing the client. As a recipient of counselling, he emphasized the fact that he was unique and so were his challenges and as such counsellors should ask more, because if not, that counselling would be misplaced.

“I think the counsellor ought to listen to what I have to say not to assume what the source of my challenges may be. I know me better. They should also probe for clues of what I think could be done to solve the problem, after which we stick to what we agreed on under my suggestions.” [Mandla]

In fact, Mandla generally preferred one-on-one counselling but also believed as clients they had unique needs that required exploration of other forms of counselling. In his criticism, of the facility-based approach which everyone was offered, he wished for that opportunity to determine where, and how they can be more comfortable to share their personal stories and problems during counselling.

“I think there should be options! The client be given options. There are us who can share face to face but others may not be comfortable and need to share but blindly. There is stuff that may not be sensitive to me but another person would find sensitive and want to get advice on anonymously.” [Mandla]

Imposed obedience

Most clients had gained the understanding that counsellors often believed that by virtue of being healthcare workers, they occupied a position of authority above their clients. This assertion of knowing better had resulted in a state of leaving clients out of decision making.

Clients' involvement as stakeholders however was, as clients experienced it, not an issue for most counsellors because the healthcare provider "Knew better" and their instructions had to be obeyed. When asked to elaborate on how she feels about the care she receives, *Nompe* said she takes healthcare orders without question despite being a healthcare worker herself.

"I told myself that when the clinic says drink Panadol for your headache, I do that without asking twice." [Nompe]

Sharing how much knowledge they have as counsellors on ART, *Mbali* used the expression 'we are experts in taking HIV medication, clients must listen to us!'

"I try to make the client see the importance of taking medication. It is important to tell the client that we are called 'Expert clients' because we are experts in taking ARVs. "[Mbali]

As stakeholders in their own health management and as much as he would have loved to have more clarity, *Mandla* said he was told about new changes in his care and he felt it was a directive:

"When it came to changing my medication, they told me that I would be switching to different medication on my next visit. I would have loved to know why but I never had an opinion in that decision neither was I given reasons why." [Mandla]

Esihle said "I wish I had an opinion!" [*YAll Esihle*]

It is clear that from a client perspective the care received was often disrespectful and paternalistic while the peer counsellors described themselves as experienced ART users, as experts who should be listened to. At the same time, the counsellors they described a scenario where they had little freedom to develop the counselling on an individual basis. They had been given points to cover and limited time for each session

A rush to initiate ART

Nosisa, whose work as a counsellor dated before an enhanced initiation to ART programme in 2017 described how initiation to treatment changed from being a process to becoming an event. She narrated how the pressure to start on treatment all clients who tested positive for HIV immediately led to retention challenges and more.

"I have an example of a student who tested positive after being recruited for voluntary medical male circumcision and was initiated on treatment and referred to us. He was

tested at school and disclosed to, parents not involved. He developed anger, put blame on his mother and defaulted care and treatment. We tried following up with his mother and she reported suicidal gestures exhibited by the client. We do not know how to handle suicidal people; it is beyond our scope so we escalated it to our supervisors. Instead of taking rapid measures to follow-up on the case, they just ignored it. To date the child is not on treatment, I'm sure even if he killed himself by now we do not know, the referral wasn't closed till today. What they did instead was say call a social worker or refer the child to the national psychiatric centre. In short, there is a clear path to initiate, but when we face challenges, some we run into problems we cannot handle and our supervisors do not want to take charge" [Nosisa]

Motivation

Most counsellors admitted to having limited training on their job. Despite this lack of skill, the willingness to help others was what drove them to offer effective counselling. For *Nompe*, this intrinsic motivation was inspired by her experiences during when she was a client.

"There is training yes, but I believe it depends. Like me, since I started working here some six months back, we have only had one training. I have been conducting counselling without any training, I learnt on the job. I do believe this has to come from within. I think the counselling that helped me is what inspirers me to help other people. Another person cared for me; therefore, I should do the same." [Nompe]

Despite all the good stories counsellors had to share about determination to help their peers, there was one issue that made their commitment difficult; remuneration. Not only were they struggling to make ends meet due to poor pay and stigma, they were losing motivation to do the job in the process.

One of the counsellors, *Lebo*, believed that the work she was doing was worth more than she was getting paid. What was even more frustrating for her was that even professionally there was no development that their trainings added because they were not certified. As such, there was no personal development and no better opportunities they could seek in the field.

"I do this job diligently but sometimes reality gets to me that I do this work out of passion, but the money I earn is not motivating at all. Last month I was nearly locked out, even affording rent and buying food is tough, I have a kid you know. I help people

find their feet in living with HIV and taking treatment. The money is too little and worse they do not certify us with each training. I personally work through experience, there is no certificate or any document I can produce to say I am a counselor and this is the training I have.” [PC6 Lebo]

Bandile added that as a result of the poor pay, they were experiencing a high turnover as a department.

“...what can I say, the pay is not good. I am not educated yes but I believe the pay can be better. I have been here and have had two colleagues quit because of this. The other counsellors you will see here are at least four months old here and already complaining and dare me they will leave too.” [PC5 Bandile]

Dedicated social support

Counsellors detailed how they counted the number of pills as an initial objective measure of client adherence. Subsequently, they would rely on viral load count to determine if the client is achieving expected treatment outcomes as a confirmation if indeed the client had been taking the medication.

“When we say the client has taken their medication well we are looking at between 95 and 105 percent of drugs taken in that time period. If there is a trend of poor results, the virus continues to multiply and we see that through a high viral load result.” [PC5 Bandile]

Accepting HIV status

All informants mentioned that they had accepted their HIV status. While others credited adherence-counselling and support in the facility, some clients felt that the support they got at home was central to this milestone. Explaining the importance of acceptance of HIV as a general prerequisite to successful adherence, Owe mentioned what they ask of their clients and said,

“...this is not the end of life. We ask that they should take care of themselves and try to live with HIV, we understand it is a difficult, painful situation that is not easy to accept overnight, but to be able to live a healthy life, they should accept it...” [Owe]

Understanding that HIV is currently incurable, Sino explained how she got to eventually accept her status.

“Adherence counselling helps us understand that HIV is incurable therefore to adhere to treatment and stay healthy. The counselling itself helped me to accept my status even though it took me long.”[YA9 Sino]

A non-linear process

Informants discussed how client acceptance was affected by other stressors facing the client. This made the time to accept vary with each client. *Bandile* explained how she believed acceptance was not always achieved.

“...It’s common that newly discovered pregnant women are also required to start on treatment at the same time. Acceptance is not an indicator for readiness to treatment and poor adherence issues are common in this group. We give ongoing counselling, however it takes some time to accept, some don’t but just hang in there for the sake of their child.”[Bandile]

In a personal experience, *Sandile* shared his struggle coming to terms with living with HIV because the home environment was not as supportive.

“I have managed to accept my situation now. The past few weeks I was home, visiting my grandmothers’ place so I was afraid and hid when I had to take my treatment because I had previous experience with the adults treating me differently and it was visible to me that it was because I had HIV. My cousins saw me and asked what the medication was for and I told them it’s HIV treatment. They too made fun of it but I ignored them and took my morning dose without a problem. After struggling a lot with accepting my status and hiding, I now know what I want” [YA4 Sandile]

Disclosure as a measure of acceptance

Some informants believed that overcoming the fear of being disclosed as living with HIV was also an indicator for someone who had accepted their HIV status and integrated treatment to their daily life. Counsellors mentioned the importance for people living with HIV to disclose their status to someone to help establish their treatment support base. *Nompe* elaborated on how they stop at nothing to help the client disclose.

“It is key to know who is closest to the client that they can disclose their HIV status to. This is often their close relative or partner they stay with. We even help our clients to navigate disclosure because it is a hard thing to do and tricky and we have certain tricks

on how to do it. Disclosure helps get the client treatment and moral support to take necessary action and precautions, to become virally suppressed.” [Nompe]

Mandla explained how after accepting his status he was able to share his status with his peers.

“I think I have gained courage to stand before people and talk about my HIV. I am a naturally shy person but through the health clubs I have learnt to accept my status, I am not alone. I teach and share on my experiences.” [Mandla]

For Tibu, learning that her counsellors were also living with HIV, made her feel less different from other people. She said,

“I felt better after my counsellor told me she is also living with this disease and is on the same treatment. I used to feel like I was the only one who had HIV so this helped me a lot knowing there is more of us dealing with HIV.” [YA12 Tibu]

On a similar account, having been hiding her status in the house and battling fear of being known for some time, Sino decided to disclose her status to which she received nothing but support.

“I was nervous but I eventually disclosed to everyone at home and I received tremendous support. Only my aunt knew but she said it’s my choice to disclose when I feel comfortable. They promised to help wherever they can and I am quite happy, even more so because I am the only one who takes treatment.” [YA9 Sino]

Having worked on counselling for nearly six years, Nosisa had learnt that the help she gave to her clients in fact helped her more. This was the reason she had confidence in counselling but felt as if she spoke from a privileged position than clients who only received and didn’t have the opportunity to learn through working with other people’s challenges. Sharing her own story and disclosing her status to her patients just to inspire them and show them they were not alone, she learned even more to accept her own status and live with it. Her job had become her support.

“Yeah, well what has helped me is working in this job because I then was able to understand myself, my condition and then accepted myself and helped others by disclosing my status. I have learned that acceptance is not a once off thing here, you accept yourself and this life every now and then. This way I know it is not easy for our clients and honestly, I don’t think if I was not working here id have accepted myself to the level I am so comfortable with myself now. I doubt I would be here telling my story

today. So, this job helped me and became my support in my situation on top of the support I get at home.” [Nosisa]

Being present for the client

For each client newly diagnosed with HIV, the facility would recommend starting treatment as soon as possible. Most counsellors believed that their clients needed active support during this period to adjust to the new routine and way of life. *Bandile* explained her understanding of counselling needs in different stages of the client’s journey and said,

“Counselling is ongoing, once HIV positive it does not stop. In the initial stages it is to prepare the new client for lifelong ART. As you go on it becomes corrective, for maintenance. Clients should be able to accept ART as an integral part of their health and lives ahead and as such, we become a consistent part of their care through counseling.” [PC5 Bandile]

Counsellors believed that practice had helped them to categorize their clients according to amount of support they needed, common challenges and solutions to these. For instance, *Mbali* described her doubts about both HIV positive and negative pregnant mothers on implementing HIV preventive strategies with fidelity to protect the child from transmitting the disease. She was however fortunate to have had experience that she could share with her clients on how adherence to ART helped her give birth to a healthy baby.

“I help pregnant women, both positive and negative throughout pregnancy until child is two years old. The objective is to have the positive mother take medication diligently and the negative woman prevent contracting HIV. Honestly, I doubt during pregnancy people use condoms, as such it’s crucial to keep the reminders coming. I didn’t see the need myself during my pregnancy and I share with my clients how consistency in ART helped me deliver a negative child.” [PC3 Mbali]

New clients who had just started on ART were also earmarked for close monitoring. According to the counsellors, these had a higher risk for detaching from treatment and as such had unique follow-up needs before they could be considered successfully linked to care and treatment.

“...they have adherence challenges. We encourage that they have reminders not detached from their ordinary routine, like their favourite TV program. If the challenge persists, we resort to calling them daily to remind them until a time where they are used

to their medication schedule. They are new to this life, have doubts and resentment, and are not yet used to daily medication." [PC5 Bandile]

For *Nompe* it was young people that needed to be checked on consistently even beyond clinic visits. She believed this helped for the counsellor to understand the client and provide care that was relevant and effective.

"I think they are people who you should not only see but also make constant calls to check up on. They easily get worried. A pimple can give them an AIDS scare. The tricky part is there is a lot of information they access outside; parents have opinions, friends too. At this day there is the internet. It's a constant struggle to bust myths and align health education hence one needs to have more time and chat with them." [Nompe]

These challenges and the strategies that were already being implemented by counsellors were eventually adopted and standardized by the Ministry of Health. According to *Nosisa*, for the first time as counsellors they had a remote client follow-up schedule.

".... due to a consistent rise in defaulters among clients in early ART, the initiative to call clients constantly became formalized as a package of care for all newly initiated clients. They called it Linkage case management and from what were already doing, it just standardized the calling intervals. After three days of initiation, we call to check if the client has started taking treatment. This is done again after seven days from initiation and on the 14th day they visit the clinic. Again after 21 days we call up until 60 days in 7 days intervals" [Nosisa]

A collaborative achievement

One of the main enablers of treatment success that emerged from this study was adherence. All informants interviewed expressed how they were working towards achieving this. In their experience, informants believed there were a number of factors that enabled for adherence to be realised around each client's clinical, personal and social interactions on a daily basis. Amongst these was efficacious treatment, consistent support in the facility and most importantly at home where the actual administration of the medication happened. Where these were not sufficient enough, a threat to successful care and treatment was constituted.

With a standardized monitoring for adherence system in place, *Nosisa* believed it allowed for quick identification and response to unmet viral load suppression. She said,

“The main referral laboratory that runs our viral load tests fast tracks results showing high viral load. Through the HIV testing officers we as counsellors receive them and we have to call the associated client immediately to see them ideally the next day to begin stepped up adherence counselling. We have monthly sessions and adherence reviews for three months after which we repeat viral load test to evaluate progress...”

[Nosisa]

If the challenges facing the client fell beyond the ability or scope of the counsellor, she would escalate them to be addressed in a multidisciplinary clinical team.

“Well if I fail despite numerous attempts to help my client achieve adherence, I rope in facility expert clients and the ART nurse and collaborate to prioritize the case.” [Mbali]

Nompe added that some issues required expertise that the facility did not have and for this reason they had to link and refer clients to other facilities.

“For others whose challenges we are convinced are mostly at home, we refer to Baylor for further management...Baylor is a paediatric facility that has Doctors and social workers and are able to help on issues involving the home situation.” [Nompe]

Clinical attention towards poor treatment outcomes could only do so much for adolescents. The facility could measure the gap, but working towards improving the outcomes required the involvement of parents in the plan of care to directly monitor drug administration in the home.

“We found that adherence was poor and viral load too high. On that we scaled up follow up and we involved parents to assist with directly observed treatment at home. I can say it was fruitful because all those children are virally suppressed now “[Nosisa]

Dedicated support

Clients shared various experiences of support that helped them manage to pull through difficult periods in their early days of learning to live with HIV and lifelong ART. *Mandla* explained how his grandmother’s consistency in caring for him laid a firm foundation for him to adhere to treatment and grow independent in caring for himself.

“She made sure she did not shout for everyone to hear when it was time to take my medication. I grew up in an extended family so we were quite a number. I took my medication at 7 am and I remembered easily because this was the same time I had to leave for school. Even in the evening, at 7 pm we would be back from playing and if we would still be playing, it was inside the compound so it would be easy. Now, when I got to stay with my mother I was already used to my situation. For the first few months after moving in with my mother, my granny used to call my mom say 5 minutes before time to remind me my medication. I changed medication time to six in the morning and evening when I moved and she continued to remind me until I got used to the new arrangement.”
[Mandla]

For Nompilo coming from a not so supportive extended family and without both parents it was that lady who offered her an HIV test in the first place that carried her with timeless support.

“The lady who offered me an HIV test became a mother to me, she was always there for me. She made sure to encourage me to take my medication all the time, telling me everything will be okay you know. Even out of sight she always called to check up on me each morning, afternoon and evening. [YA1 Nompilo]

As someone who had always shown him unconditional love, Sandile was inspired by her mother to give ART a chance and he committed himself.

“I thought of giving up! The thought of taking medication till my last day was hard. My mother told me that I can't stop taking the medication. She advised that I should try taking out of my mind the thought that these are HIV medication but treat them as a part of me that is necessary for me to live.” [YA4 Sandile]

Peer to peer support

Informants spoke of how a peer-to-peer approach was applied extensively in adherence support. This was done by bringing young people living with HIV together in support groups to discuss, learn and share their experiences. This was also displayed through the use of people living with HIV to support other people living with HIV as peer counsellors. According to some counsellors, support groups had helped clients who were afraid to speak out deal with distress.

“...most have improved on adherence thanks to the teen clubs where we teach and attend to personal dilemmas as a group. You find that one may be ashamed to mention their problem, but someone in the group will and that way they get assistance. You will

just see improvement in their engagement and making friends and ultimately on adherence results.” [Bandile]

A number of clients shared how support groups created a sense of belonging, restored confidence and encouraged them to continue with treatment and not lose hope. They believed it was a safe space where they could share their experiences and disclose their status freely.

“I think it helped me a lot because we share experiences and how we have been coping. At first I didn’t feel comfortable because I have always thought I was the only one, so coming to this group to be with others in a similar situation made me feel comfortable and it made me accept myself better” [YA9 Sino]

“I used to feel like I was the only one in the area who had HIV. This changed when I came to the support group and met other young people, some from my area who were also on treatment....The support group is perfect. There is a lot of support and comfort, I often forget I have HIV sitting and discussing around all the young people there. There is good counselling we get there as well so I think it is awesome.” [YA12 Tibu]

“I feel the support both at home and here. In the facility I used to be afraid I might be exposed but counselling from the team and meeting other young people living with the same condition I am in during Teen club meetings helped me to accept and live with myself and my ART.”[YA11 Elihle]

Elihle continued to mention how she preferred support groups due to the less likelihood of counsellors being rude. She further liked the idea that in a group the counselling is not a product of one view but it’s like a negotiated view which is more inclusive and more effective.

“It is hard to be freely express on a one on one because counsellors sometimes shout at us. The environment should be a group instead because in a group it’s less likely to be shouted on and its empowering to hear and see peers agree with the manner in which you are being addressed and the advice you are given at that time.” [YA11 Esihle]

Availability of efficacious ART

A number of counsellors had the opportunity of working with clients in various HIV treatment regimens. Almost all of them had experience taking more than one regimen in their time living with HIV and taking treatment. This made them particularly understand efficacy of the medication as well a common side effects which were a major concern for clients starting ART.

Nosisa saw the introduction of a newer drug called Dolutegravir as a major improvement and game changer in HIV care with improved efficacy and minimal side effects.

“Newer drugs always bring improvement from the ones we used previously and I think Dolutegravir has been a good introduction and quicker in achieving viral suppression. I say this because people with high viral load have reduced drastically since its introduction and this within three months especially in pregnant women. Even though some still don’t record excellent adherence, they are suppressed, nearly all of them, with a few exceptions” [Nosisa]

Structural impediments in the facility

One of the issues singled out to pose challenges in treatment adherence success was the structure and organization of services and components thereof, particularly in the health facility. Most informants, despite being a counsellor or client came from a background where confidentiality was amongst the most important components of treatment adherence. However, they felt it was undermined by factors including organization of services, counsellor related issues and other external issues.

Queue numbers

Mandla narrated how his friend was exposed in the facility due to a queue number. What was a means to organize the flow of services, became a let off for his friend, something that changed his friend’s life and his forever.

“... For each department the queue number has a different colour paper. This is a local clinic, we come to fetch treatment and others come for other reasons and we share a waiting room. Now, an outpatient queue number has a different colour the next service and this would naturally create curiosity which people may follow on, wanting to see why the numbers are different. Seeing you go into the HIV care room is all the confirmation they need; you have HIV and they spread it. The trend is noticeable and exposes us, I mean there is a segregation through these numbers and service rooms in the facility which I think is a challenge.”[Mandla]

When questioned on whether he had a personal experience of such before, Mandla continued to say,

“Not me but my friend! He even had to drop out of clinical care as well as school and eventually relocated to South Africa. The story was all over his school and so bad that even teachers were saying bad things about him. His studies were affected, and he dropped out. I would have done the same too!” [Mandla]

Noise made by ART in container

It never appeared to *Velile* that just the rattling noise made by the medication inside its container would be enough to expose that she was on HIV treatment. She explained,

“...I thought my confidentiality was protected until one day I had put the medication in my school bag and went to school from the clinic. They made this sound and I didn’t think that it could be noticeable to someone who hears it. That they could hear and know that the sound was from HIV medication still strikes me. I mean a pencil case or something else could make the same sound anyways. My desk mate in class heard that sound apparently and spread that in the whole class...” [Velile]

Counsellor turnover

Clients mentioned how they believed demotivated counsellors left the facility exposing them to a turnover that killed motivation on them too mainly because it disrupted trust relationships they built over time. These combined influenced poor treatment adherence outcomes.

Mandla was actually affected by this turnover of counsellors. He shared how this disrupted the continuity of care, set them back on their plans in the support group which was met with dissatisfaction by the group.

“The high rate of changing counsellors affects us big time. The last one left when we were in the middle of something. We shared the same mind-set, had mutual confidence and the one who replaced her had varying views and we abandoned our plans. Unlike the other, this one was hard to convince and that felt like she wanted to have things only her way. Inadvertently the group was devastated because taking initiative for the first failed just because counsellors changed. I was the teen leader and I had to explain thing is didn’t know because she didn’t even say goodbyes. That killed relationship killed our plans and high spirits and the daunting task of building a new trust relationship takes too much, it takes longer to build these bonds, unfortunately we have no control over them.” [Mandla]

Echoing this, *Velile* explained how they attach to their counsellors. Rapid changing therefore eroded that valuable mutual understanding they developed over time.

"I think it's not good because there is a trust relationship we build with the counsellors. These people have helped us get to where we are today and bringing someone new like that is not good. There is one who left who I had a very good relationship with but got to hear they had left, I don't even know the name of the new one. I do not appreciate it. I feel like I need one person to open up to and not every other one." [*Velile*]

According to *Lusha*, changing counsellors made them revisit hurtful memories

"Well I feel like I'll be fine but I really don't like the part of talking about one and the same thing that befell me, it brings back memories and it hurts. Even so I decided to come and yeah, I have learnt a lot. I can say I feel like the current one won't understand me like the first one and then there's the part where I keep explaining the same thing to different people. It irritates me." [*Lusha*]

For *Tibu*, changing counsellors created confusion. She said,

"It makes me feel like we are playing because each one tells something different and it confuses me because I end up not knowing which is which." [YA12 *Tibu*]

Stigma

Most informants would highlight instances where the care encounter and environment presented an atmosphere where their HIV status would be used to make them feel bad and as a constant reminder that they were worthless.

Once known to be living with HIV, *Velile* experienced widespread intolerance which made day to day social life hard. She shared the hardship at school after her peers had found HIV medication in her school bag:

"I felt so much hurt and I felt like giving up. They spread it in the whole class immediately and that left me asking myself, 'what exactly does HIV have that people cannot accept it as yet another disease?' I think such treatment is what makes young people give up." *Velile*

The perception of stigma and its inherent self-pity as described by *Nosisa*, was a nightmare that made her miserable. In her new marriage, *she* could not fathom genuine support and acceptance

of her HIV status by her husband. She believed HIV was a deal breaker which would end her marriage so she concealed her status notwithstanding she did not know her partner's status as well.

"I got into marriage aware of my status. I couldn't disclose to my husband because I feared the unknown. We did the test together eventually and he was negative. To this day I do not believe his calmness and reassurance he gave me. Each day was more difficult because I didn't know what he'll wake up to the next morning. I limited myself on a lot of things I used to do before knowing my status, that until he said 'your being positive does not really scare me because what if I [was] left you and find worse on the next person?' Even after he said all this it was tough such that in every disagreement, I would use My status as an excuse... "you treat me like this because I have HIV". He insisted "if I didn't love you, I would have left you when you tested positive." I'm sure in his mind he was trying to motivate me to be free yet in mine I would interpret it that he was trying to remind me that I have HIV. It is a journey one can embark on but there are some real difficulties along the way" [Nosisa]

Despite working on herself and eventually getting used to enjoying support at home, Nosisa could not say the same for her workplace. In the facility where she took a job as an HIV expert client, she experienced that nurses used her HIV status to belittle and kill her confidence. According to her, such levels of stigma did not only erode her dignity, it also compromised the support she offered to her peers.

"Even though it took me long, I feel accepted at home and my partner is supportive. However in this job I am always reminded that my qualification is HIV. It's really consuming to say the least, because my inputs are met with 'I cannot be told by someone employed with an HIV positive result on what to do.'" How ridiculous and stigmatic is that? Here you can accept yourself and the situation a 100%, but there is always some person who will really take you aback. What is fascinating is that it is nurses who still discriminate HIV positive people. This makes teamwork even harder. It is annoying and degrading because how can one feeling like a misfit be able to work on helping others remain in care and treatment? How will you give effective counselling to other HIV positive people when you yourself are struggling with the same labelling, stigma and discrimination in your own workplace! It's not easy" [Nosisa]

There was entrenched scepticism about taking treatment in the first instance because of the history of how side effects would easily be associated with ART. *Lebo* made an example of well-known accounts about side effects of a previously used drug ‘Stavudine’ which would cause disfigurement in users as a result of its permanent fat redistribution. This new physical appearance would not only result in clients having a low self-esteem, it also exposed their HIV status resulting in marginalization in the community. Such experiences made newer clients, even counsellors, to be reluctant to change drug regimens.

“It is really hard because the side effects are scary, clients have that hesitancy because of what they have heard and seen. The results of stavudine treatment in the past doesn’t help any bit in dealing with regimen switching. It is even harder here we have a colleague who bears those effects of stavudine and they look at her that way.” [Lebo]

Despite not being actively isolated, discriminated or even known to have HIV, one client still felt like people saw that she had HIV nonetheless. In *Sino’s* experience, being with friends felt like she was seen right through, something that was hard to cope with:

“When I got to know I had HIV, I had the feeling that people could see that I have it and that way coping was difficult. I would isolate myself; it was hard to live among them because of this feeling.” [Sino] perceived stigma

Being a client came with high expectations. In particular during continuous counselling clients got to learn more about their counsellors. Despite a show of caring from their social circles, clients described an absent desire to help from counsellors but reprimand for being HIV positive. *Mandla* felt that they had no desire to help when he was scolded for a high viral load result.

“I have come to think they are in the wrong field. They are impassionate. This one time I came to get my medication; she disclosed my high viral load result and without asking she said it’s because I was not taking the medication well. I literally broke down in tears on my way home when all the words she said came back to me that ‘why do you behave as if you are the only one who has HIV? Many people have HIV and take their medication unlike you!’ I was hurt. Being shouted at is not nice!” [Mandla]

From her own experience *Nompilo* concluded that they do not behave like people also living with HIV, they were rude.

“When I learnt I had HIV, I had no one to talk to. I lost both parents when I was young and so I was alone. That is what I think made it so difficult to cope and take my medication well. Coming here I believed I would be able to share my frustrations but no, I was rebuked for my poor adherence, rudely so! They know we need support; they have been there too I believe.” [Nompilo]

In one instance a client eventually abandoned care because of ill treatment. According to *Velile*, their peer dropped out of care because of counsellor attitude.

“He left because he did not feel comfortable. He said they were not nice to him; they shouted and treated him like a non-thinker.” [Velile]

Systematic labelling

Informants perceived the local name for HIV, ‘*UMBULALAVE*’ as a label that condemned people living with the disease as a taboo in the Swazi society. Translated as ‘destroyer of the nation,’ most informants felt like this name created an impression that HIV was a death sentence and anyone living with it was a threat to the nation. *Esihle* reckoned, the name alone prevented people from seeking or staying in care because the risk of being known to have HIV was not bearable.

“It pains me that HIV is equated to a killer that they would even name it this way. People see us as a threat and discriminate against us. This makes other people not take the test or better yet default treatment.” [Esihle]

Sino depicted the Ministry of Health as ignorant and long overdue in reconsidering the local name. In her view, the name was the root of all associated stigma out there and could not be convinced that custodians of health in their perfect mind would allow such a name. If the name was around since the beginning of the epidemic response, then basic HIV education for the ministry should be implemented she reckoned.

“I think calling HIV ‘Umbulalave’ somewhat condemns people with HIV as already dead. This perpetrates the stigma and discrimination associated with the disease. It does not sit well with me who is living with HIV. I think there is a lot of education that needs to be given even to the ministry of health for their role in endorsing this name,

it's pathetic. HIV is not a death sentence as the name suggests. It is possible to live a long healthy life with HIV." [Sino]

Clients from beyond catchment area

Given that their job largely involved doing home visits, community-based counsellors could not achieve this on clients coming from outside their designated community. The clients who would cross the catchment boundaries did it for their privacy. However, according to *Mbali*, the system setup limited such clients to access to a comprehensive healthcare package but also created follow-up challenges for the facility.

"Clients from beyond our catchment area leave their local clinics to come here. When you ask why, they say 'I do not want people in my community knowing that I live with HIV.' This makes follow up difficult because we can only do physical home visits only within the catchment area" [PC3 Mbali]

When asked on how this affected their work, *Mbali* was more eager to mention that it was the client who lost a lot. According to her, home visits provided a platform for understanding the client better and in turn inform their care plan, which if not done, the care would be lacking.

"I think facility expert clients have a limited period of time with the mother yet I have ample time to spend with her at home where she can even ask that which she couldn't in the clinic. I mean if people are at home, in their space they may be free to express all their concerns and challenges without worrying about being delayed or delaying others on queue as in the clinic. If we cannot access them at home, we miss this crucial element" [PC3 Mbali]

DISCUSSION

This study explored peer-counsellors' and young-adult clients' experiences on HIV-treatment adherence counselling in one HIV care centre in Eswatini. Using the cognitive behavioural change model underpinned by the social cognitive theory as an analytical lens, this study explored descriptions of peer counsellors' HIV treatment-adherence counselling practices, being a peer counsellor, as well as perceptions and experiences of clients with receiving HIV treatment-adherence counselling.

This study used qualitative methods to understand how clients and counsellors perceive their encounters with adherence counselling. The findings suggest four key themes; The first being how under-care young adults living with HIV desire to live a normal healthy life and as such welcome counselling as an integral part of achieving adherence to treatment. Secondly, how living with HIV constitute burden for both clients and peer counsellors. The third theme provides an appreciation of stigma embedded in HIV from society, to the clinical facility and within the individual. Lastly, the findings provide an understanding that young people living with HIV occupy passive role as recipients of care which is largely influenced by the hierarchical setup of the health system and by way of reciprocation, peer counsellors inherit and implement authoritative counselling delivery infrastructure.

Counselling and adherence to ART

As the findings illustrate, achieving adherence and good treatment outcomes critically depended, not only on the counselling provided by the health system, but on support from family and peers. This is in line with Shabalala et.al who argue that in order to understand the experiences and responses to living with HIV, the family, societal and community structures of the client must be considered (57). In both support systems, the issue of disclosure is critical (57). As demonstrated in the current study, disclosure is intimately tied to the HIV positive youth's acceptance of their HIV status, and the confidence they have in the acceptance of their HIV status by peers and family.

In the facility the client is first taught on the importance and benefits of disclosure particularly in activating and enhancing treatment support. Through sharing their own HIV positive status during the first counselling encounter, the counsellors believe they lay the psychological building blocks of equality based on shared experiences, and as they put it, helps the client grow towards accepting their status too and consequently the belief in disclosure. The client is

encouraged to disclose their status to a family member they trust, at which point the focus is activating the potential of familial support as the mainstay of treatment adherence in the long term (57). Studies on disclosure of HIV status to children in resource-limited settings recommended supportive resources to parents and children during the disclosure process (58). Adolescents who had open communication with their parents who were also living with HIV and on ART appear to fare better in terms adherence, indicating not only the important role of family in management of the HIV disease but also that of open communication about the disease and illness itself thus making the disease and illness a shared responsibility.

Parental disapproval was the main challenge to disclosure in one study in Togo (59). Issues including fear of rejection and loss of supportive relationships with partners after disclosure, anger and resentment as well death have been found to compound challenges with disclosure (57, 60).

Some counsellors believed that previous direct or indirect experience with HIV had a bearing on the level of seriousness clients viewed the disease with and their attitudes towards treatment. Absence of this experience was believed to lead to a casual approach towards treatment and the easy decision to skip doses in some days without regard for the consequences. On the contrary, a study on factors affecting adherence to treatment in Ethiopia found that Clients who had been sick from HIV before had poorer adherence than those who were not, and that longer duration on ART was highly linked to adherence (61). Adherence to ART has been found to be a huge challenge among adolescents and young people in many settings and targeted counselling has been implemented as a basic care package in particular for clients with evidence of high viral load (9, 19-21). Such high viral load is regarded to be as a result of poor adherence. A number of studies conducted in resource limited settings show that counselling had limited association to viral suppression amongst adolescents and young people (45, 46).

Two sets of Burden

Hoenig and Hamilton (1966) suggest that activities, and specific events are distinct from emotions, feelings, and attitudes associated with caregiving. Hence, they should be separated (62, 63). This concept was further developed by Montgomery et.al to classify the concept of burden as both subjective on the part of the healthcare provider and objective on the part of the effects of healthcare on the client (63).

This study found two sets of ‘burdens’ that challenge clients living with HIV in their quest for a long healthy life. The first being accepting HIV as a permanent aspect of their lives; and secondly the burden of daily, lifelong ART as the main component for a healthy, normal life.

These processes were common amongst most clients. The responsibility to live a healthy life while actively undergoing treatment gets overwhelmed by factors such as negative descriptions of the disease in the community (57, 64), and how these, in the opinion of the clients, play a role in sustaining desire for a healthy life as a double burden. These ‘labels’ as described by the participants, would include negative descriptions of HIV depicting that anyone who gets infected actually has a death sentence, impact the service delivery chain, in this case, treatment adherence counselling both from the giving and receiving end.

In the context of this study, burden included an additional challenge on top of general hardships in life including poverty, confusion secondary to identity forming stage and peer pressure. For the client, the behaviour depicting impatience with counselling and the act of actively avoiding sessions and appointments was common during home visitation. The thought of living with HIV and ART on top of these dilemmas made coping difficult for the clients.

On the other hand, counsellors shared similar socioeconomic conditions and doubled as clients themselves. This made their experiences and perceptions comprise two views: the task of caregiving on the one hand and their own adherence to treatment responsibility amidst similar personal struggles to accept the diagnosis itself, just like their clients. The counsellors in their quest to help their clients who are suffering, were actually suffering too. In the field of psychotherapy, this, according to a study on caregiver burden, encapsulated self- perception, multi-faceted strain amongst others findings as key challenges facing caregivers in chronically ill clients (65).

Stigma

Despite a generally positive reception of lifelong ART among young people, stigma remains prevalent and affects adherence to care and treatment. There is genuine appreciation of counselling as a necessary and useful intervention in the management of HIV treatment adherence, notwithstanding loopholes in the way it is implemented and the environment under which it is practised.

Counsellors believe that discrimination in the workplace is somewhat institutional and impedes their service delivery to clients. Such an environment impacts the well-being of the health

workforce living with HIV- the stigmatized condition wherein they [peer counsellors] end up delivery sub-standard care, develop anger and resentment (66). On the other hand, it may lead other healthcare workers to conceal their own HIV status from colleagues and be reluctant to access and engage in care.

Stigma in this context followed a hierarchical path in that, as a lay cadre, counsellors occupy the lowest level in client care and as such are vulnerable to positional discrimination by nurses who remind them of their lay cadre-ship whose HIV got them employment. Parker and Aggleton (2003) refer to concepts like discrimination and power for understanding stigma. They posit that beyond the individual, there exist an intersection between culture, power and difference where stigma functions. In this area, it is where stigma influences the composition of social order which consequently, *'promotes the interests of dominant groups as well as distinctions and hierarchies of ranking between them, while legitimating that ranking by convincing the dominated to accept existing hierarchies through processes of hegemony (67).'*

There is heavy reliance on intrinsic motivation for lay counsellors to perform their duties (68). However, frustrations, like discrimination that are not as a product of the interaction with the client have a potential to limit the overall performance of the counsellor as well as interrupt their professional identity (69), and continued exposure to such conditions added more vulnerabilities than they already knew they had accumulated (70).

We found that anticipating stigma blurred genuine treatment support from the perspective of the client. Not only did informants require experiences of discrimination against them, they inherited and internalized the local negative descriptions of HIV and for them these created a sense of no social belonging (57). Empirical studies conducted in sub-Saharan Africa suggest that stigma is amongst the most common and critical barriers to engaging clients living with HIV (71). Jonathan Mann in his speech to the World Health Organization in 1987 in what he described as an epidemic of responses to AIDS. He argued that high levels of stigma and discrimination was as central to the global AIDS challenge as the disease itself (72).

Lived experience as shared by the informants shaped how they perceived social responses to disclosure of HIV status from community, clinic and down to household level. A study conducted in Eswatini in 2016, looking into the context of care for adolescents living with HIV found that perceived stigma was highly prevalent among adolescents who would then use concealment, skipping of adherence to ART and silence as methods to manage their status (57). A combination of internalized and social stigma may lead to a myriad of challenges including

poor responsibility for health, difficulty with treatment adherence and access to healthcare services, negative self-descriptions and poor self-esteem resulting in prolonged difficulties with disclosure and effective management of HIV (73, 74).

The role of counselling therefore in this regard is targeted at fostering a new routine of daily medication and helping the client stick to it. However, it does not consider the disruption in the client's social fabric where, in the context of stigma as described by Parker and Aggleton, 2003 (67), whether self-inflicted or experienced, the client experiences a shift in perception of society and how society perceives them back. This way, adaptive measures thereby disturb erstwhile activities of daily living in particular interaction with family and peers.

Passive receipt of care

Despite general consensus of the centrality of client involvement in decision making over their own care plan, clients experienced the clinical encounter as authoritative and dominated by the counsellors from diagnosis, preparation for ART, adherence and stepped-up adherence counselling, in which case the ultimate therapy needs of each client were overlooked. This routine has somewhat proliferated into "what Cialdini and Goldstein, (2004) termed "Conformity bias- an act of changing one's behaviour to match the responses, norms and behaviours within populations, commonly referred to as peer pressure (75). In this case, the conformity was exhibited by the counsellors who mimicked the authoritative treatment they received in the system hierarchy.

In the study, the counselling, as described by the clients did not only miss the communication component but it also did not serve to resolve any problems. Instead, it was experienced as a tool to force compliance to treatment. These limitations in the delivery of the service show that their root cause emanates from the structural setup of the services and the associated hierarchy. In themselves, the counsellors believed that authority goes one way and the one below in the hierarchy has one responsibility, and that is to listen, a routine they had gotten used to (70). For instance, counsellors felt it was generally difficult for them to influence how service provision can be improved, not only because they are so low in the hierarchy but also because authority in the facility is somewhat measured by qualification. In this sense, the nurses do not seek views from the counsellors and the counsellors in essence have adapted to this way and do not try to ask but also do not seek views from their clients either. With each client attended, there is a sequence of activities to be followed, a routinisation of care that does not facilitate

user involvement. After one counselling session, the same points are repeated irrespective of the needs of the client.

In spite of the desire to receive care and the recognition of counselling is a prerequisite and an important building block to lifelong treatment, the young people in this study regarded the entire process as being only instructions and not as a dialogue about challenges as they had hoped. This lack of involvement of the client as an active and central stakeholder in their own counselling has been studied before and stems from cultural categorization of adolescents common in Eswatini. Shabalala et.al phrased the position of youth in the Eswatini context as ‘...*passive beings whose needs can best be addressed by their elders* (57).’ In this regard, the clients perceived the entire session as a campaign for counsellors to express how much they know about HIV, treatment as well as trends of deviant behaviour associated with being young, in which case individuals are rewarded for behaving in accordance with the opinions, advice, and directives of the counsellors as authority figures (75). Having to deal with yet another double tragedy of expert authority in the facility and inherent stigma in the community - clients felt de-dignified, inadequate, and would lose confidence in the counselling. and isolate or prefer to hide their reality.

Youth-centred studies suggest that young people as Individuals are not mere passive recipients of social norms and practices, but are capable of challenging, resisting, shaping and being shaped by social exposures, beliefs and practices (57, 76) and as such must be part of the planning of their own therapy in a human rights context.

Positionality

Reflexivity requires researchers to recognise, acknowledge and reflect on how their position and their role in the study, their culture, as well as personal background and experiences may influence their interpretations of the data (77). Awareness of such biases enables researchers to guard against their influence in order to produce fair and unbiased accounts of the situation under study.

I went to the field as a native Swazi, conducting a study in a field I had worked on for about three years as a nurse working in HIV care. I was aware of the relationship I had with the healthcare workers having worked in the clinic since 2016 for two years. In as much as this relationship helped gain access to the clinic, I paid particular attention to balancing my previous training and practice and their influence on my new role as a researcher.

I entered the field as a professional mental health nurse who had worked in HIV care for three years. I had spent about two of those years working as a clinical nurse responsible for HIV services, in particular adolescent and youth care. During that time, I came across young people from different walks of life who came for both continual HIV care, new HIV treatment initiation and others with treatment challenges. It is during that time where I realised that a significant number of young people generally had treatment-adherence problems and the follow-up as well as the client monitoring provided was not adequate on the side of the health facility. During this period, I got trained in psychosocial support for adolescents and youth receiving HIV care, I led a viral load monitoring and treatment-adherence support quality improvement project. I also led a youth-friendly clinical services initiative within the same facility to help improve clinical encounters of youth with the belief that these would help improve treatment outcomes. Amongst many clinical duties I got trained and did HIV treatment initiation, treatment refills and general out-patient care of clients. I was also responsible for conducting counselling of complicated cases especially those youths with poor treatment adherence and sometimes poor prognosis.

On my third year of practice, I changed jobs to work as a clinical research nurse servicing multiple HIV care centres under a research project focusing on differentiated models of HIV care delivery for young people. My role involved data collection as well as clinical care and counselling of mother-baby pairs or mother-adolescent pairs. During this period, I interacted with various clients and amongst other key discoveries, I learnt that some adherence challenges extended beyond the young person to include the home, community or school and other social dynamics as primary determinants for treatment-adherence.

I anticipated that some of the peer counsellors and clients would be people I had worked with before. I was aware that remaining objective and avoiding the conflict between my previous role and new role as a researcher whilst preserving my relationship with them would be my biggest challenge.

I understood that a few cultural differences would exist due to generational differences between me and the group of clients. Being in the same age group as the peer counsellors in relative terms, however, was going to help us relate better.

Since I am a native Swazi and spoke the same language and shared the same culture with the participants, I believe that helped me understand in-depth meanings attached to words, phrases, and expressions in context.

Credibility

Emergence of similar results from different sites gives findings greater credibility (78) because recruiting participants from different health facilities essentially minimises the effect on the study of particular local factors unique to one facility. However, this was not possible due to limited time and resources.

Drawing participants from both users (young-adult clients) of HIV treatment adherence counselling and the providers (peer counsellors) who delivered it helped in triangulation of data sources such that diverse perspectives were sourced to help understand the case under study. Participants were assured of the voluntariness of participation and given an opportunity to refuse participation. This was done to ensure that the data collection involved only those genuinely willing to partake and willing to offer data freely. This according to Shenton (2004) increases trustworthiness (79).

Limitations

The limited time and cross-sectional nature of the study could not allow for a time trend prospective analysis of adherence counselling impact on behaviour change. Secondly, conducting participation observation physically interfered with the natural flow of the counselling process as such the session had to be kept as brief as possible. Furthermore, the COVID-19 global pandemic had a strong impact on how the entire fieldwork was carried out resulting in unforeseen adjustments that led to extension of the data collection period.

CONCLUSION

This study aimed at exploring perceptions and experiences and perceptions of peer counsellors and their young adult clients on HIV treatment adherence. We found that the interplay during efforts to assist clients achieve adherence relies heavily on self-efficacy of clients. However, prevalent stigma in the healthcare setting and in the community present challenges in achieving this goal. However, dedicated family support has been shown to present an opportunity for clients to adhere to treatment and create a safe haven under which HIV treatment adherence can be assured. These results give an indictment for policy makers to also rethink counselling approaches in adherence support. A number of studies have shown that behavioural change approaches have little effect in adherence support and this study has shown that.

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APPENDICES

Appendix 1: Informed Consent- Peer Counsellors

This Informed consent form is for Peer counsellors (Expert clients) who are invited to participate in research titled “**HIV-treatment adherence counselling: Exploring experiences of peer counsellors and young-adult clients in HIV Care centres in Eswatini**”

Principal investigator: Thabo C. Dlamini

Institution: University of Bergen

Supervisor: Professor David Lackland Sam

Co-supervisor: Professor Karen Marie Moland

This consent sheet has two parts;

Information sheet (to share information about the study with you)

Certificate of consent (for signatures if you choose to participate)

Part 1. Information sheet

Introduction

My Name is Thabo Cebolenkhosi Dlamini, a Global health master student at University of Bergen in Norway. I am doing a research on HIV focusing on treatment adherence counselling. I will give you information and invite you to take part in the study. It is important that you take time to ask where you feel you do not understand before you can make a decision whether or not to participate.

Purpose

A lot of young people are taking HIV treatment in Eswatini, but a higher proportion has been shown not to be doing well despite treatment support including counselling. This study aims at

understanding provider perspectives on their role in treatment adherence counselling as well as the nature in which counselling is done. It further seeks to explore how young people receiving the service perceive it. We believe you can help by telling what you know about the counselling process and your experience giving it as well as how you understand your role in this regard. We want to learn how exactly the counselling process takes place (through observation) and how you go about conducting counselling, what works for you and what does not and your overall experience with adherence counselling in young people. The information you share will help us understand better how counselling is done in the context of the setting you work in which will assist us in making an analysis of the counselling against the persistent challenge in achieving treatment goals in young people.

Participant selection

You are being asked to participate in this research because you have been working as a peer counsellor for at least 6 months. We think your experience working as a peer counsellor can contribute much to our understanding and knowledge of adherence counselling practises and its dynamics in your setting from a provider perspective. The research will involve your participation in two parts; a one on one interview estimated to last between 45- 90 minutes and observation whilst you conduct adherence counselling.

Voluntary Participation

It is your choice to participate or not in this research, it is entirely voluntary. Whatever decision you take will not have an impact on your job and position. If you choose to participate, you reserve the right to choose whether or not to answer some questions or to completely withdraw from the study at any time you may feel the need to do so.

Duration

The research is expected to take three months. If you agree to participate, we will arrange an interview session that will be a once off. The time shall be at your convenience during work hours in a private room to be arranged within the facility you work in. The participant observation part will last as much time you take during a counselling session.

Risks

We foresee no physical or economic risks if you participate in this research. However, some of the questions may be sensitive to you and your emotional being. If any questions ask

confidential or sensitive information, and any that you are not comfortable with, feel free to not answer. You do not have to explain yourself for choosing not to answer.

Benefits

Your participation in this research has no direct benefits to you. However, the information we collect through your participation will help us understand how HIV treatment- adherence counselling for young people can be improved.

Confidentiality

Data collected from the research shall be kept private. No one outside the research team will have access to the data. Your name will not be used anywhere in this work and no one will know that you are taking part in a study like this. Data collected shall be locked in an encrypted file in a password protected computer and kept with the researcher at all times.

Sharing the results

All data you share will not be given to anyone outside the research team nor will your name be used to identify data. At the end of the research, information gained will be summarised and shared to participants. Results from the study will go towards the completion of the research and will be published in international journals so that relevant people can learn from them and use them.

Right to withdraw participation

You do not have to participate in this research if you do not want to. If you participate and at any point during the study and for whatever reason you feel that you do not want to continue, you have a right to do so. Your withdrawal will not affect your job or any evaluations in any way.

Contacts

If you have any questions or complaints you can contact the following;

Thabo C Dlamini: mobile no. +268 76750850 David

Sam (English only) email: David.Sam@uib.no

Eswatini National Health Research Review Board:

Part 2: Certificate of consent

I have been invited to participate in a research about HIV treatment-adherence counselling among young people.

I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and all questions have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print name of participant _____

Signature of participant _____

Date _____

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what the study entails and all their rights.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print name of researcher _____

Signature of researcher _____

Date _____

Appendix 2: Informed Consent- Young-Adult clients Interview

This Informed consent form is for Young-adult clients who are invited to participate in a research titled “**HIV-treatment adherence counselling: Exploring experiences of peer counsellors and young-adult clients in HIV Care centres in Eswatini**”

Principal investigator: Thabo C. Dlamini

Institution: University of Bergen, Norway

Supervisor: Prof. David Lackland Sam

Co-supervisor: Prof. Karen Marie Moland

This consent sheet has two parts;

Information sheet (to share information about the study with you)

Certificate of consent (for signatures if you choose to participate)

Part 1. Information sheet

Introduction

My Name is Thabo Cebolenkhosi Dlamini, a Global health master student at University of Bergen in Norway. I am doing a research on HIV focusing on treatment adherence counselling. I will give you information and invite you to take part in the study. It is important that you take time to ask where you feel you do not understand before you can make a decision whether or not to participate.

Purpose

A lot of young people are taking HIV treatment in Eswatini, but a higher proportion has been shown not to do well in treatment despite support including counselling. This study aims at understanding provider perspectives on their role in HIV-treatment adherence counselling as well as the nature in which counselling is done. It further seeks to explore how young people receiving the service perceive it. We believe you can help by telling what you know about the

counselling process and your experience as a recipient of the service and how it has or is impacting your journey in HIV care and treatment as a young person; what works for you and what does not and your overall experience with adherence counselling. The information you share will help us better understand how counselling is perceived and experienced by young people in the context of the area you receive it and individually. All this will assist us in making an analysis of adherence- counselling against the persistent challenge in achieving treatment goals in young people. **Participant selection**

You are being asked to participate in this research because we think your experience and perceptions as a young person in active HIV care receiving or having received HIV-treatment adherence counselling can contribute much to our understanding and knowledge of adherence counselling practices and its dynamics in your setting from a client perspective. The research will involve your participation in a one on one interview.

Voluntary Participation

It is your choice to participate or not in this research, it is entirely voluntary. Whatever decision you take will not have an impact on care and treatment. If you choose to participate, you reserve the right to choose whether or not to answer some questions or to completely withdraw from the study at any time without any prejudice.

Duration

The research is expected to take three months. If you agree to participate, we will arrange for an interview session. The time shall be during the week where it can be merged with your drug refill time to avoid much inconvenience, to be arranged within the health care facility you receive HIV care in.

Risks

We foresee no physical or economic risks if you participate in this research. However, some of the questions may be sensitive to you, your private self and emotional being. If any questions ask confidential and sensitive information, you are free to either choose to answer them or not. You do not have to explain yourself for choosing not to answer. Some questions may be sensitive, however, if it is overwhelming a counsellor nurse shall be available to help you through that moment.

Benefits

Your participation in this research has no direct benefits to you. However, the information we collect through your participation will help us understand how adherence counselling for young people can be improved.

Confidentiality

Data collected from the research shall be kept private. No one outside the research team will have access to the data. Your name will not be used anywhere in this work and no one will know that you are taking part in a study like this. Data collected shall be locked away in an encrypted file in a password protected computer and kept with the researcher at all times.

Sharing the results

All information you share will not be given to anyone outside the research team nor will your name be used to identify data. At the end of the research, information gained will be summarised and shared to participants. Results from the study will go towards the completion of the research and will be published in international journals so that relevant people can learn from them and use them.

Right to withdraw participation

You do not have to participate in this research if you do not want to. If you participate and at any point during the study and for whatever reason you feel that you do not want to continue, you have a right to do so. Your withdrawal will not affect your care and treatment in any way.

Ethical approval

Ethical approval for conducting the study will be obtained from the Regional Committee for Medical and Health Research Ethics (REC) in Western Norway. At the same time, ethical approval was also obtained from the Eswatini National Health Research Review Board (NHRRB).

Contacts

If you have any questions or complaints you can contact the following;

Thabo C Dlamini: mobile no. + 268 76750850 David

Sam (English only) email: David.Sam@uib.no

Eswatini National Health Research Review Board:

Part 2: Certificate of consent

I have been invited to participate in a research about adherence counselling among young people.

I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and any questions and have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print name of participant _____

Signature of participant _____

Date _____

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what the study entails and all their rights.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print name of researcher _____

Signature of researcher _____

Date _____

Appendix 3: Informed consent- Young Adult clients (Participant observation)

This Informed consent form is for Young-adult clients who are invited to participate in a research titled “**HIV-treatment adherence counselling: Exploring experiences of peer counsellors and young-adult clients in HIV Care centres in Eswatini**”

Principal investigator: Thabo C. Dlamini

Institution: University of Bergen, Norway

Supervisor: Prof. David Lackland Sam

Co-supervisor: Prof. Karen Marie Moland

This consent sheet has two parts;

Information sheet (to share information about the study with you)

Certificate of consent (for signatures if you choose to participate)

Part 1. Information sheet

Introduction

My Name is Thabo Cebolenkhosi Dlamini, a Global health master student at University of Bergen in Norway. I am doing a research on HIV focusing on treatment adherence counselling. I will give you information and invite you to take part in the study. It is important that you take time to ask where you feel you do not understand before you can make a decision whether or not to participate.

Purpose

A lot of young people are taking HIV treatment in Eswatini, but a higher proportion has been shown not to do well in treatment despite support including counselling. This study aims at understanding provider perspectives on their role in HIV-treatment adherence counselling as well as the nature in which counselling is done. It further seeks to explore how young people receiving the service perceive it. We believe you can help by allowing us observe you during

one of your counselling sessions as a recipient of the service so we can understand what happens and what does not during counselling. The information will help us better understand how counselling is perceived and experienced by young people in the context of the area you receive it and individually. All this will assist us in making an analysis of adherence-counselling against the persistent challenge in achieving treatment goals in young people.

Participant selection

You are being asked to participate in this research because we think observing counselling as it happens will assist us understand how it works and how the whole interaction is. Any reactions inside the counselling room will help us understand the relationship between counsellors and young people in counselling and the manner in which counselling evolves. All this will contribute to our understanding and knowledge of adherence counselling practices and its dynamics in your setting. The research will involve your participation in an observed counselling session.

Voluntary Participation

It is your choice to participate or not in this research, it is entirely voluntary. Whatever decision you take will not have an impact on care and treatment. If you choose to participate, you reserve the right to choose whether or not to answer some questions or to completely withdraw from the study at any time without any prejudice.

Duration

The research is expected to take three months. If you agree to participate, we will arrange to observe your counselling session in progress. The time shall be during the week where it can be merged with your drug refill time to avoid much inconvenience, to be arranged within the health care facility you receive HIV care in.

Risks

We foresee no physical or economic risks if you participate in this research. However, having a third person in a counselling room may feel like interfering with your privacy and confidentiality of personal information. If any questions ask confidential and sensitive information, you are free to withdraw from the study at any time or ask the researcher to give you privacy during that moment. You do not have to explain yourself for choosing to end your participation.

Benefits

Your participation in this research has no direct benefits to you. However, the information we collect through your participation will help us understand how adherence counselling for young people can be improved.

Confidentiality

Data collected from the research shall be kept private. No one outside the research team will have access to the data. Your name will not be used anywhere in this work and no one will know that you are taking part in a study like this. Data collected shall be locked away in an encrypted file in a password protected computer and kept with the researcher at all times.

Sharing the results

All information you share will not be given to anyone outside the research team nor will your name be used to identify data. At the end of the research, information gained will be summarised and shared to participants. Results from the study will go towards the completion of the research and will be published in international journals so that relevant people can learn from them and use them.

Right to withdraw participation

You do not have to participate in this research if you do not want to. If you participate and at any point during the study and for whatever reason you feel that you do not want to continue, you have a right to do so. Your withdrawal will not affect your care and treatment in any way.

Ethical approval

Ethical approval for conducting the study will be obtained from the Regional Committee for Medical and Health Research Ethics (REC) in Western Norway. At the same time, ethical approval was also obtained from the Eswatini National Health Research Review Board (NHRRB).

Contacts

If you have any questions or complaints you can contact the following;

Thabo C Dlamini: mobile no. + 268 76750850 David

Sam (English only) email: David.Sam@uib.no

Eswatini National Health Research Review Board:

Part 2: Certificate of consent

I have been invited to participate in a research about adherence counselling among young people.

I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and any questions and have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print name of participant _____

Signature of participant _____

Date _____

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what the study entails and all their rights.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print name of researcher _____

Signature of researcher _____

Date _____

Appendix 4: Interview Guide- Peer counsellors

HIV-treatment adherence counselling: Exploring experiences of peer counsellors and young-adult clients in HIV Care centres in Eswatini

Date.....

Place.....

Interviewer.....

Interviewee

ID.....**Sex**.....

.....**Age**.....

Occupation.....

Recorder/Notes.....

By now you have given your consent to participate and be interviewed on the above topic. We anticipate that you may have questions, if they are urgent and important for the success of the conversation we can discuss them before we start, otherwise we will gladly attend to all other questions in the end. I would like to confirm again your permission to audiotape/ take notes of our conversation. I would like to emphasize that your rights to answer or not answer anytime you feel like remain in force. If you are ready we will continue.

1. It is quite nice to see you today looking healthy and well, I hope everyone back home is well and fine too. Tell me, how do you like the weather these days?
2. I would like to begin by understanding you in relation to your work, what is your title and how long have you been working doing what you do?
3. I understand you work here in the HIV department, how would you describe your job responsibilities?

- a. What happens to an HIV positive client who comes here, can you take me through the process?
 - b. What measures do you apply in ensuring treatment support to clients?
4. In your work experience with HIV treatment and adherence, what existing differences can you describe about treatment outcomes in various age groups?
 - a. Particularly for young adults (15-24) how is their response to treatment?
5. How have you experienced HIV treatment-adherence counselling? What is it and how does it work?
 - a. What is your role in it?
 - b. For this role is there any training required? If yes, could you take me through components of the training you have had?
 - c. Could you share your experiences counselling young-adults? How would you describe outcomes of the counselling?
 - d. What makes an ideal counsellor to you?
6. About yourself, could you share with me your HIV and treatment journey; from when you learnt about your HIV status, what challenges have you faced?
 - a. Can you describe your own treatment support system?
 - b. In your journey has there been instances that exposed you to receive adherence counselling? If yes, could you share your perceptions and experience?
7. From what you currently offer under adherence counselling, what do you think works and what does not?
 - a. What do you think may be done to help improve adherence support to young adults?
 - b. Do you have any suggestions for the counselling curricula used and your role as a counsellor?
 - c. In your own thinking, do young-adults receive well adherence counselling?

Appendix 5: Interview Guide- Young-adults

HIV-treatment adherence counselling: Exploring experiences of peer counsellors and young-adult clients in HIV Care centres in Eswatini

Date.....

Place.....

Interviewer.....

Interviewee

ID.....**Sex**.....

.....**Age**.....

Educational level.....

Occupation.....

Recorder/ Notes.....

By now you have given your consent to participate and be interviewed on the above topic. We anticipate that you may have questions, if they are urgent and important for the success of the conversation we can discuss them before we start, otherwise we will gladly attend to all other questions in the end. I would like to confirm again your permission to audiotape/ take notes of our conversation. I would like to emphasize that your rights to answer or not answer anytime you feel like remain in force. If you are ready we will continue.

1. It is quite nice to see you today looking healthy and well, I hope everyone back home is well and fine too. Tell me a little bit about yourself both at home and at school.
2. I would like to first know briefly about you and your journey with HIV and treatment. Could you take me through when you first knew your HIV status, started treatment to now?

- a. What would you describe as your support system that has kept you going this far?
3. Could you describe how healthcare workers have and continue to assist you live with HIV and continue your treatment?
 - a. Could you share your highlights of how you have seen and think of adherence counselling?
 - b. What do you think makes for effective counselling?
 - c. Would you consider yourself involved in the decisions made about your care? Please elaborate.
 - d. Ever since you started receiving adherence counselling what changes have you seen in your life?
4. Now about your counsellors, how would you describe your relationship experience with them?
 - a. Could you describe what ideal counsellor could be according to you?
 - b. How often do you change counsellors in your HIV care? How do you feel about this?
5. During your treatment journey what have you found most hard as a young person taking HIV treatment?
 - a. What advice would you give to other young people in the same situation as you?
6. Given the opportunity to make inputs on how the counselling process and content should be, what suggestions would you make? Why?

Appendix 6: Participant Observation checklist

Date.....

Place.....

Observed **ID**.....

Age.....**Sex**.....

Item	Notes
Privacy- setting	
Rapport	
Mood	
Presentation (both parties- any influence on process or dynamics)	
Approach (client-centeredness), who leads the discussion?	
Comfort and expression	
Flow of counselling- linkage	
Facts- understanding subjective data and giving objective counsel	
Counselling Skills- Empathy, leadership, agreement, tasking,	

Closing- emphasis, scheduling follow up	
Duration	
Other	

Appendix 7: Ethical Clearance



RESEARCH PROTOCOL CLEARANCE CERTIFICATE

BOARD REGISTRATION NUMBER	FWA 00026661/IRB 00011253		
PROTOCOL REFERENCE NUMBER	SHR285/2020		
Type of review	Expedited	<input checked="" type="checkbox"/>	Full Board
Name of Organization	Student (Master')		
Title of study	HIV-treatment adherence counselling: Exploring experiences of peer counsellors and young-adult clients in HIV Care centers in Eswatini		
Protocol version	1.0		
Nature of protocol	New	<input checked="" type="checkbox"/>	Amendment
			Renewal
			Extension
List of study sites	Mahwalala Red Cross Clinic, Pigg's Peak Hospital (VCT)		
Name of Principal Investigator	Mr. Thabo Cebolenkhosi Dlamini		
Names of Co- Investigators	Professor Sam, David Lackland		
Names of steering committee members in the case of clinical trials	N/A		
Names of Data and Safety Committee members in the case of clinical trials	N/A		
Level of risk (Tick appropriate box)	Minimal		More than minimal
		<input checked="" type="checkbox"/>	High
Clearance status (Tick appropriate box)	Approved	<input checked="" type="checkbox"/>	Disapproved
Study approval validity period	Start date	03/11/2020	End date
			03/11/2021
Secondary approval validity end dates	Renewal end date		
Signature of Chairperson			
Signing date	03/11/2020		
Secretariat Contact Details	Name of contact officers	Babazile Shongwe	
	Email address	ethicsswaziland@gmail.com	
	Telephone no.	(00268) 2404 7255	



