University of Cape Town

FACULTY OF HEALTH SCIENCES

School of Public Health and Family Medicine

Department of Social and Behavioural Sciences

PROJECT TITLE:

An exploration of the health facility staff's perspectives on patients who disengage from HIV care: A qualitative analysis from Khayelitsha, Cape Town, South Africa.

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PART A: STUDY PROTOCOL

An exploration of the health facility staff's perspectives on patients who disengage from HIV care: A qualitative analysis from Khayelitsha, Cape Town, South Africa.

Synopsis

This project will be completed as a requirement for the Master of Public Health (MPH) degree at the University of Cape Town. This study is linked to an already existing project of Médecins Sans Frontières (MSF), which is called the Welcome Service. The Welcome Service focuses on addressing barriers that HIV+ patients face when they are returning to care after disengagement from treatment. One of the common barriers to re-engaging in treatment that the project seeks to address is the unwelcoming approach that health care workers have towards patients that disengage from treatment. To address this barrier the Welcome Service provides intervention through training packages for health care workers. The training packages seek to address staff behaviour that is unhelpful and unsupportive to patients that intend to re-engage with treatment. The Welcome Service was initially implemented at Michael Mapongwana Clinic in Khayelitsha. This Clinic is in a peri-urban settlement in the Western Cape province of South Africa. This was then scaled up to Ubuntu Clinic, also in the same location. To measure the change in the Welcome service project, baseline semi-structured interviews with health facility staff at Ubuntu Clinic were conducted. Health facility staff that were interviewed at baseline will participate in an in-depth interview as a follow-up after attending Welcome Service training.

As an MPH project, I will conduct secondary data analysis from baseline interviews of health facility staff at Ubuntu Clinic. The analysis will focus on interviews in which the perceptions and attitudes of health facility staff towards patients who disengage from treatment were gathered. These interviews may also explore health facility staff's perspectives on the reasons for patients disengaging from HIV treatment and reasons that might help patients to reengage with HIV treatment. This current project seeks to address the research question: What are the perspectives of health facilities staff on patients who disengage from HIV care in Khayelitsha, Cape Town, South Africa. This study will use inductive thematic analysis and the analysis will be done in NVivo, a qualitative data management software program. The researcher will identify themes from the trancripts and will not use a predetermined theory to derive themes, but will allow the data to guide theme development.

Interviews were conducted by the MSF research team in English. The participants included in the study were doctors, nurses, counsellors, data clerks, security guards, and allied health professionals at Ubuntu Clinic. The respondents were above eighteen years old and were in the capacity to give consent on their own. The MSF research team was responsible for the recruitment of participants. All health facility staff that participated in this study were requested to give written informed consent to participate in the interviews. The findings of the primary study have not been published yet because the project is still in progress. The researcher received the questionnaire that was used in the study and from there the researcher developed a research question for this project. Some of the questions from the questionnaire asked the health facility staff if they feel able to deal with patients who disengage and how they feel when dealing with a patient who is returning to care. A data-sharing agreement was signed by the researcher and MSF before the researcher received the data obtained from MSF's project. The researcher will have access to the transcripts of the interviews, which have already been transcribed. In reporting, the researcher will not include the participants' names or any identifying information to ensure anonymity and confidentiality. This analysis aims to inform current and future health interventions to re-engage people living with HIV (PLWHIV) who have disengaged from care.

Background

In the previous years, the effects of the HIV/AIDS epidemic were severe, sweeping the globe with little intervention available to assist in stopping the epidemic (Killian & Levy, 2011). An HIV+ diagnosis during that time was seen as an ultimate death sentence (Killian & Levy, 2011). There has been great progress since the advent of antiretroviral treatment (ART),where the widespread accessibility of HIV treatment has moderated the effects of HIV(Jones, Sullivan & Curran, 2019). As a result, a reduction of up to 60% in AIDS-related deaths since the peak in 2004 can be noted (Joint United Nations Program on HIV and AIDS [UNAIDS], 2019. However, this does not mean the epidemic has been fully conquered as it is estimated that about 37 million people are living with HIV (UNAIDS, 2019). South Africa has the largest population of people living with HIV globally, having a national prevalence of 13.1 % (UNAIDS, 2019). South Africa has the largest antiretroviral (ARV) programs in the world and 62% of people who are HIV positive are on treatment (UNAIDS, 2019). Nevertheless, the availability of treatment has not always translated to viral suppression among patients in the country due to difficulties with adherence (Venables et al., 2019). There are many barriers to adherence which include poverty, pill burden, migration, fear of stigma, and many others (Kagee et al., 2011). In 2013, the UNAIDS set treatment targets to help end the epidemic which is commonly known as the “90-90-90: Treatment for all” targets (UNAIDS, 2014). One of the goals set by UNAIDS is that those who are living with HIV should be aware of their status and there should be sustained availability of medication and viral suppression (UNAIDS, 2014).

Disengagement from treatment stands in the way of the UNAIDS target of achieving viral suppression in 90% of those on ART by 2020 (UNAIDS, 2019). Disengagement from treatment has become an obstacle to the gains of ART, viral suppression included (Kaplan et al., 2017). Moosa et al., (2019) note that optimal adherence to ART is essential for viral suppression. In recent studies, optimal adherence has been set at more than 95%, this is dependent on the ART regimen, the duration of treatment and previous ART exposure (Moosa et al., 2019). Schaecher (2013) noted that poor adherence leads to a number of adverse consequences on both individual and public HIV healthcare systems. This is because, patients who poorly adhere to ART may acquire resistance to first-line medication (Moosa et al., 2019). This results in them being transferred to second and third-line ARV regimens which are more costly and have a higher pill burden and often have less tolerable side effects (Moosa et al., 2019). In addition, the second-line, third line and rescue treatment regimens are less accessible in developing countries as it is often limited and, in some cases, unavailable (Moosa et al., 2019). Another adverse consequence of poor adherence is that resistant HIV strains can be transmitted to others which then results in primary resistance to first-line treatment regimens in those newly infected and those already infected (Schaecher 2013). Nonadherence is also associated with a greater risk of progression to AIDS and mortality (Moosa et al., 2019). Hospitalisation due to HIV disease progression and opportunistic infections further adds to the burden of public health costs in resource-limited countries (Moosa et al., 2019).

Due to the importance of adherence and the consequences of poor adherence, there have been several interventions to promote adherence in South Africa. Individual or group adherence counseling, mobile health (mHealth) interventions, community, and home-based care, task shifting, and community-based adherence support are some of the interventions put in place to curb nonadherence (Ridgeway et al., 2018). Despite the interventions, nonadherence is still a problem in the country.

Recent studies in South Africa have shown that there is an increasing number of patients who present themselves to care at an advanced stage of HIV disease after a period of disengagement (Ford et al., 2018). Ford et al (2018) go on to note that an increasing number of people with advanced HIV disease are patients who had previously engaged with the health system, started ART, and subsequently disengaged from care. Some studies have shown that patients return to care when they have developed complications (Estill et al., 2016). A qualitative study done in Cape Town, South Africa has shown that factors associated with patients restarting treatment after defaulting include being female, older, and time since defaulting (Kranzer et al, 2010). The results of the study highlighted that the probability of a patient reengaging with treatment increases as the time after defaulting increases (Kranzer et al, 2010). In addition, females are more likely to reengage with treatment compared to males, and the older the patient is the more likely they are to reengage to treatment compared to younger patients (Kranzer et al, 2010).

The Welcome Service project with which this study is linked focuses on addressing barriers to re-engagement that patients face. MSF project focuses on attitudes of health care workers towards patients as barriers to returning to care and other factors that hinder patients from returning to care. The negative attitude that some health care workers have towards patients who disengage from treatment acts as a barrier to patients reengaging with treatment. The Welcome Service has a series of workshops that aim to change the attitude of health care workers. The Welcome Service seeks to ensure that the health facility staff and the health system in the clinics are more welcoming to patients who disengage from treatment by implementing various interventions. This current research project is linked to the MSF project, specifically addressing the aim of understanding the attitudes that the healthcare workers have at baseline towards patients who return to care after disengagement. For the MPH project, the researcher will explore the perspectives of health facilities staff towards patients who disengage from HIV care in Khayelitsha. The researcher also seeks to explore factors that might contribute to people living with HIV (PLHIV) reengaging with antiretroviral services.

Problem Statement/Research Justification

There is a body of research on interventions that promote adherence to HIV treatment due to the rising trends of patients who disengage from treatment. Some research studies have also been conducted on understanding the barriers to accessing ART and taking treatment. Sweeney and Vanable (2015) conducted a systematic review looking into the impact of HIV-related stigma on treatment adherence. Their study revealed that there is a strong relationship between stigma and non-adherence to treatment (Sweeney & Vanable, 2015). Treves-Kagan et al. (2015) also conducted a study in rural South Africa which showed that the increasing availability of ART is not enough as stigma acts as one of the barriers to adherence to treatment.

The negative attitudes of health care workers towards patients who disengage from treatment have turned out to be a barrier to patients returning to care. Health care workers view these patients as “bad” patients and rebels (Eshun-Wilson et al., 2019). In some studies, negative healthcare worker attitudes are one of the many health system barriers to continued patient engagement and are recognised as a “final driver” in causing a patient to disengage (Claborn, Beth Miller & Meier, 2015). Non-adherence has in itself become stigmatized by health care workers (Eshun-Wilson et al., 2019). There is not much research on the perspectives of health facility staff workers towards patients who disengage from treatment. Most of the studies have focused mainly on the health care workers and not on all facility staff while patients are also in contact with other staff members before and after meeting health care workers. There is a need to know the perspectives of facility staff workers towards patients that disengage from treatment because knowing this will help to understand what informs the way heath facilities staff treat patients who disengage from treatment. There is a need to know their perspective of what drives patients back to treatment after disengagement. There may be many layers of factors that affect retention in care and adherence, the focus of this project will be on health system-related factors and socio-economic factors.

Few studies have looked into the issue of patients who default and returned to care in resource-limited settings (Kranzer, 2010). Kranzer et al (2010) note that the proportion of patients who briefly interrupt treatment in resource-limited settings is largely unreported. This study will be looking primarily at a lower socioeconomic status area in South Africa, as low socioeconomic status is associated with a high HIV rate, low adherence, and lack of access to ART (Geng et al., 2015). There is a need to know more about the factors that inform people's decisions around getting back to treatment. To know how and why they return to care is important as that could impact positively the effectiveness and efficiency of programs and interventions for following up on patients that disengage. Gaining this information through this research could assist to make changes that would not necessarily combat all barriers to adherence or retention in care but may contribute to the work being done to keep PLWHIV engaged in treatment. It would have been ideal to conduct interviews with the patients that disengage from treatment as they would give in-depth information from their own experiences. However, due to the COVID-19 pandemic, the researcher cannot have access to patients. The researcher has thus resorted to the use of data from health facility staff for analysis. In that regard, the researcher seeks to explore the factors that might contribute to PLWHIV reengaging with treatment from the health facilities staff perspective.

Statement of Objectives

- To explore the perspectives of health facilities staff on patients who disengage from HIV care.
- To identify some of the factors that may contribute to PLWHIV who have disengaged from ART reengaging in treatment from the perspective of health facility staff.

Research question

- What are the health facility staff's perspectives on patients who disengage from HIV care in Khayelitsha, Cape Town, South Africa?

Methodology

Study Setting

The study was conducted in a peri-urban under-resourced area called Khayelitsha in the Western Cape province of South Africa. Statistics show that Khayelitsha has the highest HIV prevalence in the Western Cape (Stinson et al, 2016). Studies have shown that HIV-infected individuals from areas with limited resources will have lower levels of ART adherence than HIV-infected individuals in resource-rich areas (Geng et al., 2015, Mills et al.,2006). Studies have revealed that poor retention in care is a result of limited basic amenities, high rates of migration, crowded living conditions, family violence, and substance abuse (Geng et al., 2015). Despite efforts to decentralise services in poorly resourced areas, some patients still travel long distances and incur troublesome opportunity costs to access care (Geng et al., 2015). This depicts some of the challenges that patients from poorly resourced areas face in getting treatment. In Khayelitsha, residents experience many of these factors which may contribute to non-adherence to ARVs.

Khayelitsha has extensive HIV prevention and treatment services available and a strong history of activism and community mobilisation for the availability of ART (Stern et al., 2017). The community is also known for its efforts to combat stigma towards people living with HIV (Stern et al., 2017). Advocacy efforts have been led by the Treatment Action Campaign (TAC) in Khayelitsha and by MSF and many other organisations which work together with local stakeholders to develop and implement innovative models of care for HIV (Stern et al., 2017).

This project is a sub-study of an existing intervention in Khayelitsha that is being conducted by MSF which seeks to address health system barriers to re-engagement that patients in the community face. In the bid to address the barriers to re-engagement, they designed the Welcome Service. This service has been implemented operationally at Michael Mapongwana Community Health Clinic and it is to be scaled up to Ubuntu Clinic. The MSF project seeks to evaluate the Welcome Service. To do the evaluation, MSF is conducting a mixed-method study, collecting qualitative data from in-depth interviews and quantitative data from surveys. ART staff from Ubuntu Clinic were invited to take part in baseline interviews to explore their attitude to disengagement and their experience of managing patients who struggle with adherence. Another objective of the baseline interviews with ART staff was to understand the acceptability and experience of the Welcome Service implementation (at follow-up). This research study is linked to the qualitative research part of their study which focuses on ART's staff experiences of managing patients who struggle with treatment adherence. The MSF research project and this sub-study are both focused on understanding the experience of ART staff when managing patients that disengage from treatment and eventually return to care, while the MSF project also seeks to qualitatively evaluate the Welcome Service and has a series of additional quantitative aims.

Study Design

The researcher will use qualitative secondary data analysis to address the objectives of the study. Qualitative secondary data analysis uses existing qualitative data to examine and explore new research questions (Hinds, Vogel & Clarke-Steffen, 1997). One of the advantages of using this method is that one can generate new knowledge or new hypotheses or support existing theories while reducing the human subject burden (Hinds, Vogel & Clarke-Steffen, 1997). This method is the most suitable for this study given that access to participants (health facility staff and HIV patients) is limited due to the COVID-19 pandemic. The researcher will be able to explore the research question using secondary data analysis because the question explored in the primary study overlaps with the research question that the researcher intends to explore. The MSF project seeks to explore the attitudes of health care workers towards patients who disengage from treatment as one of the barriers to patients who intend to return to care. The current project seeks to explore the perspectives of health facilities staff on patients who disengage from HIV care. The two research questions intersect because they both focus on how health facility staff relate to patients who disengage from treatment. The MSF project conducted in-depth interviews, to address the objectives of the study, which are known to yield rich in-depth data. The researcher will make use of the rich in-depth data from the interviews to explore the perspectives of health facility staff on patients who disengage from HIV care. Qualitative research will be useful in this study as qualitative research is known for yielding in-depth information on the phenomenon that is being explored.

Sampling and Recruitment

Purposive sampling was used in this study. Purposive sampling is based on the researcher's judgment of the sample, that the sample will most be feasible in answering the research question (DeVos et al., 2005). In this study, the selection of the sample is based on the knowledge that the sample of staff who work with HIV positive patients, who have previously disengaged from treatment and have re-engaged to treatment will have a perspective on patients who disengage from treatment. In addition, health facility staff might be able to identify some of the factors that may contribute to PLWHIV who have disengaged from ART reengaging in treatment because they interact with these patients making them knowledgeable on this phenomenon.

Sampling Characteristics

The research included staff that is involved with the ART program of Ubuntu clinic. This includes doctors, nurses, counsellors, data clerks, security guards and allied health professionals. Staff was ineligible to participate in the study if they reported having been working at the clinic for less than three months. They were not eligible to participate in the study if they were working professionally for less than a year, are not permanently based at the clinic, or were likely to leave the clinic before the first follow-up interviews take place. This was at the discretion of the recruiting study team member. The respondents were eighteen years old and above and were in the capacity to give consent on their own. Fifteen participants were selected for interviews.

Sampling Procedure

The researcher will get ethical clearance for this study from the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee (HREC). This study is a sub-study of MSF project that has ethical clearance from HREC REF- 542/2019 as well as the Department of Health to conduct a study at Ubuntu Community Health Clinic. After obtaining ethical clearance the MSF research team informed the facility manager of Ubuntu clinic about the study and its objectives, this included the relevance of obtaining staff perspectives. The MSF research team obtained an agreement from line managers so that the healthcare workers can be relieved of their duties for interviews, provided it did not interfere with patient care. Staff was approached individually and invited to participate. This was done so that they can be able to agree or refuse in private. If the staff member refused to take part, they were not approached again. If they agreed to take part an appointment was made to conduct the interview.

Data collection

Semi-structured interviews

Semi-structured interviews were used to collect data from the participants. Semi-structured interviews are typically used so that participants can fully express their experiences and give an account of their experiences (De Vos et al., 2005). The study explored attitudes that are shaped by the beliefs and values of a person. These can be complex and personal, thus in-depth interviews were ideal to allow the participants a safe space to express their beliefs, values and behaviours towards patients who disengage and reengage with ART services. An interview schedule was used in this study. This is a list of questions used to guide the interview (De Vos, 2002). A copy of the interview schedule is attached (see appendix B). Interviews were conducted in English, as this is the standard language used professionally in the Department of Health and by staff in facilities in Khayelitsha.

The data from the transcripts of interviews will be shared with the researcher, who has signed a formal agreement with MSF. Since this is not on the list of allowable appendices, it has not been attached but can be provided to HREC upon request. Interviews were conducted in private rooms with one participant at a time. Before the interview, the researchers informed participants that they can refuse to answer any question that they feel uncomfortable about, stop answering halfway through a question, withdraw their answer to a question either during or after the interview, and withdraw their participation completely either during or after the interview. With the consent of participants, the interviews were audio-recorded.

Data analysis

The researcher will receive transcripts from the MSF team and will conduct secondary data analysis. For analysis, the researcher will use a qualitative data analysis software called Nvivo in the analysis. The researcher will upload the transcripts in Nvivo and will use a thematic analysis approach for analysis. Transcripts will be analysed using an inductive thematic analysis approach. This means that the researcher will not use a predetermined theory to derive themes. The researcher will follow Braun and Clarke's (2006) stages of thematic data analysis. According to Braun and Clarke (2006), there are six stages in data analysis, these are familiarisation of data done through a thorough reading of transcripts, initial coding, generating themes, defining, and naming themes, interpreting, and reporting. In the first stage of analysis, I will read the transcripts thoroughly to understand the content of the transcripts. During this stage, I will be jotting down some initial ideas of what the transcripts are bringing out. After that, I will start with the preliminary coding which will involve identifying interesting and meaningful details from the transcripts. Following this stage, I will start bringing together codes and coming up with themes. The codes that have similar details will be grouped to form themes. For the next step, I will relook at the initial themes naming them and giving definitions of these themes. Lastly, I will write the report presenting the themes identified and giving examples of quotes from the themes.

Data management

A data-sharing agreement was signed between MSF as the supplier and the University of Cape Town as the recipient. This agreement stipulates that MSF agrees to provide data sets to the researcher for the exclusive purpose of the master's research project. The agreement highlights that the researcher will receive data sets that do not contain any confidential and personal data to ensure that medical confidentiality and the privacy of patients are fully respected. The researcher is obliged not to use, disclose, release, show, sell, rent, lease, loan, or otherwise grant access to the data sets or the confidential information to any third party. To ensure that the data sets are secured the researcher will store the data sets in password-protected cloud storage where no one else can access them except the researcher. These data sets will eventually be deleted when the research project is complete.

Ethical considerations

Informed consent was given by all the respondents and they signed informed consent forms as proof (see appendix C). Interviews were conducted at the clinic in a room that was secure and there was less risk of being overheard. To ensure confidentiality in this study, no identifying information will be used in any written outputs and respondents will be given a number to refer to them. The researcher will not give away the identifying details of the respondents in the reporting of this study to ensure anonymity in the study.

Potential risks

De Vos (2002) notes that harm to respondents could be either physical harm or emotional harm. The primary study posed a minimal physical risk to the participants, however, the interviews had the possibility of interrupting the workflow which could inadvertently increase the pressure on the staff workload. To mitigate this, interviews took place during times when the clinic was less busy. There was the risk of health facility staff feeling evaluated or judged. To curb this, the researchers assured the participants that the purpose of the interviews was for a research study of their experience of working with patients. They were assured that their performance was not going to be reported to their supervisor. The participants were also reassured that their participation in the study was not going to affect their current or future employment in any way. They were reassured that all information in the study was confidential and that no identifying data (such as their job title or descriptive demographic information) was going to be used in reports, presentations, or in publications. In this current project, there is no likelihood of physical harm and emotional harm as this is secondary data analysis.

Potential benefits

This is an important area to explore because findings could inform current and future health system changes and interventions to re-engage PLWHIV who have disengaged from care. There is an indirect benefit which means that the participants will not benefit directly from participation, but society and the broader population living with HIV will benefit from this study.

Rigour

Transferability

The lengths to which the findings can be applied to other contexts or individuals are known as the transferability of the study (Babbie & Mouton, 2001). The researcher will not try to generalise the findings in this study because of the sample size and the research methodology. Instead, the researcher seeks to have an in-depth understanding of this phenomenon. To ensure that there is transferability, the researcher will give details about how the analysis process unfolded. To obtain a diverse sample the researcher will select varying transcripts to ensure that a variety of people's perceptions can be captured.

Credibility

Tobin and Begley (2004) cited by (Nowell et al., 2017) note that the agreement between participants' views and the researcher's representation of them is known as credibility. Credibility is when the researcher offers explanations that are consistent with the data collected and explanations that are understandable to the study population (Nowell et al., 2017). To ensure credibility in the project, the researcher will receive clean transcripts that are not coded already, this will allow the researcher to develop themes that are not influenced by themes from the MSF project. In addition, it allows the researcher to develop themes that are based on participants' views rather than the interpretations from the primary study.

Dependability

To achieve dependability in a research project, Tobin and Begley (2004) cited by (Nowell et al., 2017) note that the researcher can document the research process, this can be done by keeping audit trails. In this project, the researcher will document how decisions about themes were made. The researcher will keep a reflective journal throughout the process of data analysis documenting the researcher's values, interests, and insights information about the self to ensure that these do not influence the findings from the study.

Table 1: Study Period and Time frame

Months	July	August	September	October	November	December
Study approval	🟧	🟧	🟧			
Data analysis		▨	▨			
Write up and dissemination.			🟦	🟦	🟦	🟦

Dissemination

Given that this project is in conjunction with MSF, the findings of this study will be shared with them. The findings of this study will also be published as a journal article. The researcher will also share findings with the participants of the study through the Welcome Service as the participants are part of the Welcome Service project. To avoid the risk of stigmatisation or identification of participants, results will be shared as summarised findings rather than using specific quotes.

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PART B: JOURNAL MANUSCRIPT

BMC Public Health

RESEARCH ARTICLE

Between empathy and anger: healthcare workers' perspectives on patient disengagement from antiretroviral treatment- a qualitative study in Khayelitsha, Cape Town.

Tsephiso Nhemachena; Alison Swartz & Carmen Späth.

Abstract

Background & objectives: The benefits of long-term adherence to antiretroviral treatment (ART) are countered by interruption in care, or *disengagement*. Healthcare workers (HCWs) play an important role in patient engagement, yet little is known about their perspectives on disengagement. We explored HCWs' perspectives on ART disengagement, in Khayelitsha, an HIV-prevalent, peri-urban area in South Africa.

Method: Semi-structured interviews were conducted with 30 clinic staff to explore their perspectives of patients who disengage from ART. This included doctors, nurses, counsellors, social workers, data clerks, security guards, and allied health professionals. HCWs were asked to give examples of patients who interrupt treatment and how they feel when dealing with a patient who is returning to care. Transcripts were analysed using an inductive thematic analysis approach.

Results: Most staff were knowledgeable about the complexities of disengagement and highlighted potential barriers to sustaining adherence on ART, including mental health challenges and non-disclosure to family and partners. Participants expressed empathy for patients who interrupted treatment, particularly when discussing potential barriers to engagement. However, many also expressed feelings of anger and frustration towards these patients, partly because they reported these patients increase workload. Some staff, particularly those taking chronic medication, perceived that patients who disengage from ART do not take adequate responsibility for their health. Findings from this study show that staff had contradictory feelings towards disengaged patients, experiencing both empathy and anger.

Conclusion: Many psychosocial factors contribute to a patient's willingness and ability to sustain lifelong retention in ART services. HCWs play an important role in patient empowerment and negative or authoritarian attitudes can drive patients to disengage. Although HCWs express empathy for patients, further work needs to be done to support staff to feel less overwhelmed by patients requiring intensive psychosocial and medical support.

Key words

Disengagement; ART Adherence; Health facility staff; perspectives; South Africa

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Background

Notable progress has been made regarding the HIV/AIDS epidemic which can be attributed to the several innovations that have been introduced for the prevention and treatment of this disease [26]. The advent of antiretroviral treatment (ART) and the widespread accessibility of HIV treatment are some of the advancements that have been put in place for the prevention and treatment of HIV/AIDS. Consequently, globally there has been a reduction of up to 60% in AIDS-related deaths since the peak in 2004 [40]. However, this does not mean that the epidemic has been fully conquered as it is estimated that at present, 37 million people are living with HIV [40]. South Africa has the largest population of people living with HIV (PLHIV) globally, having a national prevalence of 13.1 % [40]. Additionally, South Africa has one of the largest antiretroviral (ARV) programs in the world, 62% of people who are HIV positive are on treatment [40]. The availability of treatment has not always translated to viral suppression among patients in the country due to difficulties with adherence at individual and systems levels [41]. Treatment interruption or *disengagement* from treatment has become an obstacle to the gains of ART [29].

According to UNAIDS, disengagement from treatment stands in the way of achieving viral suppression in 90% of those on ART by 2020 [40]. Schaecher [36] goes on to note that poor adherence contributes to several adverse consequences on both individual and public HIV healthcare systems. The consequences for the individual are that the patients who interrupt treatment may acquire resistance to first-line medication [34]. This results in them being switched to second and third-line ARV regimens which are more expensive, have a higher pill burden, and often have less tolerable side effects [34]. In addition, the second-line, third line and multiple drug rescue treatment regimens are less accessible in developing countries [34]. Another adverse consequence of poor adherence is that resistant HIV strains can be transmitted to others which then results in primary resistance to first-line treatment regimens in those newly infected and those already infected [36]. Nonadherence is also associated with a greater risk of progression to AIDS and mortality [34]. The consequences of disengagement from treatment for the individual filter into adverse impacts on the public health system. Hospitalisation due to HIV disease progression and opportunistic infections further adds to the burden of public health costs in resource-limited countries [34].

A recent study in South Africa has shown that there is an increasing number of patients who return to care at an advanced stage of HIV disease after a period of disengagement [18]. Studies have shown that several people with advanced HIV disease are patients who had previously engaged with the health system, started ART, and subsequently disengaged from care [17, 18]. Another study has also shown that patients cycle in and out of care and they usually return to care after developing complications [15]. Gao [19] used the health belief model to patients' adherence based on their perception of disease severity and found that patients who have experienced more disease symptoms were likely to seek medical assistance. Evidence from these studies shows that disengagement is a growing problem in South Africa and that a major reason for patients returning to care is the development of complications.

Studies show that there are numerous challenges that PLHIV are faced with which contribute to them disengaging from treatment [9,13,28]. In addition, after a period of disengagement, they are faced with barriers to reengagement. A major barrier to patients reengaging with treatment in sub-Saharan Africa, South Africa included, is the negative attitude that health care workers have towards patients who interrupt treatment [12,24,44]. A significant number of adherence studies are from the patient's perspective. Moucheraud [35] note that health facility staff serve as gatekeepers and that they impact the patients' HIV care experiences, yet less is known about the perspective of health care providers, particularly in low-income countries. This limits our understanding of disengagement.

Investigating the perspectives of healthcare workers (HCWs) on disengagement could influence interventions that may endow HCWs with better strategies for coping with patients who disengage from treatment. Additionally, the perspectives of health facility staff need to be explored as this may influence interventions that aim to improve treatment adherence and could assist in addressing some barriers to patients reengaging with treatment. Hence, this study explored what providers think and how they feel about patients who cycle in and out of care. Findings may have implications for interventions that may improve the lives of PLHIV and the HCWs who work with them. This study draws on qualitative data collected in a project called Welcome Service project spearheaded by Médecins Sans Frontières (MSF). The MSF project aims to address the barriers of patients adhering to treatment and returning to care. To address these barriers the Welcome Service provides intervention through training packages for HCWs. The data used for secondary analysis in this study is from baseline interviews with health facility staff before the implementation of the interventions.

Methods

Study setting

The study was conducted in a peri-urban under-resourced area called Khayelitsha in the Western Cape province of South Africa at a clinic called Ubuntu clinic. Statistics show that Khayelitsha has the highest HIV prevalence in the Western Cape [38]. Ubuntu clinic has the largest number of patients enrolled on antiretrovirals (ARVs) in the country, serving over 8000 people living with HIV from the surrounding districts in Khayelitsha [43]. The clinic was established by MSF in 2001, during the early days of the HIV treatment crisis in South Africa and was then transferred to the South African Government in 2005 [43].

Study participants and data collection

The research study participants included health facility staff that are involved with the ART program at Ubuntu clinic. These were doctors, nurses, counsellors, data clerks, security guards, and allied health professionals. Purposive sampling was used for the selection of participants in the study. Inclusion criteria were any staff who had been working at Ubuntu Clinic for more than three months. Any staff member could be approached to participate in the study given that they did not meet the exclusion criteria. Staff were ineligible to participate in the study if they reported having been working at the clinic for less than three months. In addition, they were ineligible to participate in the study if they were working professionally for less than three months, were not permanently based at the clinic, or were likely to leave the clinic before the first follow-up interviews were held. Decisions regarding the inclusion/exclusion of participants from the study were made at the discretion of the recruiting study team member. All the respondents were eighteen years old and above and were in the capacity to give consent on their own. In total, thirty participants were selected for the in-depth interviews.

The MSF research team informed the facility manager of Ubuntu clinic about the study and its objectives. Thereafter, the MSF research team obtained an agreement from line managers so that the healthcare workers could be relieved of their duties for interviews, provided it did not interfere with patient care. Staff was approached individually and invited to participate. Semi-structured interviews were used to collect data from the participants, and these lasted between 45 to 60 minutes. An interview schedule was used in this study and interviews were conducted in English, as this is the standard language used professionally in the Department of Health and by staff in facilities in Khayelitsha. Additionally, interviews were conducted in private rooms with one participant at a time except for one interview where two participants were interviewed at the same time. Before the interview, the researchers informed participants that they can refuse to answer any question that they feel uncomfortable about, stop answering halfway through a question, withdraw their answer to a question either during or after the interview, and withdraw their participation completely either during or after the interview. With the consent of participants, the interviews were audio-recorded. In total, there were 30 participants. There were 28 transcripts from the one-on-one in-depth interviews with participants and one transcript from the in-depth interview with two participants. As a result, I received 29 transcripts from MSF after signing a formal agreement.

Data analyses

Secondary qualitative data analysis of the interview transcripts was employed for this study. Data from thirty participants were included in this paper. Transcripts were analysed using an inductive thematic analysis approach. Braun and Clarke's stages of thematic data analysis were followed for data analysis [5]. According to Braun and Clarke, there are six stages in data analysis, these are familiarisation of the data done through a thorough reading of transcripts, initial coding, generating themes, defining, and naming themes, interpreting, and reporting [5]. Following the signing of a data-sharing agreement, the transcripts were shared through a Dropbox folder. NVivo, a qualitative data analysis software was used for analysis. The transcripts were imported in NVivo and the researcher read them to familiarise oneself with the data. An inductive approach was used for analysis. This means that no predetermined theory was used to derive themes. The researcher read all the transcripts thoroughly highlighting where the participants spoke about what they thought and felt about patients who disengaged from treatment. The researcher also highlighted the sections where the participants spoke about the reasons for disengagement according to their previous experiences with patients who disengaged from treatment. From the highlighted text, the researcher labelled them to become the codes. From the codes that were generated in the coding stage, the researcher developed themes. Themes were developed by finding common threads from the codes. The common threads that were found were then named, becoming themes.

Ethical considerations

Informed consent was given by all the participants, who signed informed consent forms as a confirmation of their willingness to voluntarily participate in the study. To ensure confidentiality in this study, no identifying information was used in any written outputs, and respondents were given a number to refer to them. This study was approved by the Faculty of Health Sciences Human Research Ethics Committee (HREC) of the University of Cape Town, HREC REF 495/2020.

Findings

Table 2:Demographic characteristics of study participants.

Participants	Total 30 (%)
Age categories (years)	
25-34	9 (30)
35-44	11 (37)
45-54	6 (20)
55+	2 (7)
Missing information	2 (7)
Occupation	
Support staff (management, clerks, pharmacists, data capturers, security officers)	16 (53)
Clinicians (doctors, nurses)	10 (34)
Psychosocial support staff (counsellors, facilitators, social workers, occupational therapists)	4 (13)
Time in the HIV field (years)	
<1	8 (27)
1-5	7 (23)
6-10	4 (13)
11-15	5 (17)
16+	6 (20)
Time at Ubuntu clinic (years)	
<1	10 (34)
1-5	7 (23)
6-10	7 (23)
11-15	4 (13)
16+	2 (7)
Employed by	
Department of Health	15 (50)
Non-governmental organisation	11 (37)
Missing information	4 (13)

Demographic characteristics

The study participants comprised thirty health facility staff, 53% of participants were support staff, clinicians contributed to 34% of the participants, and psychosocial support staff was 13% of participants. The participants' ages ranged from 25 years to 65 years with most participants being between the ages of 35 years and 44 years. There was a balance in terms of those who had extensive experience in working in the HIV field and those who had recently entered the field. Notably, 27% of participants had been working in the HIV field for less than a year and 20% of the participants had been working in the field for more than sixteen years. With regards to time working at Ubuntu clinic, ten of the participants had been working at Ubuntu clinic for less than a year and two participants had been at Ubuntu clinic for more than sixteen years. Most of the participants were employed by the Department of Health (50%) and 37% were employed by different Non-governmental organisations.

Three prominent themes emerged from this study. These themes are (1) Disengagement is a public health problem that needs attention, (2) Understanding the multiple complexities of adherence, (3) Feelings towards patients who disengage from treatment. Some subthemes also emerged from the transcripts these will be presented fully.

Theme 1: Disengagement is a public health problem that needs attention.

When the study participants were asked about patient disengagement from ART, most acknowledged that disengagement is a significant public health concern. The participants of the study outlined several adverse effects of disengagement on the health system and the individual. Moreover, the HCWs described the consequences of disengagement, highlighting that disengagement is a threat to the person's health, treatment resistance, transmission risk, and burden for the health care system.

> *"It is a problem because like you know, like the virus becomes resistant to medication, so which is posing danger to the person who is not taking the medication you know".* (Clinician, age 49)

Most of the participants reported that disengagement from treatment affects more than the individual because the patient's viral load increases and that increases the chance of transmitting the virus to other people. In addition, the participants noted that disengagement results in the virus becoming resistant and patients will have to be moved to second-line treatment. They also highlighted that disengagement strains the health system as patients who disengage from treatment often get sick and require hospital admission.

> *"It's a problem because a person will start all over and get sick and now hospitals have to full because of this person who just decided to stop taking their treatment whereas they had a chance to take their treatment, so they don't get sick".* (Support staff, age 38)

> *"I think it's a big problem having worked in ARV's for a long time it feels like we've hit like a second wave of the epidemic. Like initially, we had very sick people coming in, but nobody had been on ARV's before so you, we were picking up the patients who were the weakest and getting them on treatments. ... but now they're people who've been on ARV's before and stopped so it makes their treatment more complicated".* (Clinician, age 42)

From the above quotes, the participants understand disengagement from treatment to be a growing major public health problem where one participant described disengagement from treatment as a second wave of the HIV epidemic. Apart from them describing disengagement as a public health problem, the participants showed an understanding of the multiple factors that influence treatment adherence.

Theme 2: Challenges for PLHIV: HCWs express empathy.

Most of the participants outlined factors that impact adherence. Their responses show that they have some empathy towards patients as they acknowledge that patients may disengage from treatment due to mental health challenges and non-disclosure, which they saw as challenges for PLHIV. The participants went on to describe how non-disclosure is related to social support. Moreover, they illustrated how social support affects treatment adherence and could be linked to the stigma of disclosing. The participants show concern for patients who disengage from treatment. The following section presents factors that lead to disengagement as noted by healthcare workers.

Mental health challenges.

Most of the participants stated that mental health challenges contribute immensely to disengagement from treatment. The participants reported that mental health challenges such as depression affect the patients' ability to make decisions.

> *"Most of the patients that are having mental illness default their ARVs because of their poor insight or their poor judgement…… the patient comes let's say he's HIV positive on ARVs and then develops mental illness, and then because mental illness affects their judgement and their insight when they are psychotic and in a psychotic state, then they can't reason, they just do things that are very weird and things that are very odd to people".* (Clinician, age 49)

The participant drew an association between mental illness symptoms (lack of insight, poor judgement) and adherence. Here the participant notes that mental illnesses alter the patients' thought process and decision making which could contribute to disengagement from treatment. The study participants stated that disengagement from HIV treatment is a product of underlying mental health challenges. The participants, therefore, perceive mental illness to contribute to adherence and note that disengagement is not normal behaviour, but it is behaviour that comes because of mental health challenges among many other challenges.

> *"Some are not mentally okay, maybe that could also be, that could, I could say maybe it's not a normal behaviour because they also go for depression; some they have like mental illnesses…".* (Support staff, age 26)

The participants reported that disengagement from treatment reflected what the patients experience in their lives. The participants stated that when a patient is depressed, going through a rough patch and when they have lost hope in life, they are likely to disengage from treatment.

> *"when they feel that they are at the end of the road and so life is not worth it for them anymore. So, even taking the medication for ARVs they don't see like a point in taking it because they think that they are going to die anyway, so why should they bother about viral load and ARVs. So, those are common reasons why people in mental health default their medication".* (Clinician, age 49).

The quotes above from the study participants show how HCWs associated mental health challenges and disengagement from treatment. Also, the participants described the different ways in which mental health can affect adherence to treatment for HIV patients.

Non-disclosure leading to disengagement and the dilemma of disclosing the HIV status.

Participants highlighted several reasons for patients disengaging from HIV treatment. Non-disclosure was emphasised as one of the major reasons for disengagement. The participants noted that non-disclosure contributes to many cases of disengagement.

> *The disclosure, which is the major problem for them not to take them, the ARV's".* (Clinician, age 42)

Apart from nondisclosure being a major problem, the participants of the study described how nondisclosure results to disengagement. A participant noted that non-disclosure makes it difficult for a patient to take their medication. They reported that in cases where the partner and family is unaware of the HIV status, patients are less likely to take treatment in front of their partner and family thereby resulting in them disengaging from treatment.

> *"I think it's difficult disclosing and, if I haven't disclosed to my partner but every night at eight o'clock, we sit and have supper and I must take my treatment, you know?"* (Clinician, age 52)
>
> *"I see a lot of patients who are not taking treatment well because of non-disclosure so they haven't told anyone at home"(* Clinician, age 42).

The participants showed empathy for patients who find disclosing difficult as they show that some patients can not disclose their HIV status due to the fear of stigma or lack of support. However, the HCWs still stress the importance of social support that could come because of disclosing the HIV status to partners and family, which helps to ensure treatment adherence.

> *"My opinion those who do not, did not disclosed and was married they are unlikely to default because she will have to disclose her status to the husband or to the wife…. I strongly believe if a person discloses to a person it will be easy for that person even to take the medication because there is a support. Disclosing can be hard because your family may not understand"* (Support staff, age 57).
>
> *"So, sometimes they say it's the reason they can't disclose because the guy now is going to dump that person because of the HIV status"*(Psychosocial support staff, age 42)
>
> *"I am not saying people should just talk about it if they are not yet comfortable, but they should not hide it from everyone, such as their families. I don't think all your family members can judge you. You can even speak to your parent, privately, so you can get support in that way."* (Support staff, age 38)

The participants of the study show that non-disclosure of the HIV status to one's partner and family contributes immensely to disengagement from treatment. The participants highlighted that disengagement is important especially to family and partners as the patients spend a lot of time with these people. Hiding their status from these significant people makes it hard for patients to take their treatment. The HCWs acknowledged that disclosure is difficult, showing empathy for patients. Disclosure is something that needs to be better understood because the participants highlighted that it could result in one getting support and or being rejected.

Concern for patients who disengage from treatment.

Most of the participants reported that they are troubled about patients when they disengage from treatment because they are aware of the adverse consequences of disengagement. The participants showed concern for patients who disengaged from treatment and they emphasised that they are willing to help them in ways that they can.

> *"I get worried and concerned. I want to know the reasons so that we can tackle whatever challenges she has to overcome those challenges so that the patient can be able to take treatment"*. (Support staff, 46)

The participant with the quote above expressed the need for insight into the reasons for disengagement. The participant did not only express concern for the patients, but they are also reflecting on their role in being able to help the patient so that they can tackle the challenge of disengagement.

> *"I feel sorry for them because I see dangers in that, because there is a possibility that one can lose her life if she doesn't take her medication, well especially the ARVs".* (Clinicians, age 49)
>
> *"It makes me feel sad, especially the young ones…., like yho! She's still young to have this viral load".* (Support staff, age 28)

The quotes highlight that some participants show some empathy towards these patients, and they express worry for these patients and their well-being. Contradictory to the feelings of empathy, the participants expressed anger and frustration towards patients who disengage from treatment.

Theme 3: Feelings towards patients who disengage from treatment: HCWs expressing anger and frustration.

When participants were asked about the feelings that they have towards patients who disengage from treatment, their feelings varied. Generally, participants expressed feelings of frustration and anger and reported their source of these feelings.

Frustration and anger.

Most of the participants expressed frustration and anger towards patients who disengage from treatment. The participants noted that they do not understand why patients discontinued their treatment when it is lifesaving. In that light, the participants communicated that when patients do not take treatment, they are choosing not to save their own lives.

> *"...that's what frustrating me; and then somebody dies because of HIV. That I…I…I…I fail to understand, why they should die because they have treatment already. It's only the people who do not know, who did not know about this HIV or they did never started tablets or treatment, they never tested for HIV; then I would understand, but for somebody who started treatment and then they decided to leave and then they are sick like that and then they die, that's what frustrated me"*. (Clinician, age 64)

The participants stated several reasons for their frustration when dealing with patients who disengage from treatment. Health care workers expressed frustration when patients do not adhere to their treatment, as these HCWs are aware of the benefits of the medication. The data shows that the source of frustration for HCWs is when some patients provide reasons or explanations for their disengagement that the participants considered unjustifiable.

> *"…for example why didn't you take your ARV's; I don't have any reason. Now you're like, well you just… I just want to strangle her... because I don't understand, I don't understand how come the person will just disengage their treatment for no reason"*. (Psychosocial support staff, age 42)

The data shows that the source of frustration for HCWs is when some patients provide reasons or explanations for their disengagement that the participants considered unjustifiable. The above quote shows that the failure to understand the decision to discontinue treatment was not only related to frustration and anger. Some of the participants noted that they are frustrated because they put in the effort to ensure that the patients do not disengage from treatment, especially for those who cycle in and out of care. The participants noted some of their efforts do not yield the results that they expect, as patients still disengage from treatment despite their efforts.

> *"…you counsel them till you're blue in the face and they don't change. And then that, it gets frustrating in the end because you've got someone's who's sick where they wouldn't be if they just took their treatment… it's time consuming the fact that now when they come to the clinic, for starters they must come every month because their viral load now is high; they must attend a Rotov counselling sessions every morning before they go to pharmacy, before they're being seen by the sister or a doctor they must go to a group counselling the Rotov counselling and they will become now it will be seen and then so it's time consuming they end up going home late and they get a monthly appointment so every month they must be here".* (Clinician, age 42).

The participants noted that working with patients who disengage from treatment is time consuming because they need special attention which makes the process long. As a result, most of the participants reported that patients who disengage from treatment frustrate them because they increase the workload.

> *They're making me angry. I get angry. I want to slap them. Joh, joh, I get angry when someone defaults treatment. (Support staff, age 33)*
>
> *I think the anger could be for you know, with the patient sometimes because you get a sense this patient just doesn't care. (Clinician, age 52)*

The participants expressed their anger and frustration towards patients who disengage from treatment as shown by the above quotes.

Patients who disengage from treatment do not take responsibility for their health.

Most of the study participants alluded to the notion that when patients disengage from treatment it means that they do not take responsibility for their health. The participants also noted that patients who discontinue their HIV treatment do not prioritise their health. Most of the participants emphasised that for patients to remain in treatment it is the responsibility of both the HCWs and the patient. Moreover, the participants noted that the HCWs are doing their part, but patients tend not to take responsibility for their health, which is why they disengage from treatment.

> *If the nurse says or if the doctor says come back on the 8th of March, make means to come back on the 8th of March because this is your health and you only have one life honestly….* it's *honestly your responsibility, your health honestly. Your health is your responsibility and then the clinicians and the doctors are there to help you; are there to support you; they're there for anything you want to ask and want to know.* (Support staff, age 26)

Some of the participants stated that all they can do as health facility staff is to support patients so that they can adhere to their treatment and it is the responsibility of the patient to ensure that they stay engaged in care. Most of the participants noted that the patients who disengage from treatment do not take responsibility for their health.

> *They don't take their responsibility, because I don't see the reason for patients to just drop their medication without consulting with doctor*. (Psychosocial support staff, age 38)

> *...the others just do not take full responsibility of themselves.* (Support staff, age 57)

> *but the patient also has a responsibility and it's not my responsibility as a healthcare worker to go and tell your boss that you must come to the clinic every month because now you have this disease*. (Clinician, age 49)

The above quotes highlight that the participants of the study believe that it is ultimately up to the patient to adhere to their treatment when they take responsibility for their health. The study participants highlight that there is only so much that they can offer to the patients, but the patients need to take ownership of their lives and prioritise their health over anything else.

Patients who disengage from treatment are full of excuses.

When the participants were asked about their experience with patients who stop taking their HIV treatment and later return to care, most of the participants noted that these patients give excuses for disengaging from treatment.

> *Something like they went to Eastern Cape and then they didn't, that is not a good reason to me…If they are going to and their appointments are not far from coming back and then they are going away, they must come and report so that we give them referral letters, and then they can be sorted there at* the…(Clinician, age 64)

Most of the participants regarded some reasons for disengagement from treatment as unjustifiable. In most cases where the participant noted a reason for disengagement to be unjustifiable, they would give a reason why they think it was unjustifiable and they would offer a solution. Most of the participants who reported to have been taking chronic medication were the ones who showed less understanding for not taking medication. They spoke about adherence in a personal way, highlighting that if they are adhering to treatment then the patients should also do the same. They compared ART medication and their chronic medication where they highlighted that it is not difficult to take pills every day.

> *I'm diabetic, I'm taking mine twice a day, I've never really forgotten because I'm like I have to take it. So, for me,it's just an excuse... mostly excuses. ...no, not at all there's no excuse not to take it* (Support staff, age 28).

> *I don't see why it should be fatigue from one tablet. It could be fatigued from maybe more than one tablet… I think it's very traumatic when you are taking more than one tablet.* (Clinician, age 49)

The above quotes from study participants highlight that the participants regard some reasons for disengaging from treatment as unjustifiable. Some of these reasons they stated are travelling to the Eastern Cape, pill burden, and pill fatigue.

Discussion

The study findings show that health facility staff experience internal conflict as they grapple with contradictory feelings of empathy and anger towards patients who interrupt treatment. The data shows that health facility staff understand that treatment adherence is a complex phenomenon and that patients are faced with different, difficult circumstances that result in them disengaging from treatment. The HCWs also acknowledged that disengagement is a public health problem and show concern for patients who interrupt treatment. On the other hand, there is a strong discourse that patients need to take responsibility for their health. Considering that, the health facility staff stated that they play their role in ensuring that patients take their treatment and that the patients have a role to play too. The findings of the study show that the source of anger and frustration for health facility staff is when they feel that patients are not taking responsibility for their health.

Findings indicate that HCWs express empathy when they can point to factors that they perceive as out of patients' control like mental health challenges. In that regard, they are highlighting that it is not directly the patient's fault when they disengage from treatment. HCWs' perspectives suggest that patients who disengage may be experiencing mental health challenges. This is in line with the prevalence of mental illness among PLHIV where it is reported that between 20% and 60% of HIV-positive adults suffer from some form of mental illness [27]. Findings of the study reflected that certain symptoms (poor judgement and poor insight), that are associated with mental illness, were underscored as contributing to disengagement. This is consistent with the results of a previous study that explored barriers to engagement, which showed that mental health challenges such as depression, may manifest in negative emotions that may affect a patient's disposition and motivation to access treatment [7]. Additionally, the findings are consistent with evidence from a meta-analysis that looked at the association of depression and nonadherence which established that depression is a risk factor for nonadherence to treatment [20]. Since patient-focused studies have also indicated mental health challenges as a contributor to disengagement [1,33] mental health challenges are a significant factor for disengagement which has implications for interventions. Additionally, we have a greater understanding of mental illness symptoms in relation to disengagement which may also indicate that mental health challenges should be considered in addressing disengagement.

In that light, interventions designed to simultaneously target depression and support adherence could be employed to improve both depression and treatment adherence outcomes [6]. Cognitive-behavioural therapy for adherence and depression (CBT-AD) can be applied to HIV medication adherence to improve ART [37]. Interventions may target the treatment of depression which will contribute to addressing mental health challenges, which may have a positive impact on adherence to treatment. A pilot study of CBT-AD among the South African population showed that this intervention is acceptable and feasible [2]. While psychological services available at public clinics are scarce especially in low-income settings [10,16], there is a need for additional psychosocial support for patients who cycle in and out of care. Task-shifting in mental health has been found to be feasible and effective especially in resource-limited countries [2, 25]. Therefore, task shifting could also be employed by training health facility staff on all levels how to provide basic mental health support in the form of counselling for patients who cycle in and out of care. This could ensure an increase in the much-needed mental health services for patients who interrupt treatment.

The findings of this study show that disclosure may influence access to social support which in turn may help the person to cope better with treatment adherence. This is consistent with a previous study which indicated that lack of disclosure is intertwined with stigma and poor social support [4]. Notably, the fear of stigma may prevent patients from confiding in others, leading to a lack of emotional support [4]. Mental health challenges and the lack of disclosure could be an indication of limited psychosocial support. We have not explored patients' experiences in this study so we cannot for certain say that mental health challenges and non-disclosure are indications of limited psychosocial support. However, understanding how not disclosing impacts adherence could help inform interventions. Support from HCWs and counsellors may assist patients with disclosure and may equip patients with skills that can assist them when they disclose their status [31]. Therefore, in the training sessions, HCWs can be educated on the importance of providing support to patients as this can result in patients disclosing their HIV status. In addition, interventions that fight against stigma are important as these could help patients feel more comfortable disclosing their status. This is because evidence from a study suggests that PLHIV hesitate to disclose their status fearing HIV-related stigma [31]. Interventions that aim to fight against HIV-related stigma can be employed on different levels from family to communities as these could increase disclosure.

From the data, it emerged that health facility staff understand that disengagement is a problem that needs to be addressed. Insights from this study are in line with previous studies of adherence where disengagement is regarded as a public health problem [24,27,41]. Knowing that HCWs see the seriousness of the problem is encouraging because it could translate into HCWs being interested in being part of the solution. They already noted what they perceive themselves as having some of their responsibilities in ensuring adherence. From the data, it emerged that HCWs are willing to do what is in their capacity to ensure that patients stay engaged in treatment. This is in line with findings from a study that was conducted to explore provider opinions about responsibility for medication adherence [39]. HCWs felt that it is their responsibility to educate a patient and to give them the proper treatment, thereafter the personal responsibility of patients begins [39]. This means that HCWs acknowledge their responsibility in ensuring that patients adhere to treatment. It should be noted that the insights from this study are not those of the patients, however, it is still valuable as it contributes to our understanding of how significant role players, health facility staff, make sense of disengagement. There is a need to know both patients' and HCWs' experiences and perspectives in ART adherence. Notably, while some of these perspectives may not be valid or true for patients themselves, it is still valid for these HCWs and may inform their attitudes and behaviours towards patients.

Drawing from the cognitive behavioural theory, cognition processes of individuals which include assumptions, judgments, appraisals, meanings attached, and assumptions play a significant in developing and maintaining emotional and behavioral responses to scenarios [14]. It is apparent that while HCWs understand the complexities of adherence, they have feelings of anger and empathy. These feelings being influenced by their cognition relating to disengagement. The HCWs stated that patients who interrupt treatment make them angry because they increase their workload, and they view these patients as not taking responsibility for their health. The HCWs have difficulties in grappling with certain feelings of anger and frustration because of HIV patient disengagement. In this case, perspectives about the reasons for disengagement may influence the approach to assisting patients. Their interpretation that patients are full of excuses and do not take responsibility for their health contributes to their feelings of anger and frustration. This could influence how they treat patients who disengage from treatment.

In a different way their thoughts about disclosure being difficult, disengagement as a public health problem and their understanding of mental health being out of their control contributes to the empathy feeling. Health facility staff's feelings (empathy and anger) and opinions/impressions (people are irresponsible) may influence their approach to engaging with patients which in turn may affect the patient's experience of treatment and possibly their choice to engage in care.

In previous studies, HCWs have negative attitudes towards patients who disengage from treatment [24,30]. The origins of the friction that exists between HCWs and patients is scarce [30]. We cannot forget the broader context of the system in which they function. HCWs are working in a compromised health system with staff shortages, fragmented services, and financial or cash-flow problems which might also be contributing to their anger and frustration [32]. In some cases, there are reports of ''abuse'' by clinical staff, but these are neither specific to HIV/AIDS [30]. In this study we understand in the context of HIV/AIDS care how the HCWs feel about the patients who disengagement from ART could be one of the reasons for negative behaviour towards patients. Health facility staff's impressions and opinions of adherence determinants are also important as they shape patient interaction and clinical care recommendations [35]. They also influence the success of adherence interventions [8, 35]. There is a need for the Welcome Service and other interventions that address the negative feelings that HCWs might have towards patients who interrupt treatment. These interventions could be influenced by the ABC model. The ABC model influenced by CBT, notes the first step in addressing HCWs negative interactions with patients is to recognize the source of their feelings and emotions [14]. In addition, addressing the negative interaction involves promoting self-knowledge among HCWs which is the recognition that prejudices, biases and negative thoughts impact their behaviour [14]. According to the ABC model, understanding and managing stressful reactions is of paramount importance to achieving control over irrational thoughts and replacing them with rational, flexible interpretations that promote well-being and productivity[14]. For example, replacing negative thoughts that is, patients who disengage from treatment are irresponsible, with thoughts of the wider context that could have resulted in patients disengaging from treatment. Therefore, it may be beneficial for interventions to cultivate an understanding of viewing the patient holistically so that certain generalisations do not translate into how HCWs engage with patients. Notably, addressing feelings of anger and frustration and promoting empathy for patients could influence patients' retention in care. In this case, when health facility staff understand and have empathy for a patient's circumstances it may influence patients' adherence to treatment [8].

This emphasises the value of psychosocial interventions for HCWs, which could help them navigate the difficult feelings that emerge because of working with patients who disengage from treatment. There are numerous benefits to psychosocial support for HCWs, Vesel [42] noted that the provision of coping and stress management techniques for HCWs helps them to persevere within these difficult environments and this potentially impacts health service delivery and quality of care. This means that providing psychosocial support for health care workers could help them when they are working with patients who return to care and could impact the quality of service that they provide for these patients. These can be integrated into training programs for HCWs in which they can be equipped with stress management skills. Other forms of psychosocial support for HCWs could be having dedicated spaces where health facility staff can debrief, and these sessions can occur weekly or every fortnight. Concrete supervision and support for HCWs could be a form of psychosocial support for health facility staff. In essence, the findings are valuable as they may translate into psychosocial support or skills-based training interventions that could help HCWs. Ideally, these should be integrated into a routine and ongoing training, however, in an overburdened health system, it is often only NGOs like MSF, who can step into this gap. While MSF's work is essential, its reach is also limited. One might hope that benefits learnt from organisations like MSF could later become part of public health services provided.

Research exploring factors influencing adherence has been conducted over the years, which offers valuable insight into patients' perspectives and experiences of adherence. Literature from the patients' perspectives has increased our understanding of the multiple complexities of adherence, highlighting the barriers and facilitators of disengagement from HIV treatment [3,34]. Research is limited on HCWs' perspectives of treatment disengagement and therefore, we have minimal insight into their experiences and perspectives of disengagement [4]. This current study provides valuable insight into the perspectives of health facility staff towards patients who interrupt treatment, and it contributes to our understanding of disengagement as a complex phenomenon. This understanding may influence how we consider interventions for treatment-adherence and preventing disengagement. In this way, HCWs' perspectives have contributed to our thinking "around" reasons for disengagement and what this means for interventions to improve treatment-adherence or prevent disengagement.

Limitations

The data used in this study was limited to that of healthcare workers and their perspectives of patient disengagement from ART. For future research, it would be beneficial if data from both patients and health facility staff is used so that interventions will be more meaningful. This study was also limited in that I was not involved in the data collection, only secondary data analysis. This limited my ability to engage with participants and ask further probing questions. Another limitation is that interviews were conducted in English, and it was very clear from the transcripts that some participants could not express themselves and convey their thoughts fully in English. For future research, participants could be interviewed in a language that they are more comfortable speaking. This can be done by researchers enlisting the support of trained translators or research assistants.

This study identified the two feelings (empathy and anger) and how the healthcare workers experience the different feelings in different circumstances. What the study did not show is how these play out during patient interactions or for internal conflict with the provider. This could be explored in future research.

Conclusion

There is tension within healthcare workers as they expressed both empathy and anger towards patients who disengage from treatment, this can potentially be resolved with more psychosocial support for both healthcare workers and patients. Although HCWs express empathy for patients, further work needs to be done to support staff to feel less overwhelmed by patients requiring intensive psychosocial and medical support. Patients' adherence to treatment is complex and requires health care workers to be on board. HCWs play an important role in patient empowerment and negative or authoritarian attitudes can drive patients to disengage. Many psychosocial factors contribute to a patient's willingness and ability to sustain lifelong retention in ART services. In that light, MSF is rolling out a pilot called the "Welcome Service" aiming to create a more patient-centered and non-judgmental approach to HIV care.

List of abbreviations

HCWs: Health care workers; ART: Antiretroviral treatment; PLHIV: People living with HIV; MSF: Médecins Sans Frontières; HREC: Health Sciences Human Research Ethics Committee; UNAIDS: Joint United Nations Programme on HIV and AIDS

Ethics approval and consent to participate.

This study received ethical clearance from Health Sciences Human Research Ethics Committee at the University of Cape Town.

Availability of data and materials

The data used in this study belongs to MSF and is available upon request from the corresponding authors. The data is not publicly available owing to some of it containing information that has the potential of compromising the research participant privacy/consent.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

TN was involved in the data analysis, initial manuscript writing, which has been reviewed and agreed by all authors.

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PART C: APPENDICES

Appendix A: Acknowledgements

I would like to thank MSF Khayelitsha for collaborating with me in this project. MSF was responsible data collection of the data that was used in this study. I would like to extend my sincere gratitude to my supervisors Alison Swartz and Carmen Späth who played a pivotal role for the success of this project. Not forgetting Zara Trafford who supported me in the initial phase of the dissertation which is the protocol. I would also want to thank my family and friends for the unwavering support that they rendered.

Appendix B: Questionnaire used in the study.

Study number:

State: date/ time/ location/ interview number

1. Icebreaker to fill in the table of information: Firstly, can you tell me about yourself and your role here in the clinic?

Age:
Job title: doctor/nurse/counselor/navigator/pharmacist/pharmacy assistant/other How long have you worked at this facility? (months/years) How long have you worked in HIV? (months/years) Affiliation: Department of Health/ NGO

We are going to talk about patients who disengage from HIV services: either missing appointments or becoming completely lost to follow up.

2. What is ‘ disengagement’ from HIV care
    a. *What counts as disengagement/implications for patient health and resistance/ impact on patient care*

Use the opportunity to clarify that we are talking about patients who have either completely disengaged from treatment (stopped taking their treatment and coming to the clinic completely) or who are intermittently engaged (missing appointments intermittently, missing viral load blood draws, missing pharmacy pick ups or have multiple high viral loads)

3. Can you think of a specific patient who disengaged from HIV care? Who were they and what happened?

4. Which patients in your opinion are more likely to disengage from HIV care?
    a. *Common traits, socio-demographics, sex, personality*

5. How difficult do you think it is to take ARVs every day?

6. Why do patients disengage from HIV care?
    a. *Prioritization/ taking care seriously/responsibility*
    b. *Patient vs health system*

    c. *Specific reasons: side effects/ logistics/ social support/alcohol/ substance use/ treatment fatigue/violence.*

7. Are there any “good” or “understandable” reasons to disengage from care? Why?

    a. *Explore: side effects/ logistics/ social support/alcohol/ substance use/ treatment fatigue/violence*

8. Are there any “bad” or “unjustified” reasons to disengage from care? Why?

    a. *Explore: side effects/ logistics/ social support/alcohol/ substance use/ treatment fatigue/violence*

9. What is your opinion of patients who have disengaged from care or who intermittently engage with services?

    a. *Fault/ taking treatment seriously/ responsibility/ prioritisation/ Can this behavior of disengagement be described as normal?*

10. Who is to blame if a patient disengages from care?

    a. *Patient themselves/ circumstances/ society/ health system/ healthcare workers/ nobody*

Now we are going to talk about dealing with these patients in the clinic setting (tailor to job description of participant and their interaction with patients)

11. Can you think of a time when a patient reengaged in care? Who were they and what happened? What did you say to them? How did you feel when they reengaged

    a. Impacts on your time, referrals, and prescriptions

12. Describe what you think will happen if you tell the patient that interrupting treatment is normal?

13. Describe your role and responsibility with patients who have disengaged from care?

14. How do you feel when you have to manage/ deal with a patient who is returning to care?

    a. *What emotions do you feel?*

    b. *Worthy of the extra effort?*

15. Do you feel able to manage patients who disengage easily?

16. Explain what you find difficult about managing/ dealing with these patients?

    a. *Time-consuming/ complicated to manage/ emotionally draining/ill-equipped to manage/ lack of referral options for patient.*

Now we are going to talk about disengagement more broadly

17. Do you think disengagement is a problem that warrants focus/resources? Why? Which patients should get the highest priority?

    a. *Worthy of extra resources*

18. For patients who disengage from treatment and services, do you think it is possible for healthcare workers to change the way these patients behave? Why?

    a. *Futility vs worthy of additional effort*

19. What do you need to be able to manage these patients well?

Appendix C: Consent form used in the study.

Informed consent for staff interview study participants

Experience and perceptions of patients who disengage from ART care

Information sheet and informed consent form for in-depth interview of healthcare staff

This information and informed consent form is to help you decide whether you want to take part in a research study to explore staff experiences of dealing with patients who have disengaged from antiretroviral therapy services.

Your participation is voluntary and your consent can be withdrawn at any point without any explanation.

Please take time to read this form and ask questions.

You can also discuss your participation with others before making a decision. If you decide to take part you will be asked to sign this document. Once you have signed the consent form, you will be given a copy to keep.

Who is conducting the study?

Médecins Sans Frontières(MSF) are an international humanitarian organisation who have been working in Khayelitsha since 1999. They work with city and provincial clinics and have been involved with developing programmes to help people living with HIV.

Médecins Sans Frontières (MSF) are conducting this research to explore staff experiences of dealing with patients who have disengaged from antiretroviral therapy services

What is the purpose of this study?

In this study, we would like to explore the experiences and perspectives staff who manage or look after patients who have poor engagement with ART services. We will use the information we find from this study to understand disengagement and how it affects staff in more depth and use these lessons learned to develop ways to support staff and patients, and in turn inform potential policy and practice change in how ART is dispensed in clinics.

Why was I invited to take part in this study?

We are inviting between all staff who are involved with patients in the ART clinic

What will taking part in this study involve?

If you agree to participate in this study, we will ask you to take part in an individual in-depth interview about your experiences and perceptions of patient disengagement.

The interview will take around 30 to 45 minutes. We will ask questions about your opinions of people who have disengaged from care and how you deal with them in the clinic. Interviews will take place in a quiet, private location and will be conducted in English.

If you agree to take part in an interview, you will not have to answer any questions that you are uncomfortable answering, and you can stop the interview at any time

The interviews will be recorded on an audio recorder. The study team will listen to them afterwards and write down everything that was said so that we can make sure we do not lose any information that you give us. They will then be analysed to understand how healthcare staff experience managing patients who disengage. The interviewer will also take notes during the interview to help them record what you say as accurately as possible. Data (documents and audio-recordings) will be stored for five years after the end of the study on a portable storage device in a locked cabinet and will be destroyed at the end of this period.

Will my involvement be confidential?

We will not use your name when writing reports or presentations about the research so as to maintain confidentiality. During data collection, audio-recording equipment, computers and printed documents containing your information will be handled with care and every effort will be made to keep it safe and secure, using locked cupboards and codes with access limited to principal investigator and one co-investigator. Once all recordings have been typed up, the recording containing your voice will be stored on a portable storage device in a locked filing cabinet in the MSF office in Khayelitsha. The written documents will only use a code to identify the person speaking, e.g. healthcare worker 1. No names will be used.

The consent document that contains your name and signature will be placed in a locked cupboard at the MSF office for a period of 5 years after which all documents will be shredded.

MSF will make every effort that no identifying information is reflected during presentations and in reports that reflects the findings but this can never be 100% guaranteed.

The interview will be kept confidential between you and the interviewers. The written versions of the interview will be shared with the study team so that we can analyse them properly, but they will have only the study number on them. The findings will be disseminated in MSF reports, at national and international conferences and in international peer-reviewed journals but all identifying information will be removed.

Can I withdraw my consent?

Yes, you can withdraw your consent anytime before, during or immediately after the interview, up until the interview has been transcribed.

Will I be reimbursed?

You will not be reimbursed for your participation in this study.

Are there any risks or benefits to taking part in the study?

Benefits

There is no direct benefit to you for taking part in this study, but the information that we gather will help us to understand how disengagement affects healthcare staff, understand staff needs and help us inform strategies to improve ART services for patients and staff.

Risks

We will be asking personal and confidential questions about your experiences and opinions and could result in you feeling uncomfortable or even emotional. You can stop the interview at any time if you feel uncomfortable and if you would like us to refer you to an MSF counsellor after the interview, we can arrange for this.

You may feel that this is an evaluation of your performance but it will not be - the interview is for the purpose of the qualitative study into the staff's experiences and perceptions of patients who disengage from services. It will be between you and the interviewer in a private place so there is little risk of other people hearing the discussion. What is discussed will not be reported to your supervisor. All reports and write ups of the data will be aggregated and fed back to the facility together so that the confidentiality of each individual participant is maintained. If there is a risk that your identity would be revealed, this will be addressed on a case by case basis, involving the whole study team to ensure that you are protected to the best of our ability. Your participation in the study will not affect your current or future employment in any way and only members of the research team will have access to the database of information. There is some chance that you could be identified from the quotes we use from your interview, but we will not use your name when we present the findings, and will just use your study number to label any quotes that we use from your interview.

What will be done with the information collected during the study?

Interviews will be analysed and reports and presentations will be used to share the information with other people. Data may also be used for advocacy purposes. Your name will not appear anywhere in these documents. We hope that the information we collect will help us understand and improve the services for HIV patients.

Who has given ethical approval for this study to be conducted?

This study has been approved by [to be added once approved].

Who can I contact if I have any further questions?

If you have any questions or want more information about the study you can contact

Claire Keene, HIV Medical Activities Manager
Médecins Sans Frontières
Tel: +27 21 364 5490 | Cell: +27 82 958 0556 | Fax: +27 21 361 7051
Email: msfocb-khayelitsha-hivmam@brussels.msf.org

The ethical oversight of this study is performed by the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee. If you want any information regarding your rights as a research

participant, or have complaints regarding this research, you may contact: your doctor or the Ethics committee, by contacting:
Prof. Marc Blockman, the Chairperson of the Research Ethics Committee at the University of Cape Town

The Human Research Ethics Committee
Floor E53, Room 46
Old Main Building
Groote Schuur Hospital
Observatory, 7925

By signing below I show that:

1. I have read the study information form, or it has been read to me.
2. I have had the opportunity to ask questions, and to have any questions that I have asked answered.
3. I am aware that taking part in the study is my choice and I can refuse to take part or stop taking part at any time for any reason.
4. I am aware that the interviews will be recorded and I agree to being recorded.
5. I am aware that this interview will in no way affect my work, and that my job will not be affected in any way should I decide to withdraw from the study
6. I agree to take part in the study.

Name of study participant	
Signature of study participant	
Date	
Name of witness	
Relationship of witness to study participant	
Signature of witness	
Date	

Staff member taking the consent

By signing below I show that:

1. I have explained the study to the person named above.
2. I have given him/her a chance to ask questions and I have answered these questions.
3. He/she agreed to being recorded.
4. He/she has willingly agreed to take part in the study.

Name of study staff taking the consent	
Signature of study staff taking the consent	
Date	

Appendix D: The instructions for authors for the target journal

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section. Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:
  - "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"
  - or for non-clinical or non-research studies a description of what the article reports
- list the full names and institutional addresses for all authors
  - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below
- indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed, and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

- the aim, design and setting of the study

- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and materials
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval and for experimental studies involving client-owned animals, authors must also include a statement on informed consent from the client or owner.

If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication

If your manuscript contains any individual person's data in any form (including any individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

- The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]
- The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- All data generated or analysed during this study are included in this published article [and its supplementary information files].
- The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.
- Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

- The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].
- Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

All financial and non-financial competing interests must be declared in this section.

Please use the authors initials to refer to each authors' competing interests in this section.

If you do not have any competing interests, please state "The authors declare that they have no competing interests" in this section.

Funding

All sources of funding for the research reported should be declared. The role of the funding body in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript should be declared.

Authors' contributions

Please use initials to refer to each author's contribution in this section, for example: "FC analyzed and interpreted the patient data regarding the hematological disease and the transplant. RH performed the histological examination of the kidney, and was a major contributor in writing the manuscript. All authors read and approved the final manuscript."

Acknowledgements

Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

If you do not have anyone to acknowledge, please write "Not applicable" in this section.

Group authorship (for manuscripts involving a collaboration group): if you would like the names of the individual members of a collaboration Group to be searchable through their individual PubMed records, please ensure that the title of the collaboration Group is included on the title page and in the submission system and also include collaborating author names as the last paragraph of the “Acknowledgements” section. Please add authors in the format First Name, Middle initial(s) (optional), Last Name. You can add institution or country information for each author if you wish, but this should be consistent across all authors.

Please note that individual names may not be present in the PubMed record at the time a published article is initially included in PubMed as it takes PubMed additional time to code this information.

Authors' information

This section is optional.

You may choose to use this section to include any relevant information about the author(s) that may aid the reader's interpretation of the article, and understand the standpoint of the author(s). This may include details about the authors' qualifications, current positions they hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

References

Vancouver reference style

Appendix E: HREC ethical clearance letter

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

21 August 2020

HREC REF: 495/2020

Dr A Swartz
Division of Social and Behavioural Sciences
Room 3.44 Falmouth Building -FHS
Email: alison.swartz@uct.ac.za
Student: NHMTSE001@myuct.ac.za

Dear Dr Swartz

PROJECT TITLE: AN EXPLORATION OF THE HEALTH FACILITY STAFF PERSPECTIVES ON PATIENTS WHO DISENGAGE FROM HIV CARE: A QUALITATIVE ANALYSIS FROM KHAYELITSHA, CAPE TOWN, SOUTH AFRICA (MPH DEGREE - MISS TSEPHISO NHEMACHENA) (SUB-STUDY - 542/2019)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC)for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 August 2021.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Miss Tsephiso Nhemachena will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

HREC /REF:495/2020sa

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.