

THESIS TITLE:

**From Lost to Found: the Silent Transfer of Patients on
Antiretroviral Therapy in Khayelitsha, South Africa**

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THESIS SUBMITTED IN FULFILMENT OF A
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Part 0: Preamble

DECLARATION:

1. I know that plagiarism is wrong. Plagiarism is to use another's work and pretend that it is one's own.
2. I have used the Vancouver convention for citation and referencing. Each contribution to, and quotation in, this thesis from the work(s) of other people has been attributed, and has been cited and referenced.
3. This thesis is my own work.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.
5. I acknowledge that copying someone else's assignment or essay, or part of it, is wrong, and declare that this is my own work.

Signature Claudine Hennessey (electronic Signature)

DEDICATION:

I dedicate this thesis to my family – to my Mum, Dad, Heidi, Bryan, Michael, Jack and Nanny for your love, and for supporting me every step of the way. You are the best family anyone could ask for.

THESIS ABSTRACT:

From Lost to Found: The Silent Transfer of Patients on Antiretroviral Therapy in Khayelitsha, South Africa

Claudine Hennessey, BScN; Andrew Boulle, PhD; Kathryn Stinson, PhD

Incorrect classification of silent transfer (STF) patients as lost to follow-up (LTF) negatively impacts accurate assessment of retention in care for antiretroviral (ART) programmes. Understanding reasons why patients STF and what proportion of LTF patients constitute this silent transfer phenomenon is necessary to ensure patient continuity of care. We attempted to identify STF patients using the routine government electronic monitoring systems. Furthermore, we sought to identify potential reasons for the STF phenomenon through patient surveys and healthcare provider interviews, in order to guide policy and improve programmatic outcomes.

In this mixed methods approach, we selected patients identified as LTF between 2008-2012 in three health facilities from Khayelitsha, Western Cape. Identified patients were subsequently searched for using a combined provincial patient data set. Once consent was obtained, sampling of patients and healthcare providers, using convenience and snowballing methods respectively, were selected for participation.

Ninety percent of patients believe it necessary to inform facility staff of the intent to transfer, 56% of patients interviewed cited fear of negative attitudes from staff regarding transfer request (65%), family situations (30%), and long waiting times (11%) as contributing factors to silently transferring care between facilities. Healthcare providers cited stigma, family obligations and/or support, and migration to the Eastern Cape as main reasons for patients transferring. Healthcare providers cited incomplete or lack of transfer documentation as the biggest barrier to timeous treatment of the transfer patient.

Incorrect reporting of patients as lost to follow-up negatively affects the treatment programmes retention in care. Negative staff attitudes and poor operational services prevent patients informing staff of transfer intent. The treatment programme must

adapt current transfer policies in order to facilitate the transfer process for all patients, including those experiencing emergencies and life events. Linked electronic patient monitoring systems will improve accurate retention in care reporting and improve fluidity of transferring of patients between health services.

ACKNOWLEDGEMENTS:

I would first like to thank all the patients and staff in Khayelitsha for their participation and support during this process, and each time I came to the facilities.

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I am forever grateful to Meg Osler, Katherine Hilderbrand, Jonathan Euvrard, Robin Burley, Meagan Stuurman and the rest of the barefoot runners for your ongoing support during this process.

Thank you to my advisor, Kathryn Stinson for guiding me through this journey.

Special thanks to Morna Cornell for your dedication, commitment and guidance...here is the story...

Finally, a big thank you to my family and friends here in South Africa and around the globe who have supported me, laughed with me, fed me, wined and dined me and pushed me up this steep mountain.

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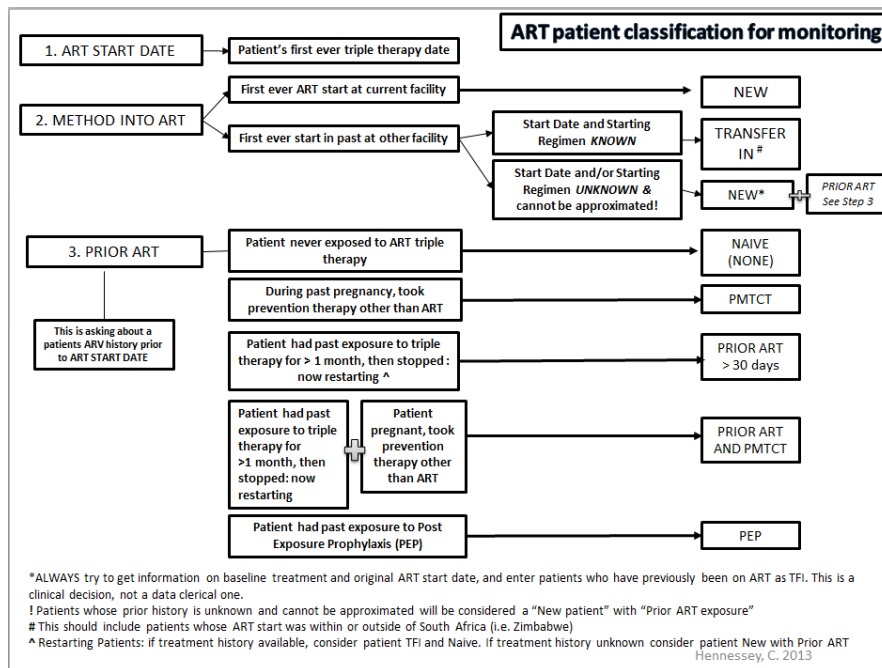
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Part A: Protocol

- Figure 1: ART patient classification for monitoring



- Figure 1: Map of Western Cape Cape Town Metro District Health Services and Sub-District Health Areas



- Table 1: Variables for Qualitative and Quantitative Data

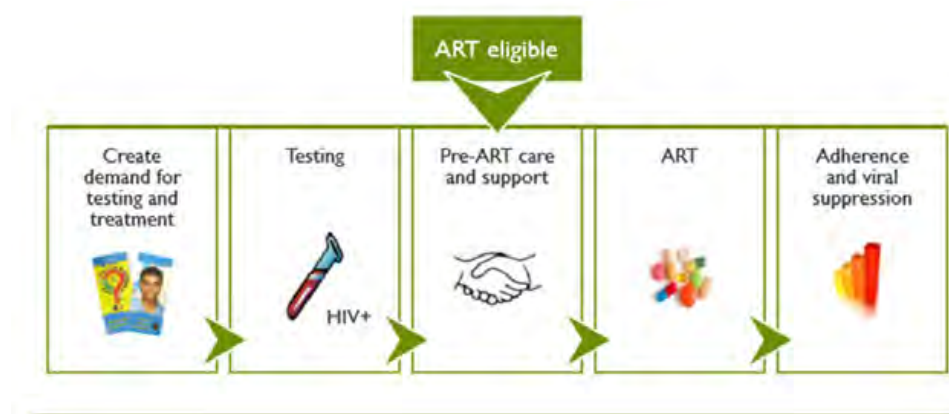
Variables Table				
	Description	Data Source	Name of Variable	Type
Baseline	Demographics	eKapa	Current Age	Numerical

			Sex	Categorical
	ART information		Age at ART Start	Categorical
			Outcome	Categorical
			Name of facility	Categorical
Follow-up	ART information	Provincial data set	Name of STF facility	Categorical
			Location of clinic	Categorical
			Method into ART	Categorical
			Prior ART	Categorical
			Number of transfers	Numerical
	Healthcare provider information	Health provider in-depth semi structured interviews	Type of health provider	Categorical
			Duration of employment	Numerical
			Duration of employment in ART service	Numerical
			Type of transfer patients	Thematic
			How do you assess transfers who arrive without documentation?	Thematic
			Clinical requirement pertaining to transfer	Thematic
			Reasons for transfer	Thematic
			Health providers perceptions of transfer	Thematic
			Health providers perceptions of silent transfer	Thematic
			Health providers perception of transfer limitations	Thematic
			Health providers reasons for transfer limitation	Thematic
			Managing STF or transfer patients	Thematic
			Health providers policy and programmatic classifications	Thematic
	Patient Information	Patient Survey	Duration on ART	Numerical
			ART status	Categorical

			Distance from home to health facility	Numerical
			Time to travel	Numerical
			Type of transport	Categorical
			Cost of transport	Numerical
			Information regarding transfer rules	Categorical
			Type of information	Categorical
			Care Satisfaction	Categorical
			Patient Care improvement suggestions	Categorical
			Moving clinic notification	Categorical
			Reasons for not informing transfer	Categorical
			Reasons for transferring	Categorical
			Medication interruption	Categorical
			Duration without treatment	Numerical

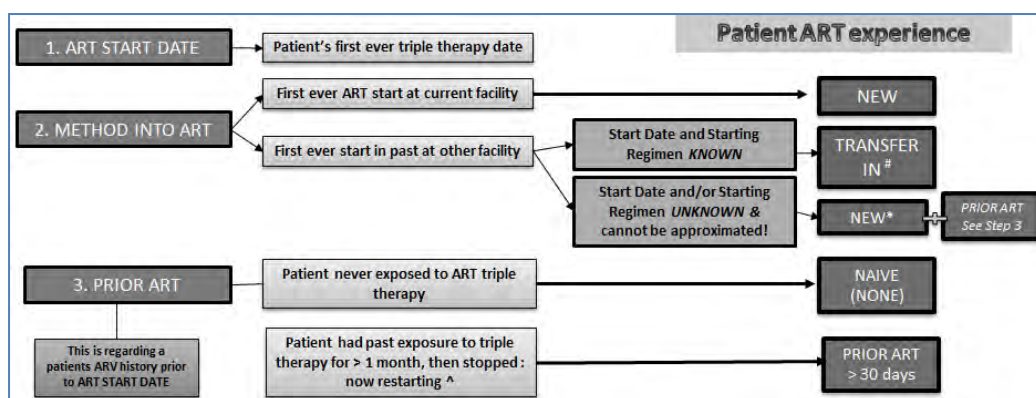
Part B: Literature Review

- Figure One. 2: WHO Patient Treatment Cascade (1,17)



Part C: Article

- Figure 1: Patient classification at time of entry into health facility



- Table 1: Patient Characteristics of Silent Transfer Patients and Non Silent Transfers

Table 1: Patient Characteristics of Silent Transfer Patients vs Non Silent transfers		
Characteristic	Adults (≥15 yrs), N=4166	
	STF patients n=1521	Non STF patients n=2645
Age at ART Start (yrs), median (IQR)	31 (27-36)	33 (28-40)
Age Categories, n (%)		
15-24 yrs	227 (15)	258 (10)
25-34 yrs	792 (52)	1209 (46)
35-44 yrs	373 (25)	777 (29)
45+ yrs	129 (9)	401 (15)
Gender, n (%)		
Women	1027 (68)	1533 (58)
25-34 yrs	561 (55)	770 (50)
35-44 yrs	197 (19)	380 (25)
Men	494 (32)	1112 (42)
25-34 yrs	231 (47)	439 (39)
35-44 yrs	176 (36)	397 (36)
Number of times transferred, n (%)		
Once	1283 (84)	
Twice	196 (13)	
2-5 times	42 (3)	
Location of Silent Transfer within Western Cape Province, n (%)		
Cape Town MDHS** District	1380 (91)	
Khayelitsha Sub-district (within MDHS District)	968 (70)	

Outside of Metro	141 (9)	
Recorded 'Method into ART' status at transfer in (TFI) facility*, n (%)		
Incorrectly recorded as 'New' at TFI facility	1097 (72)	
Of these patients, incorrectly captured as 'ART Naïve', meaning no prior ART experience	1039 (95)	
Correctly captured as TFI at transfer facility	424 (28)	
<p>**Metro District Health Service;</p> <p>*Programmatic classification used to determine if a patient is new to treatment or has come from another facility. 'New' implies that a patient has not been on triple therapy before their arrival at ART enrolment facility.</p> <p>*Programmatic classification used to determine if a patient is new to treatment or has come from another facility. 'New' implies that a patient has not been on triple therapy before their arrival at ART enrolment facility. 'Naïve' refers to a patient never having exposure to ART prior to their first triple therapy ART start date.</p> <p>^Patients who were not linked, who may have been true LTF or STF care outside of the Western Cape.</p>		

Part A: Protocol

STUDY PROTOCOL:

UNIVERSITY OF CAPE TOWN

**From Lost to Found: the Silent Transfer of
Patients on Antiretroviral Therapy in
Khayelitsha, South Africa**

Master of Public Health (General Track)

Study Protocol for Mini-Dissertation

Claudine Hennessey HNNCLA007

December 1st 2014

Supervisor: Dr. Kathryn Stinson

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INTRODUCTION:

In 2012, there were an estimated 35.5 million people living with HIV with 25 million of those living in Sub Saharan Africa (1). In South Africa, over 6.1 million people are living with HIV (2) with just over 2 million having ever been initiated on antiretroviral therapy (ART). There is global consensus that patients who remain adherent on ART can virally suppress the disease, reduce the risk of transmission to others, and live their lives with minimal interruption to activities of daily living (2–4). However, a weak and overburdened healthcare system can negatively impact on patient outcomes, by influencing a patient's ability to access and remain on treatment (5).

Scale up of Antiretroviral Therapy (ART) Services in South Africa:

The rapid scale-up of the ART program in South Africa over the past decade has enabled almost 2 million HIV-positive patients to initiate lifesaving ART (6). There have been significant advances within the South African HIV treatment program including changes to the enrolment criteria, improvements in regimens and nurse-driven initiations and management of patients. Specific programmatic targets set forth by the National Strategic Plan for HIV/AIDS have contributed to the rapid expansion and scale-up of the ART program (2,7,8).

In the Western Cape, the rapid scale-up of ART has enabled over 100,000 patients to initiate treatment between 2001 and 2012 (9), with over 30,000 patients having initiated in the township of Khayelitsha (10). Khayelitsha not only is one of the largest cohorts of patients on ART, it is also one of the oldest in South Africa, with ART being made available in April 2000 through the collaboration with Médecins Sans Frontières (MSF) and the Western Cape Provincial Department of Health (3,11).

The burgeoning patient population due to scale-up within a constrained health system has necessitated the need for new and innovative ways to keep patients on ART. This has led to a shift in program strategy from concentrating on scale-up and roll out, to optimizing models of adherence and retention in care (12–14) whilst developing strategies to decongest the overburdened health facilities. Although

several innovations are showing positive results, still more must be done to ensure that patients, who initiate ART, remain on ART for life.

Health System Impact on the rapid expansion of the ART programme:

The rapid expansion and scale-up of the ART program is a challenge in itself, frequently with weak and insufficient health services contributing suboptimal implementation. Linkage and referral of patients between services is often poor; patient monitoring systems are not operationally prioritized, and human resources are not sufficiently capacitated to actively follow up those patients defaulting treatment, resulting in an increasing number of patients being lost to care (15,16).

At the inception of the HIV treatment program in South Africa, patient to clinician ratios enabled patients to receive intensive, individualized and focused care resulting in few patients defaulting treatment and subsequently becoming lost to the program (4). However, over time, it has understandably been challenging for healthcare providers to provide the same individualized care for such a large group of patients as changes in ART eligibility criteria have enabled more people to begin treatment and the long-term service burden of patients on ART has increased (8). This is also compounded by an ever-increasing mobile population. The mobile population includes patients who move for a variety of reasons between health facilities. This movement can be from one facility to another within a sub-district or district, provincial or country health management structure that move between facilities, or 'silently' transfer their care. Some evidence points to more common reasons for movement being associated with socioeconomic factors, for instance transport, financial and family responsibility challenges as found in a study in Uganda (17).

Health facilities are struggling to cope with the surge in patient numbers, which has led to operational difficulties in monitoring defaulting patients who have become LTF, including identifying those who have potentially silently transferred, given that this activity is time consuming and costly on a large scale. This has contributed to the increase in defaulting patients documented as LTF (15). In a study conducted in 4 rural health facilities in Malawi, 7% of patients considered LTF had in fact silently transferred their care to another health facility (16). As the South African ART program matures and continues to grow, it is important to learn more about the silent

transfer and and the current transfer processes, and adapt those policies in order to provide the optimal care for this cadre of patients.

Monitoring of ART Services- the 3 tier approach:

The monitoring of the ART services in South Africa has undergone expansion and changes in response to scale-up since its introduction in 2001. The Western Cape Department of Health was one of the first government health programmes to implement longitudinal monitoring of patients initiated on ART and in 2011 the National Department of Health adopted the 3 tier monitoring strategy (18). The 3 tier monitoring system monitors the clinical and programmatic outcomes of the ART programme (19). Through the use of cohort monitoring the ART programme has been used to guide policy and programmatic changes. The HIV Programme has primarily focussed on retention in care and the monitoring of health outcomes (defined below) in order to guide programmatic interventions.

ART programme outcome definitions:

In the South African ART programme, there are four definitions used to classify a patients ART treatment status: Remaining in Care (RIC) and Outcomes of Died (RIP), Transfer/Moved-out (TFO) and Lost to follow-up (LTF). In addition there are two classifications of patients used when commencing ART at a health facility. New patient (New) refers to those patients who are beginning ART for the first time at the time of ART initiation (meaning they have not been on lifelong ART prior to commencing), or those patients who have been on ART previously but who have defaulted treatment and are restarting; Transfer In (TFI) refers to those patients who are coming from another ART facility, already on treatment and are continuing their care at a new facility without interruption. These programmatic definitions follow those guidelines established by the World Health Organization (WHO) and adopted by the South African National Department of Health (NDoH) in monitoring the ART programme (19–22).

Lost to Follow-up (LTF):

According to the SA national M&E guidelines which follow the WHO Monitoring and Evaluation Guidelines patients are defined as unconfirmed loss to follow up when

they have not accessed a health facility in 3 months, and/or have gone without drugs in hand for > 90 days (21). Patients are described as confirmed loss to follow if they are confirmed LTF through active attempts at tracing, through the use of either home visits or telephonic follow up, usually conducted by community health workers (CCWs) or other designated healthcare workers. In this study the term LTF will be generalized to include confirmed and unconfirmed LTF as documentation of confirmed loss to follow up is difficult to ascertain given the constraints of the healthcare system.

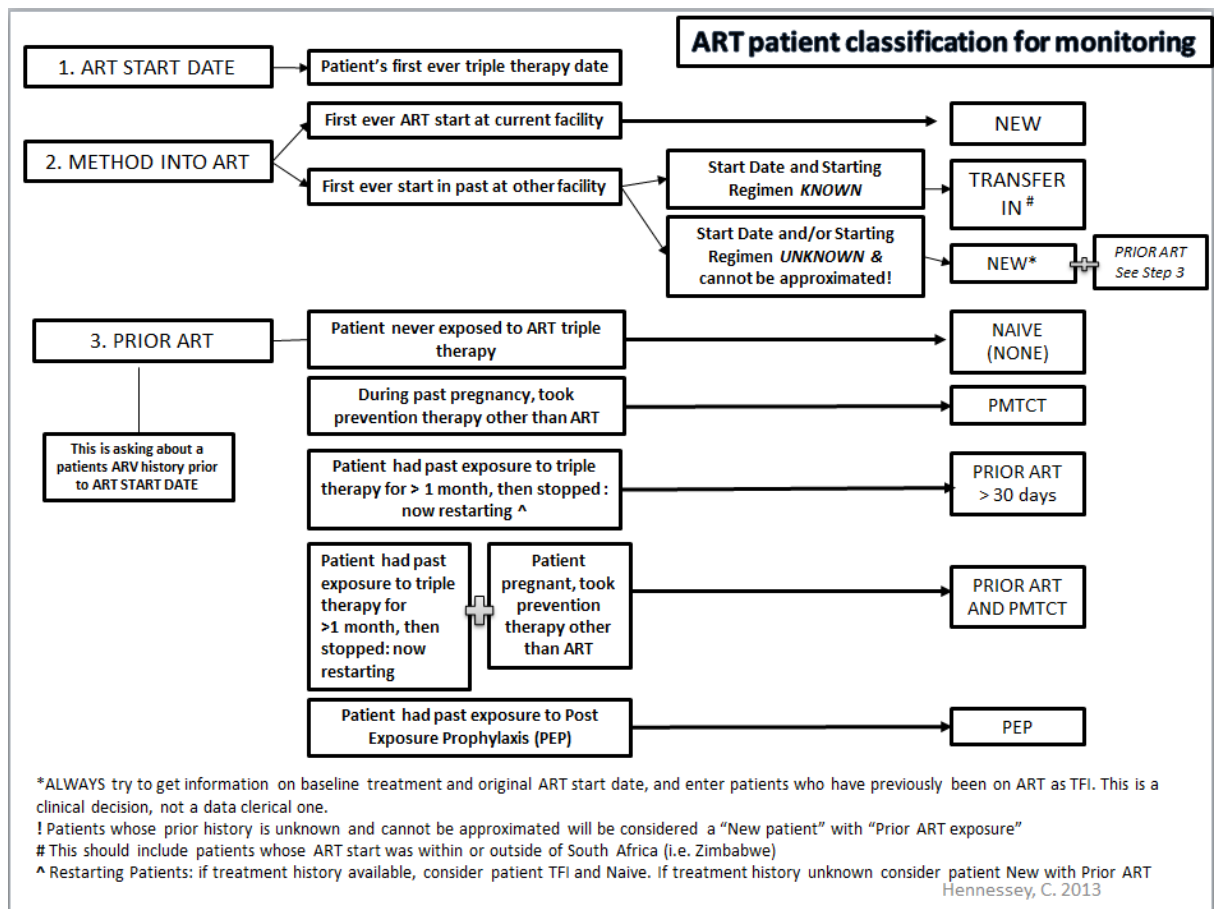
Silent Transfers (STF):

Although there are defined criteria for classifying a transfer out (TFO) patient, for the purpose of this study we will be looking at those patients considered a LTF who are actually alive and in care at another facility, hence making them a 'silent transfer' and not a true LTF. The definition for a silent transfer within the context of this research study is a patient who leaves clinical care at one health facility without notification to the departing facility of their intended transfer, and arrives at a new facility to continue their care

This cohort of patients will include patients who are considered LTF at their previous facility, and may be considered restarting patients at their new facilities depending on how long they have been without treatment.

Figure 1 indicates how patients who move between facilities are to be captured into the monitoring systems. Health providers are responsible for identifying patients as New or TFI patients depending on the findings during consultation with their patient. A New patient is defined as any patient who is initiating triple therapy for the first time. Prior ART refers to those patients who have been on treatment before for greater than 30 days. Historically and prior to the provision of ART being made available to all patients, many patients were receiving ART in either a private sector or as part of a research trial. In order to accurately account for a patients experience on ART the term Prior ART was used to differentiate those patients from patients who were Naïve to treatment. In the monthly data, only patients who are New, Naïve are included in the ART initiation numbers for a facility; under or over reporting of New initiations can have negative implications for the ART programme.

Figure 1: Patient flow between ART services



Justification of Research:

LTF has become one of the most important outcomes to identify ART programme effectiveness (23,24). It is known that patients move between health services, sometimes requesting official transfers between facilities or sometimes silently transferring (STF) to other health facilities, although neither of these movements are monitored, managed or well documented (16,25). This may result in an inflation of LTF proportions. The constraints of the healthcare system in tracing patients can contribute to an over-inflated reporting of LTF; as patients who are deemed LTF may be on treatment in other health facilities, however, the capacity of monitoring systems to identify them as such are not currently in place.

In order to ensure continuity of patient care it is essential that the HIV programme explore the relationship between LTF patients and STF. Could it be that improved monitoring of transfer patients may reduce the overall number of patients identified as LTF within the ART programme?

Problem Statement:

As more patients become eligible for life long ART and treatment duration increases, it is likely that services will experience more patients becoming lost to clinical care or LTF. It is imperative to identify whether patients considered LTF are in care at another facility. Understanding this STF population will improve and ensure effective management of this patient within the ART programme.

Aim:

The aim of this research is to identify and describe the characteristics of the STF patient in three primary healthcare ART services in Khayelitsha in order to inform ongoing clinical care and programmatic management of patients accessing ART services over time.

Objectives:

The objectives of the proposed study are as follows:

1. To determine how many patients in the three ART services who are identified as LTF are STFs.
2. To describe the characteristics of these patients including the geographical location of STF facilities.
3. To describe reasons why patients STF between services.
4. To identify the perceptions and attitudes of health providers towards STFs, in order to identify any potential barriers which could impact on the continuity of care.

Research Questions:

1. What proportion of patients documented with a LTF outcome are STFs?
2. What are the patient characteristics of a STF patient?
3. What is the geographical context for patients between 'lost' and 'found' facility?
4. What are patient reasons for STF?
5. What are the perceptions of clinical staff regarding the overall and STF transfer process?

Methods:**Study design:**

The study will apply a mixed method study design using retrospective cohort data, and patient and health provider's interviews.

Population:

The study population comprises all adult patients (>15 years of age) ever initiated on ART with an outcome of LTF in the health sub-district of Khayelitsha.

Study Sample:

The study sample includes adults initiated on ART between January 1st 2001 and September 30th 2012 with a documented outcome of lost to follow-up (LTF) between January 1st 2008 and December 31st 2012 within three identified provincial health facilities within Khayelitsha.

Catchment Area:

Located in the Cape Town Municipality of the Western Cape, the township of Khayelitsha is the second largest townships in all of South Africa with a population of over 0.5 million mostly African Xhosa speaking residents. Created during apartheid and officially established in 1983 to resettle African residents, Khayelitsha consists of over 22 proximately informal settlements and is plagued by high crime and unemployment (Affordable land and housing data centre, n.d). In terms of health, antenatal HIV prevalence was measured at 31.1% in 2008 with an HIV/TB co infection rate of close to 70% (26). It also has one of the oldest and largest cohort of patients on ART, due in large part to the support of MSF working in collaboration with the City of Cape Town and the Provincial Government of the Western Cape (11).

Figure 3: Map of Western Cape Cape Town Metro District Health Services and Sub-District Health Areas



Sampling Methods:

Sample Size:

Quantitative Data:

The proposed sample (n=4166) is any adult (≥ 18 years of age) who ever initiated ART in one of 3 Primary Healthcare (PHC) facilities in the sub-district of Khayelitsha (Michael Mapongwana, Nolungile and Ubuntu) who had a recorded outcome of LTF between January 1st 2008 and December 31st 2012.

Inclusion criteria:

1. Adult patients who initiated ART at Michael Mapongwana, Nolungile or Site B (Ubuntu) facilities.
2. Patients with an outcome of LTF from January 1st 2008 – September 30th 2012.

Exclusion Criteria:

1. Patients considered LTF without an ART start date will be excluded from the study, as these patients will most likely be patients who have defaulted having never started treatment.
2. Patients who were considered a TFI, meaning their ART initiation occurred at another health facility.
3. Patients less than 15 years of age at time of ART initiation.

Qualitative Data:

A convenience sample of 30 patients and 5 health providers from different ranks in the health service¹ will be selected for a survey and in-depth interviews respectively.

Since the purpose of interviewing patients and health providers is to understand

¹ Although doctors had initially been considered for the inclusion criteria, interviews were conducted with nurses only, due to the clinical referral process. Nurses were more suited to answer questions regarding transfer patients as doctors were allocated to consult patients who had already been assessed by nurses.

potential reasons for and perceptions of silent transfer, this sampling strategy should be adequate to provide sufficient thematic data of a formative nature for the study.

Inclusion Criteria (Patient Survey):

1. Adult (over the age of 18 for consenting purposes) patients on ART
2. Patients on ART at Michael Mapongwana, Nolungile, and Site B (Ubuntu) CHCs.

Inclusion Criteria (Healthcare provider in-depth semi-structured interview):

1. ART health provider (nurse or doctor)
2. ART health provider (nurse or doctor) working at Michael Mapongwana, Nolungile, Site B (Ubuntu).

Data Collection:

Quantitative Data:

To identify those patients with an outcome of LTF, data from the routine HIV monitoring system used by the Provincial Government of the Western Cape and National Department of Health will be extracted. In order to determine whether patients identified as LTF, the provincial HIV monitoring system will be used to search for any evidence of presence at another facility in the Western Cape after the period of documented LTF. Patient identifiers, including Patient Folder Number, Name, Sex, Date of Birth, and South African/Foreign ID number, will be used to ascertain whether transfer to another facility occurred. Given the data available, searches will be limited to movement within the Western Cape Province, however, effort will be made to record any indication of migration outside of the province where possible.

Identified patients will be described in terms of age, gender, number of transfers and, location of STF facility, prior ART and previous ART status.

Qualitative data:

A survey of patients and semi-structured in-depth interviews with health providers will be conducted at the three Khayelitsha provincial health facilities in order to explore the health system barriers facing silent transfers and patient reasons for silently transferring.

Given the resource constraints of the study, patients attending the three ART services will be selected to describe their potential reasons for transfer. The survey will be given to patients waiting in the ART reception area(s) of the health facility and the health provider questionnaire will be given to health providers working in one of the three health facilities. The recruitment of patient participants and the selection of HCPs will be done using convenience-sampling methods. A research assistant will provide participants with a written explanation of the study and informed consent will be obtained before administration of the study instrument. No names will be recorded on the questionnaire, and all of the participants will be assigned a number for identification purposes (see Ethical considerations below). The study lead or research assistant will be on hand to administer the survey and answer any questions that arise.

Patient surveys will be translated from English into Xhosa, the predominant languages spoken in Khayelitsha. The surveys will be back translated as a measure of quality control in order to ensure that conceptual equivalence is maintained, rather than merely being a direct translation. Health provider questionnaires will only be offered in English, given that this is an officially recognised spoken language within the services.

Instruments and data sources:

Quantitative data:

Retrospective cohort data will be assembled from the Western Cape Government provincial ART electronic monitoring system (eKapa), the combined Western Cape Government provincial ART data set that contains a combination of data from several patient information systems (TIER.Net, Prehmis, eKapa, NHLS).

Qualitative data:

Qualitative data will be assembled from patient surveys and from semi-structured in-depth health provider interviews.

Variables:

Data collected will yield the following variables:

Table 1 Variables Table for Qualitative and Quantitative Data

Variables Table				
	Description	Data Source	Name of Variable	Type
Baseline	Demographics	eKapa	Current Age	Numerical
			Sex	Categorical
	ART information		Age at ART Start	Categorical
	Outcome		Categorical	
	Name of facility		Categorical	
Follow-up	ART information	Provincial data set	Name of STF facility	Categorical
			Location of clinic	Categorical
			Method into ART	Categorical
			Prior ART	Categorical
			Number of transfers	Numerical

health provider information	Health provider in-depth semi structured interviews	Type of health provider	Categorical
		Duration of employment	Numerical
		Duration of employment in ART service	Numerical
		Type of transfer patients	Thematic
		How do you assess transfers who arrive without documentation?	Thematic
		Clinical requirement pertaining to transfer	Thematic
		Reasons for transfer	Thematic
		Health providers perceptions of transfer	Thematic
		Health providers perceptions of silent transfer	Thematic
		Health providers perception of transfer limitations	Thematic
		Health providers reasons for transfer limitation	Thematic
		Managing STF or transfer patients	Thematic
		Health providers policy and programmatic classifications	Thematic
Patient Information	Patient Survey	Duration on ART	Numerical
		ART status	Categorical
		Distance from home to health facility	Numerical
		Time to travel	Numerical
		Type of transport	Categorical
		Cost of transport	Numerical
		Information regarding transfer rules	Categorical
		Type of information	Categorical
		Care Satisfaction	Categorical
		Patient Care improvement suggestions	Categorical
		Moving clinic notification	Categorical
Reasons for not informing transfer	Categorical		

			Reasons for transferring	Categorical
			Medication interruption	Categorical
			Duration without treatment	Numerical

Data Management:

Quantitative:

The researcher currently has access to the provincial monitoring system (eKapa), has been provided with a user name and password, and is monitored through the Western Cape Health Information Management Programme as part of Protocol 395/2005 – ‘Enhanced Routine Surveillance of Patient in HIV Care in Khayelitsha’. Linkage data will be sought from the routine system and analysed using Stata 12 (StataCorp, College Station, USA).

Qualitative:

Completed surveys will be kept in a sealed envelope for transport between the facility and the study lead’s office. Once the envelopes arrive, they will be captured into an excel spreadsheet with the date and the number of the survey or interview form. No named data will be collected on the forms, thereby ensuring participant privacy and confidentiality. Data from the surveys and interviews will be translated, transcribed, and captured verbatim into a word processing programme and thematically categorized using Atlas.ti.

Data analysis:

Quantitative Analysis:

In order to analyse the data generated by the proposed study, univariate analysis will be conducted.

To begin with, exploratory data analysis will be performed in order to detect and clean errors or unexpected patterns within the data. Information on any participants with missing or incorrect data will be re-examined and entered if possible, or otherwise these observations will be removed if deemed necessary.

Descriptive statistics will be compiled using the socio-demographic and patient characteristics data as shown in Table 1. The proportion of LTF patients who are STF will be calculated and confidence intervals will be calculated using this proportion in order to estimate the population proportion of silent transfers. This will allow an extrapolation of the STF prevalence within the sample to an estimated prevalence at the population level.

The proportions of outcomes at last visit will be described along with sex, age, time to transfer and number of transfers. Chi squared test will be used to test an association between categorical variables.

Qualitative Analysis:

The data will be sorted using a thematic classification approach. The results will be examined for common themes that are repeated in the results and will be used to analyse the findings.

Data from the surveys and in-depth interviews and the cohort data will enable data triangulation, thus strengthening the evidence and generalizability of the study.

Pilot Study:

A pilot study will be conducted prior to beginning of the qualitative data collection.

The main objectives of the pilot study are to test:

1. Sampling Strategy

2. The data collection and measurement methods
3. The patient and health provider survey

In order to conduct the qualitative study, a research assistant will be trained on the use of the survey, maintaining participant confidentiality, data capturing and recording. The pilot study will involve administering the survey to three randomly selected patients and health providers from a similarly defined primary healthcare facility. The aim of the pilot study is also to assess the feasibility recruiting and completion of the survey. During the pilot study, the research assistant will record the length of time it takes to complete each survey, preferred survey language, challenges of the survey questions and other difficulties encountered. Through this process, it is hoped that any major issues will be highlighted. The pilot study will lead to the refinement of the questionnaire and sampling strategy prior to data collection.

Ethics:

The ethical principles which will be adhered to at all times during the study will be those stated in the Declaration of Helsinki, which was developed by the World Medical Association for medical research involving human participants (27). It will thus be ensured that the well-being of each individual participant takes precedence over all other interests. In addition, the proposed study will be guided by the ethical principles and guidelines set out in the Belmont Report, namely those of respect for persons, beneficence, and justice.

Ethical Approval:

Ethical approval to conduct the study forms part of an existing protocol 'Enhanced routine surveillance of patients in HIV Care in Khayelitsha' (HREC REF # 395/2005), approved through the Faculty of Health Sciences Human Research Ethics

Committee of the University of Cape Town and from the Western Cape Department of Health. The Principal Investigators are Drs'. Andrew Boulle and Eric Goemaere, with a team of collaborators from Khayelitsha stakeholders represented as co-investigators.

Ethical Considerations:

Participants will be informed during the consent process that their participation is voluntary, that they have the right to refuse to participate or to suspend their participation in the course of the survey and that confidentiality will be protected at all times. They will be reassured that there will be no negative or positive consequences of participating or not participating in the study with regards to their clinical care –in the case of patients; nor work environment – in the case of health providers.

Participants will be given full details of the need and aims of the study as well as all details regarding the methods, dissemination of results, and their role in the study.

Participants will also be informed that the research is for the purpose of an academic study contributing to the researchers' Masters in Public Health thesis and not as part of the researcher's job with the Centre for Infectious Disease, Epidemiology, and Research at the University of Cape Town. Since Khayelitsha is a predominantly Xhosa speaking population, participants will be given the option to take the survey in Xhosa or English. All health provider surveys will be offered in English only, as English is the preferred documentation method within the Department of Health.

The research assistant who has been recruited for this study is fluent in both English and Xhosa. The research assistant has worked in the clinical setting as a data clerk for several years and is aware of the programmatic and clinical terminology for the

HIV programme. This will allow for further probing of questions and themes, and more accurate responses to the patient survey, should the need arise.

Confidentiality will be maintained as no named information will be collected from the survey and interviews. Identifying variables that will be collected include only designation and facility name, however facility identifiers will be coded using an identifier that only the principle research will have access to. All surveys and interviews and will be stored in a sealed envelope and placed in a lockable drawer, accessible only to the research team.

All survey participants will be given the contact details of the researcher, the supervisor and primary investigator and the HREC should they have further queries or concerns. In addition, the contact details or the HREC will be documented on the consent form and each participant will be given a copy of the consent for their information. No participant will receive any form of monetary or in kind donation/incentive for participating.

Patient information is considered confidential under the Batho Pele principles of health services. Information found in the routine data set may be above and beyond the researcher's primary questions, however this information will not be copied or removed from the data set, In reviewing the routine data set there is a risk that information regarding patient clinical status such as non-clinically actioned unsuppressed viral loads. In this instance the information will be presented to the facility manager to ensure that the patient is recalled to the clinic in an appropriate and timely manner, and respect to the health providers privacy in the event of a required intervention and will be addressed following the ART clinical guidelines.

There will be no information collected in the patient monitoring system, or the patient and health providers' survey process that will cause risk of divulging patient identifiers researcher conducting this study understands the Batho Pele Principles and Ethical implications to maintaining patient confidentiality. There is a risk that participants may be unclear about the role of the researcher in relation to her role as a technical advisor and project coordinator with CIDER, UCT. The researcher would like to reiterate that the research is for the purpose of an academic study, contributing to her Master's thesis in Public Health, and not part of her professional portfolio with UCT. This will be made clear at the start of the interaction, to ensure that the participant is comfortable with being interviewed.

By identifying the potential reasons why patients chose to silently transfer will improve patient management for this group. Improved management would include better follow up and identification of patients who have potentially silently transferred. It is also hoped that the findings will improved the documented transfer requests from patients, thereby reducing the potential number of patients who are inaccurately identified as LTF.

By focusing on silent transfer patients, it is hoped that the research will inform the ART programme within but not limited to the Western Cape on how to appropriately identify the silent transfer, reduce the overall number of LTF patients, and help facilitate the process for patients requesting transfers to other facilities.

Other potential benefits include enhanced monitoring of silent transfer patients, improvements to clinical care, operational management within the health facility and inform policy that would benefit both the patient the facility staff and the ART programme.

Dissemination of research findings:

The proposed study will be submitted in partial fulfilment of the requirements for the Master of Public Health degree at the University of Cape Town. Findings from the study will be reported back to the Western Cape Department of Health HIV, AIDS, STI, TB Treatment Programme including, but not limited to the management structures for the Provincial and City of Cape Town departments of health, facility management, health providers, administrative staff and other stakeholders.

Publishable articles based on the findings from the research will be submitted to relevant research journals and presented to key stakeholders.

Logistics:**Budget:**

Budget for Proposed Study

Item	Cost per unit	Number of units	Total cost
Field worker	R60/hour	40 hours	R3200
Translation of surveys	R60/hour	10 hours	R600
Mileage	R3.16/km	35 visits to study sites (approximately 40km/visit)	R4424
Photocopying	R0.30/page	1000 pages	R300
			R800
Total			R9324

Funding source:

The funding for this study will be provided through the existing and approved research study – HREC REF # 395/2005

Time frame:

	Nov-14	Dec-14	Jan-14	Mar-14	Apr-14
Departmental and ethical approval	x				
Pilot study		x			
Data collection		x	X		
Data capturing			X		
Data analysis -			X		
Writing of manuscript			X	x	
Submission of dissertation and dissemination of findings				x	x

References:

1. September 2013 Core Epidemiology Slides Global summary of the AIDS epidemic □ 2012. Unaid. 2013;(September):1–12: Available from: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309_epi_core_en.pdf
2. Shisana O, Rehle T, LC S, Zuma K, Jooste S, Zungu N, et al. South African National HIV Prevalence, Incidence and Behaviour Survey, 2012. Cape Town; 2014.
3. Coetzee D, Hildebrand K, Boulle A, Maartens G, Louis F, Labatala V, et al. Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa. *AIDS*. 2004;18(August 2003):887–95.
4. Boulle A, Coetzee D. Anticipating future challenges to ART provision in South Africa: reflections on the Khayelitsha ART programme. *Acta Academica Supplementum*. 2006. p. 241–55.
5. Schneider H, Lehmann U. Lay health workers and HIV programmes: implications for health systems. *AIDS Care*. 2010;22 Suppl 1(April 2015):60–7.
6. Johnson LF. Access to antiretroviral treatment in South Africa, 2004-2011. *South Afr J HIV Med*. Cape Town, South Africa; 2012;22–7.
7. Council SANA. National Strategic Plan on HIV, STIs and TB 2012 - 2016 [Internet]. 2011. Available from: www.sanac.org.za
8. Schneider H, Coetzee D, Van Rensburg D, Gilson L. Differences in antiretroviral scale up in three South African provinces: the role of implementation management. *BMC Health Serv Res*. 2010;10 Suppl 1(Suppl 1):S4.
9. Western Cape Department of Health. Sinjani data set [Internet]. Cape Town; 2014. Available from: <https://sinjani.pgwc.gov.za/live>
10. Boulle A, Goemaere E, Coetzee D, Wilkinson L, Cox V, Hennessey C, et al. Enhanced routine surveillance of patients in HIV care in Khayelitsha. 2014, poster presentation.
11. Boulle A, Van Cutsem G, Hilderbrand K, Cragg C, Abrahams M, Mathee S, et al. Seven-year experience of a primary care antiretroviral treatment programme in Khayelitsha, South Africa. *AIDS*. 2010;24(June 2009):563–72.
12. Wilkinson LS, Sans M, Khayelitsha F, Town C, Africa S. ART adherence clubs: A long-term retention strategy for clinically stable patients receiving antiretroviral therapy. *South Afr J HIV Med*. 2013;4(2):48–50.
13. Luque-Fernandez MA, Van Cutsem G, Goemaere E, Hilderbrand K, Schomaker M, Mantangana N, et al. Effectiveness of Patient Adherence Groups as a Model of Care for Stable Patients on Antiretroviral Therapy in Khayelitsha, Cape Town, South Africa. *PLoS One*. 2013;8(2).

14. Medecins Sans Frontieres. Providing HIV/TB Care At The Primary Healthcare Level Khayelitsha Annual Activity Report [Internet]. Cape Town; 2008. Available from: www.msf.org.za
15. Cornell M, Technau K, Fairall L, Wood R, Moultrie H, van Cutsem G, et al. Monitoring the South African National Antiretroviral Treatment Programme, 2003-2007: the IeDEA Southern Africa collaboration. *S Afr Med J. South Africa*; 2009 Sep;99(9):653–60.
16. Kwong-Leung YJ, Tok TS, Tsai JJ, Chang WS, Dzimadzi RK, Yen PH, et al. What happens to patients on antiretroviral therapy who transfer out to another facility? *PLoS One*. 2008;3(4):9–11.
17. Geng EH, Bangsberg DR, Musinguzi N, Emenyonu N, Bwana MB, Yiannoutsos CT, et al. Understanding reasons for and outcomes of patients lost to follow-up in antiretroviral therapy programs in Africa through a sampling-based approach. *J Acquir Immune Defic Syndr*. 2010;53(3):405–11.
18. National Department of Health of South Africa. TIER T1 and T2 ART Monitoring and Evaluation Implementation Plan. 2011: Available from <https://tieredstrategy.files.wordpress.com/2011/10/tier-1-and-tier-2-implementation-plan-v4.pdf>.
19. Osler M, Hilderbrand K, Hennessey C, Arendse J, Goemaere E, Ford N, et al. A three-tier framework for monitoring antiretroviral therapy in high HIV burden settings. *J Int AIDS Soc*. 2014;17.
20. World Health Organization, Unicef, Unaid. GLOBAL UPDATE ON HIV TREATMENT 2013 : Results, Impact and Opportunities. *Glob Updat HIV Treat 2013 results, impact Oppor*. 2013;(June):7.
21. Western Cape Department of Health. Antiretroviral treatment programme monitoring and evaluation standard operating procedure: circular H191/2013. Cape Town; 2013.
22. National Department of Health of South Africa. National consolidated guidelines for the prevention of mother to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. 2014.
23. Grimsrud AT, Cornell M, Egger M, Boulle A, Myer L. Impact of definitions of loss to follow-up (LTFU) in antiretroviral therapy program evaluation: Variation in the definition can have an appreciable impact on estimated proportions of LTFU. *J Clin Epidemiol* [Internet]. Elsevier Inc; 2013;66(9):1006–13. Available from: <http://dx.doi.org/10.1016/j.jclinepi.2013.03.013>
24. Nglazi MD, Kaplan R, Orrell C, Myer L, Wood R, Bekker LG, et al. Increasing Transfers-Out from an Antiretroviral Treatment Service in South Africa: Patient Characteristics and Rates of Virological Non-Suppression. *PLoS One. United States*; 2013;8(3):e57907.
25. Pereko A. Tracking of Inter-Facility Patient Transfers and Retention on Antiretroviral Treatment in Namibia. 2011.

26. Medecins Sans Frontieres, Western Cape Province Department of Health, University of Cape Town, City of Cape Town Department of Health. Providing HIV/TB care at the primary healthcare level: Khayelitsha Annual Activity 2008-2009. 2010.
27. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *J Int Bioethique*. 2004;

Part B: Structured Literature Review

Literature Review:

This thesis investigates patients within the antiretroviral therapy (ART) programme identified as lost to follow-up (LTF) who have self-referred or silently transferred (STF) their care to or from another health facility. We seek to identify and describe the characteristics of the STF patients in order to inform ongoing clinical care and programmatic management of patients accessing ART services over time. We further explore the perceptions and attitudes of health providers towards the STF patient in order to identify any barriers affecting the continuum of patient care and potential reasons why patients STF between health facilities.

To inform this research, the objectives of the literature review are:

1. To describe the scale-up of the ART programme within the South African context.
2. To explore current research regarding LTF outcomes of patients and attempts to trace those patients within the ART programme, including the tracing of STF patients.
3. To investigate the impact of migration and transferring of patients and their effect on the health services.

Literature Search Strategy:

PubMed and Google Scholar were searched and a manual search of reference lists from relevant articles using the search terms using the search terms HIV, antiretroviral treatment, Lost to follow-up (LTF), transfers, migration, self-referral, silent transfer (STF) and monitoring and evaluation. A general Google Scholar search for local and international reports such as the WHO and NDoH not cited on medical databases was also conducted.

The search was restricted to English language publications and data reported from the African continent. Titles and abstracts of resulting articles were reviewed and references of included studies and existing reviews were searched. All publications available through July 1st 2015 were included in this review. Publications were included in the review if the population of interest included patients on ART where LTF, tracing, and self-referral was referenced. Articles that described the ART

programme within the context of the Primary Healthcare System and the relationships between HCPs, patients and the health system were also explored. Articles pertaining to pre-ART treatment, prevention of mother to child transmission (PMTCT), antenatal, and children were excluded from this review.

Box 1: Search strategy term used

Anti-retroviral treatment, retention in care, lost to follow-up, silent transfer, self-transfer, migration, monitoring and evaluation, programme guidelines, health provider/patient relationships.

Introduction:

In 2012, there were an estimated 35.5 million people living with HIV throughout the world, with 25 million of those living in Sub Saharan Africa (1). In South Africa, over 6.1 million people live with HIV with just over 2 million initiated on (ART) (2). There is global consensus that patients who remain adherent on ART can virally suppress the disease, reduce the risk of transmission to others, and live their lives with minimal interruption to activities of daily living (2–4). However, a weak and overburdened healthcare system can negatively impact on patient outcomes, by influencing their ability to access and remain on treatment (5,6).

Scale up of Antiretroviral Therapy (ART) Services in South Africa:

The rapid scale-up of the ART programme in South Africa over the past decade has enabled almost 2 million HIV-positive patients to initiate lifesaving ART (2,7). There have been significant advances within the South African HIV treatment programme including changes to the enrolment criteria, improvements in regimens and nurse-driven initiations and management of patients. Specific programmatic targets set forth by the National Strategic Plan for HIV/AIDS have contributed to the rapid expansion and scale-up of the ART programme (2,5,8).

In the Western Cape, the scale-up has enabled over 100,000 patients to initiate ART between 2001 and 2012, with over 30,000 patients having initiated in the township of Khayelitsha (9,10). Khayelitsha not only is one of the largest cohorts of patients on ART, it is also one of the oldest in South Africa, with ART being made available in April 2000 through a collaboration with Médecins Sans Frontières (MSF) and the Western Cape Provincial Department of Health (3,4).

Since its inception, the ART treatment programme's primary focus has been to test and initiate as many eligible patients as possible using the WHO clinical treatment guidelines (11). These guidelines have been adapted for the South African context to ensure optimal coverage of ART for all eligible patients (12).

Eligibility for ART initiation has improved since ART was first introduced, with current South African National Department of Health guidelines now including initiation for adults with a CD4 cell count below 500 cells/mm³, adults with Hepatitis B infection, adults with tuberculosis (TB), HIV-positive partners in serodiscordant couples, HIV-positive pregnant women and women within one year post-partum (13,14). Changes in ART guidelines over time has contributed to the reduction in death attributable to HIV, with more patients able to live healthy and productive lives (10,15,16).

Testing, linkage to care and initiation of patients on ART are only a few of the components of the HIV treatment cascade (figure 1). Additional components include virological suppression, prevention of death and LTF, and retention and return to care (1,8).

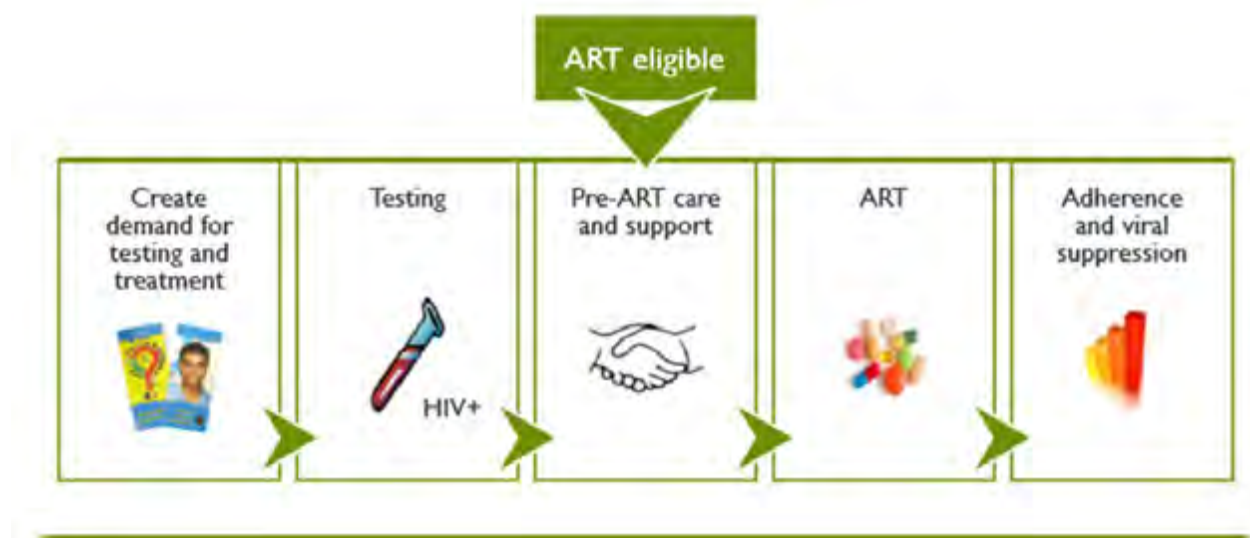


Fig. 4: Treatment Cascade (1,17)

This review will focus on LTF, retention and return to care with a specific focus on self-referral or the STF of patients.

The burgeoning patient population due to scale-up and guideline changes within a constrained health system has necessitated the need for new and innovative ways to

keep patients on ART. This has led to a shift in programme strategy from concentrating on scale-up and roll-out, to developing strategies to decongest the overburdened health facilities whilst optimizing models of adherence and retention in care (18–20).

Although the treatment guidelines have adapted to the clinical needs of the patients, little focus has been placed on the development, implementation, and management of processes and policies for patients transferring between health facilities.

Monitoring of ART programme:

Success of the ART programme should not only be measured by those who initiate ART, but include those who remain on treatment (1,21). Globally the measurement of success of the ART programme is done via routine longitudinal-cohort monitoring of patient outcomes (10,22,23). The World Health Organisation ART programme defined outcomes include: Rest in Peace (RIP) for patients who have died, Lost to follow-up (LTF) for those who have are no longer in care, Transferred Out (TFO) for patients who have requested a transfer to another health facility, and Retention in Care (RIC) for those patients on ART treatment and in care at a health facility (24).

LTF has become one of the most important outcomes to identify ART programme effectiveness (25,26), although the concept and definition of LTF is varied throughout the literature (25) with some studies considering a LTF after 4 weeks of missed appointments, and others using the WHO definition of ≥ 90 days drugs not in hand (22). LTF outcomes after one year on ART contributes to 20% of attrition within the ART programme, with the risk of LTF increasing as duration on ART increases (22,26,27). Retention in care at 24 months is 70% with the proportion of LTF patients having transferred to other facilities varying considerably between 7% and 56% (28–30).

Patients who STF add to the increase in reported LTF, as there is currently no clear identifiable outcome within the ART programme to identify this cadre of patient (22,23). Incorrect reporting of STF patients as LTF negatively impacts on patient continuum of care as financing the ART programme is heavily reliant on retention in care figures (30,31). In order for the ART programme to accurately measure

retention in care, it is crucial to account for those patients who STF between facilities (30).

Tracing of LTF and Transfer patients:

Although all efforts to facilitate the ART programmes success are welcomed, little focus has been placed on the migratory or transferring population within the context of the ART programme; and even less on the silent transfer phenomena (32–34).

Whilst transferring out of a facility is not considered punitive to the treatment programme, LTF is a negative outcome within the ART programme. When a patient is identified as LTF, this classification infers that the patient has been ‘lost to care’ at their last reporting facility and thus assumed not to be on treatment, or that the patient has been ‘lost to care’ at the last reporting facility, but is in fact on treatment at another facility. Both of these outcomes imply that at some point along the treatment continuum, that specific health facility has ‘failed’ to retain that patient in care.

Multiple studies have been conducted to ascertain mortality figures amongst patients identified as LTF (35–38) . Further studies have been undertaken to trace patients who have a documented outcome of LTF to ascertain the proportion of patients who self-referred or silently transferred (STF) their care to another health facility (29,39,40), including three systematic reviews (31,41–43). One study in Malawi found that of the 3176 patients identified as LTF, 70% were traced with 56% of those traced patients still on ART at another facility with 121 patients having silently transferred (30).

Studies have also sought to trace patients identified as TFO to understand if their outcome was a true reflection of status, with one study conducted in Northern Malawi having traced 92% of the 805 patients (19% of total cohort) with outcome of TFO having actually had arrived as intended at another treatment facility (44). Several studies have attributed the reasons for transfer with economic opportunity, family responsibility, improved access to care and improved health outcomes or decentralization of ART services (28,29,45,46).

Migration:

It is known that the world's population is on the move with over 214 million people having migrated whether that be due to economic opportunities, political unrest, internal displacement, environment factors, or human rights abuses (47,48). Migration affects the economic, social and health structures of a population, however little information is known about the programmatic dynamics and their effect on patients who migrate or transfer within the health system and more specifically the impact patient migration has on the ART programme (49). Just as global migration can destabilize a region, STFs can cause disruption within the ART programme due to challenges in correctly identifying patients remaining in care (RIC). In the broader context of migration, across-boarder migration refers to movement between countries, and internal migration referring to migration within the country borders. In addition, cyclical migration refers to those persons who at one time or another left rural homesteads in search of employment (positive migration) only to return to their original location due to illness (negative migration) (33,34).

All cadres of migration have a direct and potentially negative effect on the health system, especially in the instances of political upheaval, natural disasters, or disease outbreak. Likewise, the phenomenon of patients silently transferring within the ART programme due to reasons directly related to the health system, including lack of access, poor service, and negative patient experiences have been identified as an important area within the ART programme in need of further exploration (31,49,50).

Within the context of health, various aspects of the health system hinder the ability of a patient to easily transfer health facilities, resulting in patients self-referring or silently transferring. South African policy that describes the transfer process does not exist except in the form of the ART Monitoring and Evaluation Standard Operating Procedure [circular 191/2013] (51) and most recently the Western Cape Migration Standard Operating Procedure [circular 78/2015] (52). Dissemination of these policies to the various levels of health is often sporadic and incomplete or require a reinterpretation at source due to lack of resources or understanding (53).

Attitudes of health providers and their influence on patient care:

Communication between patients and HCPs is an essential part of a patients treatment success and positive health outcomes (54,55). Explanation by the HCP to the patient of how various services within the health system operate, and assurance of patients understanding of those services is important in the context of successful patient health outcomes (56–59). This applies to the understanding by the patient of the transfer process, as a lack of understanding can impede the transition process and lead to potential treatment interruptions or withdrawal from the health service. In addition, poor clinical documentation and complicated referral and transfer processes all contributes logistical challenges and barriers to the transfer process (60,61).

Gaps or Needs for Further Research:

Additional studies are needed to gain further insight into the magnitude of STF in different ART programme settings and to determine how the STF of patients affects the current ART programme in terms of service delivery, monitoring and reporting. Investigation into how monitoring systems could be adapted to maintain flexibility within the service context must be explored. More research to identify logistical challenges, including simplifying referral and transfer procedures that act as as barriers to the patient transfer process is needed.

As the duration of patients on ART continues, studies addressing such areas as alternate dispensing methods, work place ART distribution, extending scripting and dispensing of ART, and improved operation management of health facilities should be further explored.

References

1. World Health Organization, Unicef, Unaid. GLOBAL UPDATE ON HIV TREATMENT 2013 : Results, Impact and Opportunities. Global update on HIV treatment 2013: results, impact and opportunities. 2013.
2. Shisana O, Rehle T, LC S, Zuma K, Jooste S, Zungu N, et al. South African National HIV Prevalence, Incidence and Behaviour Survey, 2012. Cape Town; 2014.
3. Coetzee D, Hildebrand K, Boulle A, Maartens G, Louis F, Labatala V, et al. Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa. *AIDS*. 2004;18(August 2003):887–95.
4. Boulle A, Coetzee D. Anticipating future challenges to ART provision in South Africa: reflections on the Khayelitsha ART programme. *Acta Academica Supplementum*. 2006. p. 241–55.
5. Hanson K, Cleary S, Schneider H, Tantivess S, Gilson L. Scaling up health policies and services in low- and middle-income settings. *BMC Health Serv Res*. 2010;10 Suppl 1(Suppl 1):11.
6. Schneider H, Lehmann U. Lay health workers and HIV programmes: implications for health systems. *AIDS Care*. 2010;22 Suppl 1(April 2015):60–7.
7. Johnson LF. Access to antiretroviral treatment in South Africa, 2004-2011. *South Afr J HIV Med*. Cape Town, South Africa; 2012;22–7.
8. Council SANA. National Strategic Plan on HIV, STIs and TB 2012 - 2016 [Internet]. 2011. Available from: www.sanac.org.za
9. Western Cape Department of Health. Sinjani data set [Internet]. Cape Town; 2014. Available from: <https://sinjani.pgwc.gov.za/live>
10. Boulle A, Goemaere E, Coetzee D, Wilkinson L, Cox V, Hennessey C, et al. Enhanced routine surveillance of patients in HIV care in Khayelitsha. 2014.
11. WHO. Global Health Sector Strategy on HIV/AIDS 2011-2015. Strategy. 2011.
12. Cornell M, Technau K, Fairall L, Wood R, Moultrie H, van Cutsem G, et al. Monitoring the South African National Antiretroviral Treatment Programme, 2003-2007: the IeDEA Southern Africa collaboration. *S Afr Med J*. South Africa; 2009 Sep;99(9):653–60.
13. National Department of Health of South Africa, The FOR, Of P, Management THE, Hiv OF, Children IN. NATIONAL CONSOLIDATED GUIDELINES FOR THE PREVENTION OF MOTHER-TO-CHILD. 2015.
14. National Department of Health of South Africa. National consolidated guidelines for the prevention of mother to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. 2014.

15. Boulle A, Van Cutsem G, Hilderbrand K, Cragg C, Abrahams M, Mathee S, et al. Seven-year experience of a primary care antiretroviral treatment programme in Khayelitsha, South Africa. *AIDS*. 2010;24(June 2009):563–72.
16. Boulle A, Bock P, Osler M, Cohen K, Channing L, Hilderbrand K, et al. Antiretroviral therapy and early mortality in South Africa. *Bull World Health Organ*. 2008;86(October 2007):678–87.
17. WHO. HIV test – treat – retain cascade analysis. Guide and tools. 2014.
18. Wilkinson LS, Sans M, Khayelitsha F, Town C, Africa S. ART adherence clubs : A long-term retention strategy for clinically stable patients receiving antiretroviral therapy. *South Afr J HIV Med*. 2013;4(2):48–50.
19. Luque-Fernandez MA, Van Cutsem G, Goemaere E, Hilderbrand K, Schomaker M, Mantangana N, et al. Effectiveness of Patient Adherence Groups as a Model of Care for Stable Patients on Antiretroviral Therapy in Khayelitsha, Cape Town, South Africa. *PLoS One*. 2013;8(2).
20. Medecins Sans Frontieres, Western Cape Province Department of Health, University of Cape Town, City of Cape Town Department of Health. Providing HIV/TB care at the primary healthcare level: Khayelitsha Annual Activity 2008-2009. 2010.
21. Miller CM, Ketlhapile M, Rybasack-Smith H, Rosen S. Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. *Trop Med Int Health*. 2010;15(1):48–54.
22. Osler M, Hilderbrand K, Hennessey C, Arendse J, Goemaere E, Ford N, et al. A three-tier framework for monitoring antiretroviral therapy in high HIV burden settings. *J Int AIDS Soc*. 2014;17.
23. Smuts B, Mahlali U, White C, Dearham A, Moeng H, Zweigenthal V, et al. Mapping Progress of the Western Cape Antiretroviral Programme Provincial antiretroviral monitoring and evaluation team. 2007.
24. World Health Organization. Three Interlinked Patient Monitoring Systems for HIV care / ART , MCH / PMTCT and TB / HIV : Standardized Minimum Data Set and Illustrative Tools. 2010;(April):1–99.
25. Grimsrud AT, Cornell M, Egger M, Boulle A, Myer L. Impact of definitions of loss to follow-up (LTFU) in antiretroviral therapy program evaluation: Variation in the definition can have an appreciable impact on estimated proportions of LTFU. *J Clin Epidemiol [Internet]*. Elsevier Inc; 2013;66(9):1006–13. Available from: <http://dx.doi.org/10.1016/j.jclinepi.2013.03.013>
26. Nglazi MD, Kaplan R, Orrell C, Myer L, Wood R, Bekker LG, et al. Increasing Transfers-Out from an Antiretroviral Treatment Service in South Africa: Patient Characteristics and Rates of Virological Non-Suppression. *PLoS One*. United States; 2013;8(3):e57907.
27. Cornell M, Grimsrud A, Fairall L, Fox MP, van Cutsem G, Giddy J, et al. Temporal changes in

- programme outcomes among adult patients initiating antiretroviral therapy across South Africa, 2002-2007. *AIDS*. England; 2010 Sep;24(14):2263–70.
28. Geng EH, Nash D, Kambugu A, Zhang Y, Braitstein P, Christopoulos KA, et al. Retention in care among HIV-infected patients in resource-limited settings: Emerging insights and new directions. *Current HIV/AIDS Reports*. 2010. p. 234–44.
 29. Peltzer K, Ramlagan S, Khan MS, Gaede B. The social and clinical characteristics of patients on antiretroviral therapy who are 'lost to follow-up' in KwaZulu-Natal, South Africa: a prospective study. *SAHARA-J J Soc Asp HIV/AIDS*. 2011;8(4):179–86.
 30. Tweya H, Feldacker C, Estill J, Jahn A, Ng'ambi W, Ben-Smith A, et al. Are They Really Lost? 'True' Status and Reasons for Treatment Discontinuation among HIV Infected Patients on Antiretroviral Therapy Considered Lost to Follow Up in Urban Malawi. *PLoS One*. 2013;8(9):1–7.
 31. Wilkinson LS, Skordis-Worrall J, Ajose O, Ford N. Self-transfer and mortality amongst adults lost to follow-up in ART programmes in low- and middle-income countries: systematic review and meta-analysis. *Trop Med Int Heal* [Internet]. 2015;20(3):365–79. Available from: <http://doi.wiley.com/10.1111/tmi.12434>
 32. Welaga P, Hosegood V, Weiner R, Hill C, Herbst K, Newell M-L. Coming home to die? the association between migration and mortality in rural South Africa. *BMC Public Health* [Internet]. 2009;9(1):193. Available from: <http://www.biomedcentral.com/1471-2458/9/193>
 33. Vearey J. Learning from HIV: Exploring migration and health in South Africa. *Global Public Health*. 2012. p. 58–70.
 34. Vearey J. Challenging urban health: towards an improved local government response to migration, informal settlements, and HIV in Johannesburg, South Africa. *Glob Health Action*. 2011;4.
 35. Cornell M, Lessells R, Fox MP, Garone DB, Giddy J, Fenner L, et al. Mortality among adults transferred and lost to follow-up from antiretroviral therapy programmes in South Africa: a multicentre cohort study. *J Acquir Immune Defic Syndr* [Internet]. 2014;67(2):e67–75. PMID: PMC4239433. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24977471>
 36. Brinkhof MWG, Spycher BD, Yiannoutsos C, Weigel R, Wood R, Messou E, et al. Adjusting mortality for loss to follow-up: Analysis of five art programmes in sub-saharan africa. *PLoS One*. 2010;5(11).
 37. Egger M, Spycher BD, Sidle J, Weigel R, Geng EH, Fox MP, et al. Correcting mortality for loss to follow-up: A nomogram applied to antiretroviral treatment programmes in sub-Saharan Africa. *PLoS Med*. 2011;8(1).
 38. Van Cutsem G, Ford N, Hildebrand K, Goemaere E, Mathee S, Abrahams M, et al. Correcting for mortality among patients lost to follow up on antiretroviral therapy in South Africa: a

- cohort analysis. PLoS One [Internet]. 2011;6(2):e14684. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3040750&tool=pmcentrez&rendertype=abstract>
39. Marson KG, Tapia K, Kohler P, McGrath CJ, John-Stewart GC, Richardson B a., et al. Male, Mobile, and Moneyed: Loss to Follow-Up vs. Transfer of Care in an Urban African Antiretroviral Treatment Clinic. PLoS One. 2013;8(10):2–9.
 40. Bärnighausen T. Reasons for loss to follow-up in antiretroviral treatment programs in South Africa. Future HIV Therapy. 2008. p. 141–5.
 41. Geng EH, Glidden D V., Emenyonu N, Musinguzi N, Bwana MB, Neilands TB, et al. Tracking a sample of patients lost to follow-up has a major impact on understanding determinants of survival in HIV-infected patients on antiretroviral therapy in Africa. Trop Med Int Heal. 2010;15(SUPPL. 1):63–9.
 42. Abrams EJ, Myer L, Rosenfield A, El-Sadr WM. Prevention of mother-to-child transmission services as a gateway to family-based human immunodeficiency virus care and treatment in resource-limited settings: rationale and international experiences. American Journal of Obstetrics and Gynecology. 2007.
 43. Rosen S, Fox MP, Gill CJ. Patient retention in antiretroviral therapy programs in sub-Saharan Africa: A systematic review. PLoS Med. 2007;4(10):1691–701.
 44. Kwong-Leung YJ, Tok TS, Tsai JJ, Chang WS, Dzimadzi RK, Yen PH, et al. What happens to patients on antiretroviral therapy who transfer out to another facility? PLoS One. 2008;3(4):9–11.
 45. Cloete C, Regan S, Giddy J, Govender T, Erlwanger A, Gaynes MR, et al. The Linkage Outcomes of a Large-scale, Rapid Transfer of HIV-infected Patients From Hospital-based to Community-based Clinics in South Africa. Open Forum Infect Dis. 2014;1–9.
 46. Geng EH, Glidden D V., Bwana MB, Musinguzi N, Emenyonu N, Muyindike W, et al. Retention in care and connection to care among HIV-infected patients on antiretroviral therapy in Africa: Estimation via a Sampling-Based approach. PLoS One. 2011;6(7).
 47. International Organization for Migration. International migration, health and human rights [Internet]. Geneva; 2013. Available from: http://www.ohchr.org/Documents/Issues/Migration/WHO_IOM_UNOHCHRPublication.pdf
 48. Nygren-Krug H. International migration, health and human rights. [Internet]. 2004. Available from: <http://www.cabdirect.org/abstracts/20043141504.html>
 49. Miller CM, Ketlhapile M, Rybasack-Smith H, Rosen S. Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. Trop Med Int Heal. 2010;15(SUPPL. 1):48–54.
 50. Ware NC, Wyatt M a, Geng EH, Kaaya SF, Agbaji OO, Muyindike WR, et al. Toward an

- understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study. *PLoS Med* [Internet]. 2013;10(1):e1001369; discussion e1001369. Available from:
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3541407&tool=pmcentrez&rendertype=abstract>
51. Western Cape Department of Health. Antiretroviral treatment programme monitoring and evaluation standard operating procedure: circular H191/2013. Cape Town; 2013.
 52. Western Cape Department of Health. Standard operating procedure to guide treatment continuity for patients on ART traveling outside or to the Western Cape province: Circular 78/2015. 2015.
 53. Gilson L. Health Policy and Systems Research - A Methodology Reader. *Alliance Heal Policy Syst Res*. 2012;18–40.
 54. Murthy RK, Klugman B. Service accountability and community participation in the context of health sector reforms in Asia: Implications for sexual and reproductive health services. *Health Policy Plan*. 2004;19:78–86.
 55. Beach MC, Keruly J, Moore RD. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *J Gen Intern Med*. 2006;21(6):661–5.
 56. Brinkerhoff DW. Accountability and health systems: Toward conceptual clarity and policy relevance. *Health Policy Plan*. 2004;19(6):371–9.
 57. George A. Accountability in Health Services Transforming Relationships and Contexts. *Harvard Cent Popul Dev Stud*. 2003;13(1).
 58. Kishore Raga, Taylor D. Impact of Accountability and Ethics on Public Service Delivery: A South African Perspective. *Public Manag* [Internet]. 2005;34(2):22–6. Available from:
<http://search.proquest.com/docview/236295671?accountid=14549&nhttp://hl5yy6xn2p.search.serialssolutions.com/?genre=article&sid=ProQ:&atitle=Impact+of+Accountability+and+Ethics+on+Public+Service+Delivery:+A+South+African+Perspective&title=Public+Manager&is>
 59. Molyneux S, Atela M, Angwenyi V, Goodman C. Community accountability at peripheral health facilities: A review of the empirical literature and development of a conceptual framework. *Health Policy Plan*. 2012;27:541–54.
 60. Hennessey C, Osler M. How structured patient clinical records can assist nurses in the management and monitoring of patients within the South African HIV/ART programme. *Nurs Matters*. Cape Town; 2012;3(2):32–7.
 61. Egger M, Forster M, Bailey C, Brinkhof MWG, Graber C, Boulle A, et al. Electronic medical record systems, data quality and loss to follow-up: Survey of antiretroviral therapy programmes in resource-limited settings. *Bull WHO* 2008;86(November):939–47.

Part C: Journal “Ready” Manuscript

Lost to Found: the Silent Transfer of Antiretroviral Therapy Patients in Khayelitsha, South Africa

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Abstract:

Patients who Silently Transfer (STF) and who are incorrectly classified as Lost to Follow-up (LTF) negatively impact assessment of Retention in Care (RIC) of Antiretroviral (ART) programmes. Identifying the proportion of LTF patients who STF and the reasons patients STF is a priority in order to ensure patient continuity of care, improve policy and treatment guidelines, and provide accurate ART programme outcomes.

A mixed methods approach was adopted using data sourced from an ART longitudinal patient monitoring system (eKapa) and patient and healthcare provider (HCP) interviews. Adults (≥ 15 years) on ART with a LTF outcome between 2008 and 2012 were traced to determine STF proportions.

LTF outcome was defined using an established algorithm of ≥ 90 days beyond the end of the last prescription. LTF date was the last clinical date that the patients attended the facility. STF or 'Lost' patients were defined as patients who had a reported LTF outcome from one of three identified health facilities, who were subsequently 'found' as having been registered at another health facility as a New or

TFI patient. Thirty patient and five HCP interviews were completed to ascertain reasons for STF and understand the clinical management process for transfer patients.

Of the 4166 patients identified as LTF 37% were identified as STF. Sixty-eight percent of STFs were female and 52.1% of all STFs were between 25-34 years of age. Eighty-four percent of STF patients transferred once.

Patients were interviewed to ascertain their understanding of the transfer process and to identify STF reasons. Although the majority of patients (n=27/30) believed it necessary to inform staff of the intent to transfer, more than half suggested challenges in requesting a transfer, including fear of negative staff attitudes (n=11), emergencies and life events (n=5) and long transfer documentation waiting times (n=3).

HCPs acknowledged patients STF due to challenges with the transferring process and fear of repercussions when defaulting treatment. HCPs stated they would not prevent patients from requesting a transfer nor turn STF patients away who had interrupted treatment or arrived without adequate documentation. The HCPs' open acceptance of transferring patients was inconsistent with patients' perceptions that staff negatively react to patients requesting transfer or those transferring to another facility without request.

Our study showed that incorrect reporting of STF patients negatively affects RIC data and RIC in the Khayelitsha ART programme could be underestimated by as much as one third. Operational service challenges and staff attitudes contribute to STF. Cumbersome transfer documentation processes hinder HCPs' ability to effectively manage an STF. Identifying LTF patients' that STF and the reasons for STF is a priority to ensure continuity of care, improve policy and treatment guidelines and provide accurate ART programme outcomes. Adapting current transfer policies to facilitate the transfer process for all patients, including those experiencing emergencies and life events is essential. Linking electronic patient monitoring systems will improve accurate retention in care reporting and improve fluidity of transferring of patients between health services.

INTRODUCTION:

Patients who Silently Transfer (STF) and who are incorrectly classified as Lost to Follow-up (LTF) negatively impact assessment of Retention in Care (RIC) of Antiretroviral (ART) programmes (1,2) and can cause challenges in a healthcare providers' ability to provide a patient with appropriate continuum of care.

There is global consensus that patients who remain adherent on ART can virally suppress the disease, reduce the risk of transmission to others, and live their lives with minimal interruption to activities of daily living (2–4).

Patients who STF add to the increase in reported LTF, as there is currently no clear identifiable outcome within the ART programme to identify this cadre of patient (3,4). Identifying the proportion of LTF patients who STF and the reasons patients STF is a priority in order to ensure patient continuity of care, improve policy and treatment guidelines, and provide accurate ART programme outcomes.

Although the treatment guidelines have adapted to the clinical needs of the patients, little focus has been placed on the development, implementation and management of processes and policies for patients transferring between health facilities (5).

In order for the ART programme to accurately measure retention in care and to provide optimal continuous care to patients, it is crucial to account for those patients who STF between facilities (2).

Methods:

Study Design, Sites and Population:

We used a mixed methods approach using quantitative and qualitative data. The former comprised routine electronic cohort data and the latter consisted of patient and healthcare provider interviews from three public ART primary healthcare facilities in the health sub-district of Khayelitsha, South Africa. Khayelitsha is the

largest township in Cape Town, and home to over 500,000 predominantly Xhosa speaking residents of low social economic status (6).

Quantitative Data:

Setting and Participants:

For the quantitative component of the study, the relevant data were sourced from a longitudinal electronic patient monitoring system (eKapa) used by all Western Cape Provincial primary healthcare (PHC) facilities in the health sub-district of Khayelitsha (7). All adults (≥ 15 years) who ever initiated ART between January 1st 2001 and September 30th 2012 at one of three PHC facilities in Khayelitsha, who also had a lost to follow-up (LTF) outcome between January 1st 2008 and December 31st 2012 were included. Due to limitations of the routine data set, all patients identified in the data set as having ever initiated at the three CHCs (which was from inception of the programme in 2001-2012) were included, and the LTF date parameters were selected based on the expansion and support of routine monitoring and evaluation systems within the sub-district. The LTF outcome date is defined as the last recorded clinical visit based on a predefined algorithm of ≥ 90 days of drug not in hand (4,8,9). Patients were included if they had commenced ART before September 30th 2012, and database closure was on or before December 31st 2012 to allow for 3 month follow-up for LTF reporting.

These 'lost' patients were then matched using a combination of unnamed, numeric identifiers. Patients were considered "found" or having silently transferred (STF) if they were identified as having been in care at another facility in the combined data set after their recorded LTF outcome date in the original data set.

Data were extracted from the routine monitoring platform (eKapa) using the Data Exchange Standard (DES) extraction method and imported into Excel.

Data were then matched using probabilistic matching on patient folder number, South African ID, name and surname, and date of birth. Once matched, patient folder number and names were removed from the patient data set and replaced with

a unique study number identifier, the unlinked, anonymised data were then returned to the researcher for further analysis.

Measurements:

Baseline characteristics for the lost and found patients included demographics (age, sex), year of ART initiation and LTF date. Measures of transfer were the number of times a patient appeared at another ART facility after the initial LTF date and their documented method into ART and prior ART experience, as patient who transfers should be captured as Transfer In (Fig. 1). The term transfer-in (TFI) is used in the ART monitoring programme to describe a patient who transfers their clinical care from one health facility to another. This process (in most instances) requires knowledge by the patient’s current facility of their intent to transfer. The process includes the current facility clinician providing a written transfer-out (TFO) document, which contains key medical information from the transferring facility to the new facility.

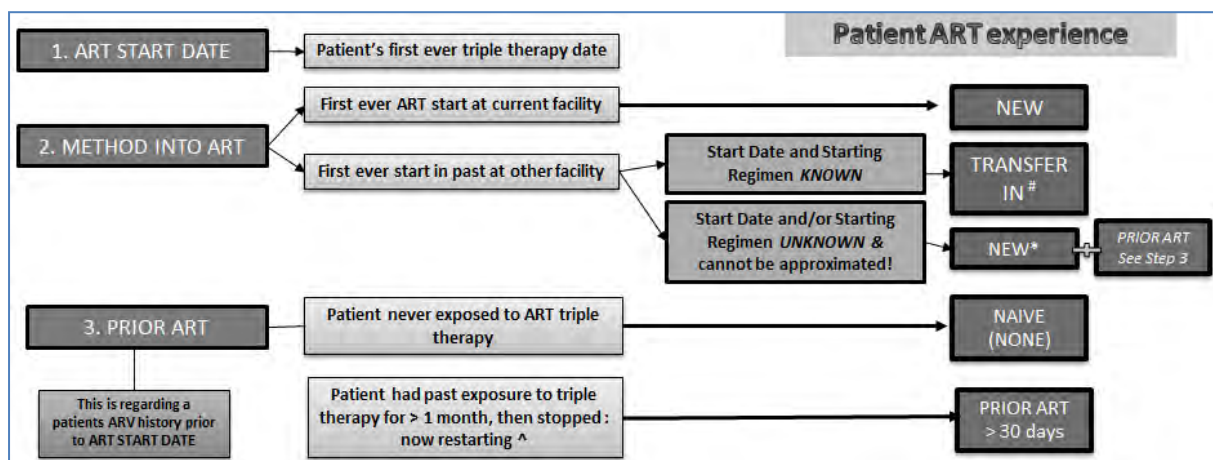


Fig. 5 Patient classification at time of entry into health facility

Analysis:

Baseline characteristics of “found” or STF, and “lost” or non- STF patients were described with summary statistics (medians, interquartile ranges, and proportions). Mean age was calculated by year of enrolment. Number of times transferred was calculated from date of last visit at one facility and subsequent visit date at another

facility name. All statistical analysis was performed using Stata 12 (StataCorp, Texas).

Qualitative Data:

Setting/Participants:

For the qualitative analysis, 10 ART patients in each of the three PHC facilities in Khayelitsha were recruited using convenience sampling techniques. Each facility has a registry and waiting area for HIV/ART and TB patients that are separate to the general patient population. Patients located in the HIV/ART waiting room in each facility were approached for inclusion in the study. Patients were eligible for inclusion if they were ≥ 18 years at one of the three facilities. Patients were recruited for the study from each of the facilities' ART waiting rooms, and each survey took an average of 30-40 minutes to complete. HCPs working in the ART services in each of the three facilities were selected using convenience sampling. Each facility manager at the participating facility was asked by the research for a list of clinicians who were working in the service to approach for participation. From that, five HCPs were interviewed.

Procedures:

The research assistant administered the survey in the patient's preferred language and responses were transcribed and verbally translated during the survey. Both the research assistant and lead researcher were present during the survey. This allowed for clarity and explanation from the study lead to the research assistant and participant during the survey and allowed for further probing of responses where incomplete information or misunderstanding occurred.

HCPs were invited to participate and all efforts were made to conduct the interview to prevent any delays of patient consultations. HCPs were interviewed in English as the standard language used by the Provincial Department of Health. Using an interpretive approach (10), the interview tool, which was a combination of main

questions, probing questions and follow-up questions was used to guide the study lead during the interview.

Measures:

The survey comprised a combination of pre-coded closed and open-ended questions. For the closed ended questions, participants were asked each question and then provided with the running prompts or responses, and each given response was circled. For those questions that had 'other' as an option, the researcher recorded the responses. Then, during analysis the responses were redefined and coded to prevent the response from obtaining a frequency value higher than the main codes (10).

Responses to the patient surveys were translated (and back translated for the Xhosa patient interviews) and then both the surveys and interviews were transcribed into Microsoft Word, then imported into Atlas.ti, for coding (10). Quantitative survey responses were captured into Microsoft Excel, coded and imported into Stata 12 (11) (StataCorp, Texas) for analysis.

Analysis:

To cover the research questions posed, simple quantitative descriptive statistics were calculated from the patients' interviews. Clinician interviews were analysed using the following themes: Reasons for Transfer, Migration, Reasons for STF, and HCP and Programmatic Challenges in Managing STF patients. Confidentiality was maintained at all times by ensuring no named information was collected. Ethical approval for the study was received from the University of Cape Town Human Research and Ethics Committee (HREC REF#: 912/2014) and from the Department of Health and local health officials.

Results:

Quantitative results:

This analysis included a cohort of 4166 patients who were identified as LTF between January 1st 2008 and December 31st 2012. Of the 4166 patients who were considered LTF or “lost” in the cohort, 37% (n=1521) were “found” and therefore considered as having silently transferred (STF) to another health facility.

Table 1 describes the characteristics of the “found” or STF patients. The median age at ART start for STF patients was 31 years (IQR 27-36). Women accounted for 68% of the total number of silent transfers.

Eighty-four percent of STF patients transferred once and 13% transferred twice. Seventy-two percent of STF patients were incorrectly captured as ‘New’ patients at their subsequent facility, and almost all of whom were documented as ‘ART Naïve’. Ninety-one percent of STF patients transferred within the Cape Town Metro District, three quarters of which were within the Khayelitsha Sub-district.

Table 1: Patient Characteristics of Silent Transfer Patients vs Non Silent transfers		
Characteristic	Adults (≥15 yrs), N=4166	
	STF patients n=1521	Non STF patients n=2645
Age at ART Start (yrs), median (IQR)	31 (27-36)	33 (28-40)
Age Categories, n (%)		
15-24 yrs	227 (15)	258 (10)
25-34 yrs	792 (52)	1209 (46)
35-44 yrs	373 (25)	777 (29)
45+ yrs	129 (9)	401 (15)
Gender, n (%)		
Women	1027 (68)	1533 (58)
25-34 yrs	561 (55)	770 (50)
35-44 yrs	197 (19)	380 (25)
Men	494 (32)	1112 (42)
25-34 yrs	231 (47)	439 (39)
35-44 yrs	176 (36)	397 (36)
Number of times transferred, n (%)		
Once	1283 (84)	
Twice	196 (13)	
2-5 times	42 (3)	
Location of Silent Transfer within Western Cape Province, n (%)		
Cape Town MDHS** District	1380 (91)	
Khayelitsha Sub-district (within MDHS District)	968 (70)	
Outside of Metro	141 (9)	
Recorded 'Method into ART' status at transfer in (TFI) facility*, n (%)		
Incorrectly recorded as 'New' at TFI facility	1097 (72)	
Of these patients, incorrectly captured as 'ART Naïve', meaning no prior ART experience	1039 (95)	
Correctly captured as TFI at transfer facility	424 (28)	
**Metro District Health Service;		
*Programmatic classification used to determine if a patient is new to treatment or has come from another facility. 'New' implies that a patient has not been on triple therapy before their arrival at ART enrolment facility.		
*Programmatic classification used to determine if a patient is new to treatment or has come from another facility. 'New' implies that a patient has not been on triple therapy before their arrival at ART enrolment facility. 'Naïve' refers to a patient never having exposure to ART prior to their first triple therapy ART start date.		
^Patients who were not linked, who may have been true LTF or STF care outside of the Western Cape.		

Qualitative results:

Thirty patients were interviewed and of those 90% were on ART with 52% having been on ART for more than three years. Of the patients who were interviewed, 70% lived within walking distance of the facility where initiated. Five HCPs, including four nurses and one doctor were interviewed. Three of the five HCPs had worked in the ART service for more than two years.

In accordance with the study objectives, the following themes were documented and are described below.

Reason for Transfer:

Of the 30 patients who were asked about their knowledge of the transfer process, 63% were aware of a formal transfer process. A 'formal transfer process' was described by patients as providing some form of documentation, usually in the form of a transfer letter, to the receiving facilities at time of transfer.

Several patients associated the lack of following the formality of the transfer process with punitive measures from staff, suggesting that if they did not have a letter, they would be "shouted at by staff" or not be helped. Those who were not familiar with the transfer procedure described that they "had never been told what to do"; with one patient suggesting that she did not feel it important to follow formalities.

Of those patients who classified themselves as an official transfer (n=7), stigma, long waiting times and post-natal transfer were reasons for transferring from another facility. Five patients stated they transferred to the facility with written transfer documentation. Although patient could not determine how well or complete the transfer documentation was.

Patient Fear:

All patients were asked about the reasons why they would not inform staff of their intent to transfer. Patients admitted to fear of negative repercussions from staff in requesting transfers. Being fearful of a negative reaction from staff was pervasive

among the patients interviewed, for example, one participant remarked, “I’m afraid of being shouted at by nurses for all to hear, that would be a barrier for me to ask them to leave [transfer]”. Despite this, most stated that they would inform staff of their intent to transfer. One nurse was aware of a patient’s fear of repercussions when defaulting and said, “The patients are scared of getting into trouble, so they say they are new”. Another patient’s reason for not informing the staff of her transfer was her fear if she did request a transfer: “I’m afraid of what they will say if I ask to leave. I do not want to get into trouble. If you do not follow the rules here, you get into trouble”.

Negative Patient Experience:

Eighty-seven percent of patients who were interviewed (n=26) agreed that they would be motivated to transfer should they encounter a negative experience at the facility, with a patient stating “If I continue to get treated this way, I will go to another clinic and I won’t tell them, I will just go”. Negative staff attitudes during the waiting period for a clinical visit and during clinical consultations were cited by half of the patients as a reason that would trigger a transfer by a patient. “The attitude of the nurses is a problem, they say it my fault I’m defaulting. It’s because of my situation. Sometimes I sleep without food...Sometimes I have no food so I can’t take the pills because I am sick”.

Patients also cited negative attitudes from clerical staff after a period of treatment interruption, “The clerks shout at me each time I came back to the clinic after not taking my pills. They get angry with me - there is no priority for disabled people”.

HCPs (n=5) did acknowledge that their attitude towards patients can contribute to a patient’s negative experience at a facility. One nurses expressed how the nursing profession must to do more to understand the complexities of patients’ circumstances that lead to transfers, defaulting or silently transferring, “We as nurses need to change our attitude, we need to embrace the patients, we don’t know their story, their problems, so we need to embrace them when they come and not punish them by making them wait until the end of the day to be seen, because then they won’t come back”.

Patients (n=14) cited dissatisfaction with long waiting time between arrival at the facility and seeing a clinician. In addition, the lack of information staff provided to patients regarding the reason for delays was identified as a frustration for patients, with one patient stating “if the clerks could just explain delays. You just watch them walking up and down and they don’t inform us of what is taking so long. I just wish they would tell us when they are having a problem”.

This also extended to pharmacy waiting times, with a patient exclaiming “Ooh the waiting time, it’s too long, we are waiting everywhere. We are always waiting, waiting, waiting...”. Forty-seven percent of patients stated they were unsatisfied with the current pharmacy waiting times.

Stigma:

Both patients and HCPs identified stigma as reason for transferring. Stigma was identified as occurring both in the community and within the facility. It was linked to the use of distinctly separate patient held appointment cards and waiting areas for HIV-positive patients, both of which identified them as HIV-infected. Patients and HCPs suggested that providing a standardized patient card would facilitate stigma reduction within the facility, “Patients go to some clinics and sit in one area and they have a green card and others have a white card. They should make it the same for all patients”.

One patient associated stigma with ridicule by staff at a facility stating, “I changed clinics because of stigma at the [other clinic]. I would go to there if they [staff] didn’t laugh at me, if they didn’t talk about me, and if it was private”.

Furthermore, stigma amounted to poor access, with one patient suggesting that he accessed ART services outside of his neighbourhood in order to avoid being recognized by community members “I travel about 2 hours. I stay in [neighbouring town]; I’m too scared for people to know I’m on ARVs. I have to borrow money to come to the clinic, R50 each time”. In addition, fear of being identified was especially prevalent amongst the younger ARV patients who were more likely to transfer to a facility where they were less likely to be identified.

Migration:

Travel between the Eastern and Western Cape was considered a common reason for transferring of patients. One HCP explained why patients may not return for their appointments, “You have patients who are going to a funeral in the Eastern Cape, and you know how things are - there is a celebration one day and there is another one and it keeps happening, so patients who don’t intend to be gone for long, stay longer and can default treatment and then when they come back they are afraid because they have defaulted and don’t want to be shouted at”.

Another HCP expressed how a patient’s improvement in health due to ARVs might cause a patient to transfer, “Patients become more mobile when they feel better. They were sick and stayed with a family member or friend and now they are feeling better, and they transfer”.

Family responsibility was also cited by HCPs as a contributing factor for reasons for transferring, “Patients need to take care of family in the Eastern Cape, why stay here when maybe they have no work and they have an elder family member who needs their help? Rather than the uncle sending his pension to help, it’s better for them to go back to be with their family-they can then help at home and also not be alone”.

A patient’s fear of dying alone and the need for family support were frequently mentioned by HCPs as reasons for patients transferring; “If they [patients] are sick and failing [treatment], they are afraid of death, so they want to go and be close to family, they don’t want to die alone”, with several HCPs stating that the fear of death by patients is a motivational factor for them returning ‘home’ to be supported by family. One HCP explained, “If it’s a patient who transfers here, it’s usually when they are very sick and they stay with family here to get well, and then they go back to the Eastern Cape”.

HCPs stated that patients who are very ill return “home to the Eastern Cape to die”, so as not to burden the family with the costs associated with transporting a body. They also “return home to the Eastern Cape at time of severe illness to be with their

families”, in some instances requesting an official transferring, and in others silently transferring.

Reasons for potential STF:

Fifty-seven percent of patients cited scenarios that would cause them to STF to another facility. Negative staff attitudes (65%) emergencies (29%) and personal choice (12%) were most commonly noted.

HCPs felt that patients who transferred without documentation or who admitted to treatment interruption usually did so because of fear of reprisals by informing the previous facilities staff of their intent to transfer. “Patients usually transfer when they have defaulted or are noncompliant. When they come back having defaulted, they are afraid of staff scolding them, so they go to another clinic and say they have never been at a clinic before”.

One patient explained that she returned after three years of having defaulted treatment because of a negative staff experience, “I defaulted three years ago because I didn’t get the attention I deserved at the clinic so I left. This one day I had enough. I dropped my card, and I waited until 4pm. I went to the clerks and asked about my folder, but they wouldn’t help me because they were leaving. I went to the doctor and he said ‘I’m off duty’ and the nurse said the same thing. So, I wrote on the top of my folder ‘I’ll come back when I am sick’, and I never came back. I came back after 3 years when I was sick”. This patient also was not aware that a patient could transfer to another facility. Both her lack of knowledge of the transfer process and a negative clinical experience were reasons she identified as being instrumental in her stopping treatment.

Although patients did speak of negative staff attitudes as a contributory reason for STF, 63% were satisfied with their current facility and the interactions with staff, although there were some issues expressed concerning staff professionalism. “Here at this clinic, when you tell someone about your problems they don’t laugh, when I got an STI, I went to [clinic] and I told them about the itching and burning and they laughed at me, so I won’t go back there. I just left and came here”.

Clinical challenges with managing a transfer patient:

There were variations amongst HCPs in how they identified a transfer or STF patient. Their responses suggest that only patients who arrived with documentation are classified as a true transfer. Several HCPs stated that they would only consider a patient as an official transfer if the patient provided a completed official transfer letter. HCPs voiced their frustrations at the transfer process due to systematic challenges, “ooh, the transfer patients, they are very [much more] difficult than the new initiations at your clinic. They are difficult because of all the work you have to do, to search for information, to phone, to ask so many questions, you spend a lot of time running up and down trying to get the information”.

HCPs were asked what minimum information they required in order to effectively manage STF patients. HCPs’ responses were varied including simply accepting a patient’s word, or a combination of pill bottles and latest blood results. Most HCPs felt that relying on a patient’s word was not sufficient due to their experience of patients falsely indicating current ART treatment, “some patients are recurrent defaulters - so they transfer from clinic to clinic to get treatment because they don’t want people [staff] to know they defaulted. They think we don’t have a way to find out, but we can”. HCPs spoke of situations where they had patients who arrived stating they had never initiated treatment, “Majority of transfers they have defaulted when they come to [this clinic] they say they are new, but they are not”, only to discover after clinical and laboratory investigation that the patients had been on treatment or had recently defaulted.

Documentation:

One clear challenge impeding the ease of the transfer process for HCPs was the lack of available transfer documentation provided by patients at time of arrival at the facility, “the paperwork – it’s always incomplete - no staging, no results, nothing. We get most of the information from the patients themselves”. HCPs said that although some patients did arrive with some form of documentation, the incomplete nature of the documentation contributed to delays in timeous processing of patients by HCPs, “We struggle for days to get the transfer letter. They [patients] know they did wrong

by not coming with information. We try to explain that we can't help you without the information".

HCPs stated that incomplete blood results and obtaining patient history from previous facilities were the main obstacles to the continuum of care process for the patient.

"You phone a clinic and no one answers, it just rings and rings – you just give up and take bloods and start from the beginning [work-up patient]"

"The information is just not there, bloods haven't been done, no follow-ups done or documented correctly"

Transfer Protective Measures:

Programmatic and operational interventions implemented by facilities can prevent a patient from STF in some instances, "if there is a problem, then I just put it in the suggestion box". In addition, HCPs and patients mentioned that adherence clubs had stopped them from STF, with one patient saying that "I wanted to transfer to another clinic because of delays and waiting times, but when clubs were introduced, I stayed".

One HCP stated that introduction of adherence clubs was a positive impact on patient treatment and adherence and cited it as a reason for patients transferring to their facility. "Patients transfer here because they know it's quicker and we have clubs, so when they come and they are stable they can go into a club. Patients tell us they prefer this clinic to other ones....in the area".

Patients were asked what improvements to operational services at the facility they would appreciate. Twenty-seven (n=30) suggested a broad range of improvements with improving waiting times (70%), addressing negative staff attitudes (41%), and increasing the number of staff at facility (37%) being the most cited.

In addition, patients cited decreasing the frequency of appointments, increasing number of months of medication dispensed, putting measures in place to lessen the risk of stigma, and improving facility cleanliness as areas for improvement.

Likewise, positive healthcare experiences for patients might prevent transfer even in cases of relocation and life events. Fifty eight percent of patients said they would not change facilities even if relocating, “There is nothing that would make me change, I am happy with the clinic”, mostly due to satisfactory service experience at the facility where they were enrolled.

In addition, when asked what reasons would lead a patient to change facilities, four respondents said a negative experience at a clinic would not cause them to transfer clinics, including one patient who stated ‘I won’t change clinic, even if the nurses shout at me, I don’t mind. I like this clinic because I’m getting all my medication at this site.

Discussion:

In this study of 4166 ART naïve patients who initiated treatment between 2001 and 2012 and who had a documented outcome of LTF, 37% were found to have silently transferred their care to another facility. Incorrect reporting of STF patients as New and ART Naive rather than a transfer could over-inflate enrolment figures, with our study finding that of those patients who STF’d, 72% were incorrectly captured as ‘New’ patients at their next facility with over 95% captured as ‘Treatment Naïve’. Enrolment figures are based on New patients and do not include TFI patients as a TFI patient would have been counted as New at their ART initiation facility. We found that operational service challenges at facilities and staff attitudes towards patients contribute to STF, with fear of repercussions by HCPs and staff towards patients who default treatment contributing to a patient’s decision to STF. Cumbersome and complicated transfer procedures and documentation processes hinder a HCPs’ ability to effectively manage a STF.

Almost one third of patients silently transferred to another health facility, these findings are in keeping with studies that show that as much as 30% of ART patients

Transfer Out of care (12). Evidence suggests that as the threshold of ART eligibility decreases, the number of mobile patients will also increase, thus perpetuating the potential of STF (13).

Current cohort monitoring only follows the clinical outcomes of those patients who are initiated as New at one facility to ensure that like is compared with like (14). However, seventy-two percent of STF patients were captured at time of transfer as a New patients resulting in the potential over estimation of ART initiations in routine data. Meaning, when patients on treatment arrive at a subsequent facility they should be captured as a transfer-in (TFI) and will therefore not be included in the cohort (15).

The implementation of a standardized monitoring system for the ART programme, allows for greater understanding of patient needs, and data could be more effectively used to adapt the treatment and protocol guidelines to improve access and treatment (4,16). Omission in the cohort reporting of patients who transfer between facilities may not be optimal given the high number of transfer and STF patients. While transferring patients are omitted from the routine cohort monitoring system, there is increasing recognition by the ART programme that patients who are LTF may have silently transferred their care to another health facility (1,17). Hence, improved identification and reporting of transfers is crucial for strengthened ART programme monitoring. Although the current National 3 tier monitoring strategy for the South African ART programme is designed to monitor those patients who transfer-in to a facility, the existing infrastructure operational challenges on the ground impede the use of this functionality within the programme (4,7,18).

In the interviews, patients identified poor treatment from staff, family emergencies, and the need to travel outside of facility operating times and lack of knowledge of the transfer process factors encouraging a STF.

Importantly, our survey results suggest that while many patients (64%) were aware of a formal transfer process, negative staff attitudes would prevent them from following procedure. This may suggest that although they said they would inform the

staff, a patient's fear of being reprimanded when requesting a transfer, could trump notification, thus contributing to a STF.

HCPs admitted that they were aware that a potential reason for STF was a patient's fear of repercussions by staff when returning to care after a period of treatment interruption and/or having defaulted. Furthermore, they recognized that patients might claim to have never been on ART when arriving at a new facility.

Cost associated with travel to a health facility is a known barrier in accessing ART (2,19). Yet the availability and close proximity of 14 ART services within Khayelitsha allows for patients to access clinical services within walking distance of their homes, eliminating the burden of high transport costs and long travel times when seeking healthcare. In the survey, over two-thirds of patients indicated that they were able to walk to their clinic – and that the administrative burden of obtaining a transfer letter would take longer than the walk to the new clinic. This suggests that Khayelitsha itself is well serviced, and that transfer factors may not be directly linked to a lack of access but rather to negative patient experiences or fear of healthcare staff.

Travel between the Western and Eastern Cape is widely practiced, and the health system recognizes that patients do migrate between provinces, with service providers suggesting that this behaviour is linked to health status and the need to family care in the rural home (20).

The movement of patients between services in the ART programme is recognized and acknowledged (21), with patients sometimes requesting official transfers or sometimes silently transferring to other health facilities as the current transfer procedure is cumbersome, time consuming and often incomplete (22,23). HCPs highlighted the complexities of the referral and transfer process as a barrier to their ability to easily process a transferring patient, which is in keeping with previously literature (24,25).

At the core of the health system, and an area unable to be easily monitored on a macro level is the relationship between the patient and HCP, and how that link between patient and provider is key to ensuring successful patient health outcomes

(26). The fact that just over 40% of patients did not know about the formal transfer process suggests that more patient education by the HCPs on the topic of transfer procedures is required.

Incomplete clinical documentation, poor communication between patients and HCPs, and difficulties in patients accessing a facility in order to request official transfer documentation, can contribute to the STF of patients. Although South Africa has implemented the use of standardized ART clinical stationery, which includes transfer letters, non-completion or the inaccurate documentation compounds the challenges faced by HCPs in receiving transfer patients (4,27). HCPs identified limited clinical consultation time between patient and providers, lack of understanding of how and what to document and insufficient stock, all of which negatively affected the ability of the staff and HCPs to adequately assess the transferring patient.

Incorrect or missing information provided by patients when they arrive at the receiving facility, further contributes to patient delays as additional clinical investigations to determine ART status, is required.

Strengths and Limitations:

There were several strengths and weaknesses with the study. The ability to triangulate the understanding a STF through the patients and HCP interviews with the proportion of STF amongst documented LTF patients was important in gaining an understanding of how to adapt the ART programme to the needs of the STF patients.

One limitation of our study was that we did not include patients who could have been a LTF and came back into care at the same facility, as these patients' outcomes would have been removed at time of re-entry into care.

Another limitation was the small number of HCPs who were interviewed, to gain a further understanding as to the limitations and challenges facing the HCPs, a larger sample size could have been used, however this was not possible given the cost and time constraints of the study. Furthermore, interviewing patients who had

experienced a silent transfer would have been more effective in understanding reasons for STF, the budgetary and time constraints for the study limited the ability of the researcher to do this.

Recommendations:

Implementing electronic monitoring systems that are networked and that would link patient movement between health services is optimal to reduce STF, as well as strengthen the ART programme. Implementation of such a system could reduce the inaccurate reporting of a transfer patient as LTF and is an important consideration in terms of reducing the number of STFs. However, the ability of a developing country such as South Africa to implement such a system is difficult given limited infrastructure and budgetary constraints.

Linkage of patients through a networked monitoring and patient management system available at each health facility is perhaps the best way in reducing the number of incorrectly documented LTFs. Understanding the STF phenomenon will also improve the ART programme ability to adequately and appropriately allocate budget and resources in order to ensure efficiency within the ART programme.

Facilitating the transfer process for patients and HCPs by prioritizing the completion of patient held card integrated across all health programmes will allow for smoother transitions for transfer patients. Including all relevant information on the card, would eliminate the need for patients to return to the clinic to request a transfer, thus reducing waiting times; provide receiving HCPs with important patient information and facilitate the accurate reporting of enrolment figures.

Interventions focusing on improving waiting times and staff-centred workshops and training in order to change attitudes is essential and a key aspect to reducing the number of patients who STF their care. Furthermore, interventions to facilitate communication between the staff and patients, such as suggestion boxes and staff informing patients of expected waiting times could positively contribute to a patient staying at one facility.

Waiting times can be reduced through the use of dedicated appointment times for patients, this should include the provision of appointments for patients who are employed. Waiting times can further be improved through efficiencies gained in the registries by streamlining tasks and duties for clerical staff through the use of electronic patient management systems, integrated registries, and training of clerical staff. This could improve the overall patient experience and reduce the number of patients who would STF their care to another facility.

Conclusion:

Whilst the ART programme continues to facilitate the initiation of HIV patients onto ART within the primary healthcare platform, cognisance of ensuring the ongoing patient-level monitoring and acknowledging their movement within the programme must be taken. This is particularly pertinent in a South African health context, given that the HIV epidemic is mature, the challenge to monitor large cohorts of treatment-experienced patients will only increase. Furthermore, policy makers should ensure that operational functionality of the health system does not impede a patient's desire, ability and right to transfer between services (28–31). Our study suggested that these processes, where in place were not well understood nor acted on by HCPs and patients alike. It is not enough to simply have access to care, but by upholding the principles for health provide patient-centric care that is ethical, efficient, compassionate, open and transparent, and evidence based, all of which facilitates the continuum of patient care. This is the fundamental right of each individual (30,32–34).

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References:

1. Wilkinson LS, Skordis-Worrall J, Ajose O, Ford N. Self-transfer and mortality amongst adults lost to follow-up in ART programmes in low- and middle-income countries: systematic review and meta-analysis. *Trop Med Int Heal* [Internet]. 2015;20(3):365–79. Available from: <http://doi.wiley.com/10.1111/tmi.12434>
2. Tweya H, Feldacker C, Estill J, Jahn A, Ng'ambi W, Ben-Smith A, et al. Are They Really Lost? 'True' Status and Reasons for Treatment Discontinuation among HIV Infected Patients on Antiretroviral Therapy Considered Lost to Follow Up in Urban Malawi. *PLoS One*. 2013;8(9):1–7.
3. Smuts B, Mahlali U, White C, Dearham A, Moeng H, Zweigenthal V, et al. Mapping Progress of the Western Cape Antiretroviral Programme Provincial antiretroviral monitoring and evaluation team. 2007.
4. Osler M, Hilderbrand K, Hennessey C, Arendse J, Goemaere E, Ford N, et al. A three-tier framework for monitoring antiretroviral therapy in high HIV burden settings. *J Int AIDS Soc*. 2014;17.
5. Nglazi MD, Kaplan R, Orrell C, Myer L, Wood R, Bekker LG, et al. Increasing Transfers-Out from an Antiretroviral Treatment Service in South Africa: Patient Characteristics and Rates of Virological Non-Suppression. *PLoS One*. United States; 2013;8(3):e57907.
6. Medecins Sans Frontieres. Providing HIV/TB Care At The Primary Healthcare Level Khayelitsha Annual Activity Report [Internet]. Cape Town; 2008. Available from: www.msf.org.za
7. Hennessey C, Euvuard J, Mangaloti L, Mshweshwe Z, Peton N, Richards J, et al. Lessons learned with the implementation of eKapa in the Khayelitsha Eastern Sub Structure in the Western Cape , South Africa. Cape Town; 2015. p. 7.
8. World Health Organization. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach [Internet]. Geneva; 2013. Available from: www.who.int
9. National Department of Health. TIER T1 and T2 ART Monitoring and Evaluation. 2011.
10. Bowling A. *Research Methods in Health*. 1999th ed. Buckingham: Open University Press; 1997. 1-422 p.
11. Stata Statistical Software. College Station, TX: StataCorp LP.; 2011.

12. Dalal RP, Macphail C, Mqhayi M, Wing J, Feldman C, Chersich MF, et al. Characteristics and outcomes of adult patients lost to follow-up at an antiretroviral treatment clinic in Johannesburg, South Africa. *J Acquir Immune Defic Syndr*. 2008;47(1):101–7.
13. Cornell M, Lessells R, Fox MP, Garone DB, Giddy J, Fenner L, et al. Mortality among adults transferred and lost to follow-up from antiretroviral therapy programmes in South Africa: a multicentre cohort study. *J Acquir Immune Defic Syndr* [Internet]. 2014;67(2):e67–75. PMID: PMC4239433. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24977471>
14. Pienaar D, Myer L, Cleary S, Coetzee D, Michaels D, Cloete K, et al. Models of care for antiretroviral service delivery. *Cape T Univ Cape T*. 2006;(June).
15. Kwong-Leung YJ, Tok TS, Tsai JJ, Chang WS, Dzimadzi RK, Yen PH, et al. What happens to patients on antiretroviral therapy who transfer out to another facility? *PLoS One*. 2008;3(4):9–11.
16. Boulle A, Goemaere E, Coetzee D, Wilkinson L, Cox V, Hennessey C, et al. Enhanced routine surveillance of patients in HIV care in Khayelitsha. 2014.
17. Geng EH, Glidden D V., Bwana MB, Musinguzi N, Emenyonu N, Muyindike W, et al. Retention in care and connection to care among HIV-infected patients on antiretroviral therapy in Africa: Estimation via a Sampling-Based approach. *PLoS One*. 2011;6(7).
18. National Department of Health of South Africa. TIER T1 and T2 ART Monitoring and Evaluation Implementation Plan. 2011.
19. Maskew M, MacPhail P, Menezes C, Rubel D. Lost to follow up: contributing factors and challenges in South African patients on antiretroviral therapy. *S Afr Med J*. South Africa; 2007;97(9):853–7.
20. Vearey J. Learning from HIV: Exploring migration and health in South Africa. *Global Public Health*. 2012. p. 58–70.
21. Pereko A. Tracking of Inter-Facility Patient Transfers and Retention on Antiretroviral Treatment in Namibia. 2011.
22. Kwong J, Yu -Leung. Lessons from the field ‘ Lost to follow-up ’ patients on antiretroviral therapy in Malawi. *Bull World Health Organ*. 2007;85(7).
23. Marson KG, Tapia K, Kohler P, McGrath CJ, John-Stewart GC, Richardson B a., et al. Male, Mobile, and Moneyed: Loss to Follow-Up vs. Transfer of Care in an Urban African Antiretroviral Treatment Clinic. *PLoS One*. 2013;8(10):2–9.
24. Miller CM, Ketlhapile M, Rybasack-Smith H, Rosen S. Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. *Trop Med Int Health*. 2010;15(1):48–54.

25. Brinkerhoff DW. Accountability and health systems: Toward conceptual clarity and policy relevance. *Health Policy Plan.* 2004;19(6):371–9.
26. Beach MC, Keruly J, Moore RD. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *J Gen Intern Med.* 2006;21(6):661–5.
27. Hennessey C, Osler M. How structured patient clinical records can assist nurses in the management and monitoring of patients within the South African HIV/ART programme. *Nurs Matters.* Cape Town; 2012;3(2):32–7.
28. Schneider H, Blaauw D, Gilson L, Chabikuli N, Goudge J. Health systems strengthening and ART scaling up : challenges and opportunities. *Heal (San Fr.* 2004;(December).
29. Programme TUN, Summit W. A HUMAN RIGHTS-BASED APPROACH TO HEALTH. 2003;
30. International Organization for Migration. International migration, health and human rights [Internet]. Geneva; 2013. Available from: http://www.ohchr.org/Documents/Issues/Migration/WHO_IOM_UNOHCHRPublication.pdf
31. Nygren-Krug H. International migration, health and human rights. [Internet]. 2004. Available from: <http://www.cabdirect.org/abstracts/20043141504.html>
32. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *J Int Bioethique.* 2004;
33. Kishore Raga, Taylor D. Impact of Accountability and Ethics on Public Service Delivery: A South African Perspective. *Public Manag [Internet].* 2005;34(2):22–6. Available from: <http://search.proquest.com/docview/236295671?accountid=14549&url=http://hl5yy6xn2p.search.serialssolutions.com/?genre=article&sid=ProQ:&atitle=Impact+of+Accountability+and+Ethics+on+Public+Service+Delivery:+A+South+African+Perspective&title=Public+Manager&is>
34. Khoza V, Du Toit H. The Batho Pele Principles in the health services. *Prof Nurs Today.* 2011;15(3):8–11.

Part D: Appendices

APPENDIX 1: QUESTIONNAIRE/DATA CAPTURE INSTRUMENT(S)

Patient survey

Question	Answer	Comments
Short Questions About Medication		
1. Are you taking ARV's?	a. Yes (0) b. No (1) c. No answer (2)	If No, skip to question 8.
2. How long have you been taking ARV's?	a. Less than 6 months (0) b. Less than 1 year (1) c. Less than 2 years (2) d. Less than 3 years (3) e. More than 3 years (4) f. No answer (5)	
3a. Did you initiate ARVs at this clinic?	a. Yes (0) b. No (1) c. No answer (2)	If Yes, skip to question 8 If No, complete 3b, 3c
3b. If no, where did you initiate?	Facility name (0) No answer (1)	
3c. Did you transfer from this clinic?	a. Yes (0) b. No (1) c. No answer (2)	If no, complete 3d. If yes, skip to question 4
3d. if no, where did you transfer from?	Facility name (0) No answer (1)	
TRANSFERS ONLY:		
4. Did you transfer with a letter	a. Yes (0) b. No (1) c. No answer (2)	
5. Did you run out of pills while you were transferring from one clinic to the other	a. Yes (0) b. No (1) c. No answer (2)	

6. if yes, how long were you without pills	a. 1 day (0) b. More than 1 day but less than 1 week (1) c. Greater than one week but less than 1 month (2) d. Greater than one month, but less than 3 months (3) e. Greater than 3 months (4) f. No answer (5)	Only answer if YES to 5
7. What are the reasons you transferred facilities?	a. Poor clinical care at other facility (circled 0/not circled 1) b. Rude admin staff at other facility (0/1) c. Waiting times at other facility (0/1) d. Shortage of meds at other facility (0/1) e. Stigma at other facility (0/1) f. Long distance between home/facility (other facility) (0/1) g. Relocated closer to this clinic (0/1) h. Postnatal (0/1) i. Other (0/1) j. No answer (0/1)	
Travel Information		
8. What is the distance from where you are staying to this clinic?	a. Less than 5 kms (0) b. Between 5 and 10 kms (1) c. Between 10 and 20 kms (2) d. More than 20 kms (3) e. No answer (4)	
9. How long does it take you to get to this clinic?	a. Less than 1 hour (0) b. Between 1-2 hours (1) c. Greater than 2 hours (2) d. No answer (3)	
10. How do you travel to the clinic?	a. Walk (0) b. Taxi (1) c. Bus (2) d. Drive (3) e. Train (4) f. No answer (5)	
11. How much do you spend to get to the clinic?	a. Between 0-10 rand (0) b. Between 10-20 rand (1) c. Between 20-30 rand (2)	

	d. Between 30 – 40 rand (3) e. Greater than 40 rand (4) f. No answer (5)	
Questions about your knowledge and how you have been treated		
12. Have you been told what to do if you want to get your treatment from another clinic?	a. Yes (0) b. No (1) c. No answer (2)	If yes, answer 13. If no, skip to Q14.
13. What were you told?	a. I was told to request a transfer letter (0) b. Other: (1) c. No answer (2)	
14. Please indicate how satisfied you are with the service you received at your clinic	a. Time you spend before you seeing a nurse or a doctor	1. Satisfied (0) 2. Somewhat satisfied (1) 3. Somewhat dissatisfied (2) 4. Dissatisfied (3) 5. No answer (4)
	b. The way which you are treated at this clinic	1. Satisfied (0) 2. Somewhat satisfied (1) 3. Somewhat dissatisfied (2) 4. Dissatisfied (3) 5. No answer (4)
	c. how the admin clerks treat you	1. Satisfied (0) 2. Somewhat satisfied (1) 3. Somewhat dissatisfied (2) 4. Dissatisfied (3) 5. No answer (4)
	d. Waiting time at the pharmacy?	1. Satisfied (0) 2. Somewhat satisfied (1) 3. Somewhat dissatisfied (2) 4. Dissatisfied (3) 5. No answer (4)

<p>15. Is there anything that you would like to see improved at the clinics?</p>	<p>a. Yes (0) b. No (1) c. No answer (2)</p>	<p>If no, skip to question 17</p>
<p>16. What would you like to see improved to improve your experience at the clinic? (circle as many as needed)</p>	<p>a. Shorter waiting time/clinic time (circled 0/not circled 1) b. If staff were more understanding/not rude (0/1) c. If there were more staff (nurses, doctors, pharmacists) (0/1) d. If we were supplied with medication that will last for longer than a month or two (0/1) e. Improved facility infrastructure (cleanliness, sanitation, better condition of building) (0/1) f. If appointments were not as frequent (0/1) g. Other: _____ (0/1) h. No answer (0/1)</p>	

HCP Questionnaire

Question	Answer	Comments	Coding	Captured (check for yes)
1. Are you a nurse or a doctor?	a. Nurse b. Doctor			
2. How long have you been working in this clinic?	a. Less than 6 months; b. 6 months - 2 yrs. c. 2-5 yrs. d. Greater than 5 yrs.			
3. How long have you been working in the ART services?	a. 6 months b. 6 months - 2 yrs c. 2-5 yrs d. >5 yrs.			
4. In your opinion, on average how many transfers from other clinics do you see on a monthly basis?	Open Ended Response:			
5. In your opinion, what proportion of patients that you see who are transfers, transfer in having defaulted treatment?				
6. Do most transfers come with written documentation?	a. YES b. NO c. other: _____			
7. If yes, what form of documentation do they come with	a. TFO letter b. green card c. paper d. other:			
8. In your experience, what proportion of transfers come with documentation/without documentation	Open Ended Response:			
9. How do you assess transfers who arrive without documentation?	a. Clinically;			
	b. Administratively:			

10. As a health provider, what do you require to continue a transfer patient without documentation: what are your minimum requirements?	a. TFO letter b. Green card c. Paper d. Pill bottles e. other:			
11. Why do you think patients transfer?	a. rude health providers			
	b. rude reception staff			
	c. long waiting times			
	d. drug stock out			
	e. Stigma			
	f. Long distance to travel			
	g. Change of Address			
	h. Employment change/opportunity			
12. Why do you think patients move between clinics without informing anyone?	a. Waiting time for TFO letter			
	b. They don't know the process			
	c. Being scolded by registry staff			
	d. Being scolded by health providers			
	e. Waiting times for transfer documentation			
	f. fear of not being accepted at new facility			
13. Do you think that we should try to limit transfers?	a. Yes b. No			
14. If yes, in what way?	Open Ended Response:			
15. Who would you allow to transfer?	a. TB/HIV co-infected patients	1. Yes 2. No		
	b. foreign nationals	1. Yes 2. No		
	c. pregnant women	1. Yes 2. No		
	d. patients with comorbidities	1. Yes 2. No		

	e. failing patients	1. Yes 2. No		
	f. repeat defaulters	1. Yes 2. No		
	g. treatment duration:	1. patients on <3mths tx; 2. patients on > 3mths tx 3. <6 mths tx; 4. 1 year; 5. > 1 year		
16. Do you find that managing a transfer patient more difficult than initiating and following up patients?	Open Ended Response:			
17. What programmatic or policy changes would you like to see regarding the management of transfer patients?	Open Ended Response:			

APPENDIX 2: CONSENT FORMS AND PARTICIPANT INFORMATION FORM

University of Cape Town Information Sheet and Consent Form – **PATIENT SURVEY**

FROM LOST TO FOUND: THE SILENT TRANSFER OF PATIENTS ON ANTIRETROVIRAL THERAPY IN KHAYELITSHA, SOUTH AFRICA

What is the University of Cape Town and what is this research about?

The University of Cape Town is a tertiary educational organisation based in Cape Town, Western Cape. The Centre for Infectious Diseases, Epidemiology, and Research is one centre within the School of Public Health at the University of Cape Town that conducts research that focuses on HIV/TB, health system strengthening and other health related topics. All research at the University of Cape Town has to be approved before it begins by the Human Research Ethics Committee. This is a registered human ethics committee, whose purpose is to make sure that the research is important, that all ethical policies and procedures are adhered to and that participants' safety and rights are respected.

In this research, we want to learn more about your thoughts on your experiences at this health facility and also on reasons for potential reasons on why you would transfer your healthcare from one health facility to another. We would like to ask 30 participants like yourself who are attending one of the 3 CHC clinics in Khayelitsha to complete a survey.

Why do you want to talk to me and what does it involve?

We have selected you to ask you to complete a survey about your experiences at this healthcare facility and understand what some of the potential reasons for transferring to another site would be.

We feel that your experience as a person who attends this clinic you can contribute much to our understanding and knowledge of why patients silently transfer their care between health services.

My colleague will provide you with a survey consisting of questions about your experiences at this current facility and what some of the reasons would be to cause you to move to another facility. If you do not want to answer any of the questions you may leave the question blank and move on to the next question. My colleague will be on hand should you need clarity on the questions. You will have the choice to complete the survey in either English or Xhosa. No-one else but the interviewer will be present unless you would like someone else there

The survey should take approximately 20-30 minutes to complete.

Are there any risks or disadvantages to me for taking part?

You may find that giving information regarding your healthcare experience difficult or uncomfortable. You may feel that disclosing information regarding your healthcare experience could have a negative impact on the clinical care you receive. There will be no negative impact on the care you receive if you consent to this research. Furthermore, you will not forfeit your appointment should you agree to participate and there will not be any delay in your treatment. The results of this study will be presented without mention of any personal information or facility names. No results will be able to be linked back to a specific person or facility.

The study methods, results, and discussion will be compiled into a journal article, a shorter summary, as well as a presentation in order to achieve maximum benefit from the research. You will also receive a copy by hand or e-mail before submission to a journal. If you do not agree with any part of the analysis, you must please inform the principal researcher, whose contact details are below.

Are there any benefits to me for taking part?

There are no individual benefits to taking part, but in answering our questions you will help us improve our understanding of transferring patients and any potential barriers in the health system facing silent transfers and patients reasons for silently transferring.

Who will have access to the information I give?

We will not share individual information about you or other participants with anyone beyond a few people who are closely concerned with the research. All of our documents are stored securely in locked cabinets and on password-protected computers.

The knowledge gained from this research will be shared in summary form, without revealing individuals' identities.

What will happen if I refuse to participate?

All participation in research is voluntary. You are free to decide if you want to take part or not. If you do agree you can change your mind at any time without any consequences.

What if I have any questions?

You are free to ask me any question about this research. If you have any further questions about the study, you are free to contact the research team using the contacts below:

PI's name(s) and contacts:

Dr. Kathryn Stinson (Epidemiologist)/Ms. Claudine Hennessey (Professional Nurse)

University of Cape Town

School of Public Health and Family Medicine

Centre for Infectious Diseases, Epidemiology and Research

Falmouth Building, Level 5

Observatory, Cape Town

Phone: 021-406-6760

If you want to ask someone independent anything about this research, please contact

The committee giving ethical approval for this study is the Human Research Ethics Committee Faculty of Health Sciences, University of Cape Town. If you have any problems or questions about this study, please contact the Ethics committee directly, at telephone number: 021 406 6338

CONSENT FORM – PATIENT SURVEY

FROM LOST TO FOUND: THE SILENT TRANSFER OF PATIENTS ON ANTIRETROVIRAL THERAPY IN KHAYELITSHA, SOUTH AFRICA

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily

Yes, please tick I agree to participate

I understand that I can change my mind at any stage and it will not affect me/my child in any way.

I certify that I have followed the study SOP to obtain consent from the participant. S/he apparently understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given opportunity to ask questions which have been answered satisfactorily.

Thumbprint of patient as named above if they cannot write:

Participants' FAQs and Some Answers

What is a research study?

A research study is a very careful way of looking at something and collecting information about what is being looked at. It can be as simple as asking a few questions such as in a survey or in an interview. Or it can be more difficult and may look at a particular sickness or testing new treatments for a particular sickness.

What is a research participant?

A research participant is a person who agrees to take part in a research study. This is completely voluntary. As a research participant you will be helping the researcher to answer the questions in the study. You can decide you no longer want to be in the study at any time.

What is a protocol?

A research protocols helps a researcher to carry out the research. A protocol is like a cookbook. It tells the researcher what can and cannot happen during the research. It includes information the researcher must follow to protect participants from harm. This protocol must be reviewed by a Human Research Ethics Committee before the research can begin.

Can anyone be in a research study?

Each study has a list of who can and cannot be in the research. This is written in the protocol. In order to protect research participants, only people who qualify can be in a study.

What is a principal investigator?

The principal investigator or PI is the person who is in charge of the research study. The PI has to make sure that everything is done properly. There may also be other people who help with the research study. There may be people who help to translate the questions into a participant's home language, there may be people who ask for

informed consent and people who make sure that participants' personal information is kept confidential.

What is a Human Research Ethics Committee?

The Human Research Ethics Committee is a group of people such as doctors, scientists, dieticians, physiotherapists and some community people. This Committee must look at every protocol before a research study can begin and it watches what happens during a study. This is to protect participants and to make sure that researchers keep any risks as low as possible.

What is informed consent?

If you decide you would like to be in a research study, the facts about the research will be given to you in an information sheet or consent form. This is to help you understand what will happen to you in the research study. It will explain the kinds of things that you can expect will happen at each visit so that you can make up your mind. You will be told about all the risks, if there are any benefits and any other options to the study. You will be able to ask any questions about the study and you may be able to speak to your family or friends before making your decision. You are also able to ask questions during the study.

Investigators

Investigators should ask questions to make sure potential participants understand what they are consenting to.

Healthcare Provider Information Sheet and Consent Form

FROM LOST TO FOUND: THE SILENT TRANSFER OF PATIENT ON ANTIRETROVIRAL TREATMENT IN KHAYELITSHA, SOUTH AFRICA

What is the University of Cape Town and what is this research about?

The University of Cape Town is a tertiary educational organisation based in Cape Town, Western Cape. The Centre for Infectious Diseases, Epidemiology and Research is one centre within the School of Public Health at the University of Cape Town that conducts research that focuses on HIV/TB, health system strengthening and other health related topics. All research at the University of Cape Town has to be approved before it begins by the Human Research Ethics Committee. This is a registered human ethics committee, whose purpose is to make sure that the research is important, that all ethical policies and procedures are adhered to and that participants' safety and rights are respected.

In this research, we want to learn more about you on why patients transfer their healthcare from one health facility to another and your thoughts on the management of such patients. We would like to ask about 6 participants like yourself who are working in one of the 3 CHC clinics in Khayelitsha to complete in-depth, semi structured interview.

Why do you want to talk to me and what does it involve?

We have selected you to ask you participate in an in-depth, semi structured interview in order to understand your perceptions of patients who transfer between health facilities and how you manage the treatment of such a cadre of patients.

We feel that your experience as a clinician working at this facility you can contribute much to our understanding and knowledge of why patients silently transfer their care between health services and how that impacts on your job as a clinician.

I/My colleague will provide you with a set of questions about the silent transfer patients. If you do not want to answer any of the questions you may ask to move onto the next question. I/My colleague will be on hand should you need clarity on the questions asked. The questions will be asked in English. No-one else but the interviewer will be present unless you would like someone else there

The survey should take approximately 30-40 minutes to complete.

Are there any risks or disadvantages to me for taking part?

You may find that giving information regarding your healthcare experience difficult or uncomfortable. You may find that giving information regarding your job sensitive and uncomfortable. You may feel that disclosing information regarding your practice of managing transfer patients could get you into trouble or have an impact on your performance review or staff relations. The results of this study will be presented without mention of any personal information or facility names. No results will be able to be linked back to a specific person or facility.

The study methods, results and discussion will be compiled into a journal article, a shorter summary as well as a presentation in order to achieve maximum benefit from the research. You will also receive a copy by hand or e-mail before submission to a journal. If you do not agree with any part of the analysis, you must please inform the principal researcher, whose contact details are below.

Are there any benefits to me for taking part?

There are no individual benefits to taking part, but in answering our questions you will help us improve our understanding of transferring patients and any potential barriers in the health system facing silent transfers and patients reasons for silently transferring.

Who will have access to the information I give?

We will not share individual information about you or other participants with anyone beyond a few people who are closely concerned with the research. All of our documents are stored securely in locked cabinets and on password-protected computers.

The knowledge gained from this research will be shared in summary form, without revealing individuals' identities.

What will happen if I refuse to participate?

All participation in research is voluntary. You are free to decide if you want to take part or not. If you do agree you can change your mind at any time without any consequences.

What if I have any questions?

You are free to ask me any question about this research. If you have any further questions about the study, you are free to contact the research team using the contacts below:

PI's name(s) and contacts:

Dr. Kathryn Stinson/Ms. Claudine Hennessey (Professional Nurse)

University of Cape Town

School of Public Health and Family Medicine, Centre for Infectious Diseases, Epidemiology and Research

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Phone: 021-406-6760

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CONSENT FORM – Healthcare Provider

FROM LOST TO FOUND: THE SILENT TRANSFER OF PATIENTS ON ANTIRETROVIRAL THERAPY IN KHAYELITSHA, SOUTH AFRICA

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily

Yes, please tick I agree to be interviewed

I understand that I can change my mind at any stage and it will not affect me in any way.

I certify that I have followed the study SOP to obtain consent from the participant. S/he apparently understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given opportunity to ask questions which have been answered satisfactorily.

Participants' FAQs and Some Answers

What is a research study?

A research study is a very careful way of looking at something and collecting information about what is being looked at. It can be as simple as asking a few questions such as in a survey or in an interview. Or it can be more difficult and may look at a particular sickness or testing new treatments for a particular sickness.

What is a research participant?

A research participant is a person who agrees to take part in a research study. This is completely voluntary. As a research participant you will be helping the researcher to answer the questions in the study. You can decide you no longer want to be in the study at any time.

What is a protocol?

A research protocols helps a researcher to carry-out the research. A protocol is like a cookbook. It tells the researcher what can and cannot happen during the research. It includes information the researcher must follow to protect participants from harm. This protocol must be reviewed by a Human Research Ethics Committee before the research can begin.

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The principal investigator or PI is the person who is in charge of the research study. The PI has to make sure that everything is done properly. There may also be other people who help with the research study. There may be people who help to translate the questions into a participant's home language, there may be people who ask for

informed consent and people who make sure that participants' personal information is kept confidential.

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The Human Research Ethics Committee is a group of people such as doctors, scientists, dieticians, physiotherapists and some community people. This Committee must look at every protocol before a research study can begin and it watches what happens during a study. This is to protect participants and to make sure that researchers keep any risks as low as possible.

What is informed consent?

If you decide you would like to be in a research study, the facts about the research will be given to you in an information sheet or consent form. This is to help you understand what will happen to you in the research study. It will explain the kinds of things that you can expect will happen at each visit so that you can make up your mind. You will be told about all the risks, if there are any benefits and any other options to the study. You will be able to ask any questions about the study and you may be able to speak to your family or friends before making your decision. You are also able to ask questions during the study.

Investigators

Investigators should ask questions to make sure potential participants understand what they are consenting to

APPENDIX 3: LETTER OF APPROVAL FROM RESEARCH ETHICS COMMITTEE



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



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492 • Facsimile [021] 406 6411
Email: Sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

16 January 2015

HREC/REF: 912/2014

Dr K Stinson
Public Health & Family Medicine
Falmouth Building

Dear Dr Stinson

**Project Title: FROM LOST TO FOUND: THE SILENT TRANSFER- LINKED TO 395/2005
(Masters candidate- Claudine Hennessey)**

Thank you for your response letter dated 12 January 2015, addressing the issues raised by the Human Research Ethics Committee (HREC).

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

Approval is granted for one year until the 30 January 2016.

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.

We acknowledge that the following student:-Claudine Hennessey is also involved in this project.

Please note that the on-going ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

Hrec/ref:912/2014

APPENDIX 4: INSTRUCTIONS FOR AUTHOR OF JOURNAL WHOSE FORMAT HAS BEEN USED

Modified January 2015

PLOS ONE
MANUSCRIPT BODY FORMATTING GUIDELINES

Abstract

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Introduction

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Materials and Methods

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Fig. 1. This is the Fig. 1 Title. This is the Fig. 1 legend.

Fig. 2. This is the Fig. 2 Title. This is the Fig. 2 legend.

File Naming for Figures

- Figure files should be saved as "Fig1.tif", "Fig2.eps", etc.
- Acceptable file formats for figures are ".tif", ".tiff", and ".eps"
- Figures should be uploaded separately as individual files.

Level 1 Heading

- Use Level 1 heading for all major sections (Abstract, Introduction, Materials and Methods, Results, Discussion, etc.).
- Bold type, 18pt font.
- Only use italics and text formatting where needed (e.g. genus and species names, genes, etc.).
- Do not use ALL CAPS.

NOTE: Do not cite figures, tables, supporting information, or references in the Abstract.

Figure Citations

- Cite figures as "Fig. 1", "Fig. 2", etc.
- Cite figures and tables in order.
- Do not cite "Fig. 2" before "Fig. 1".
- Cite multiple figures as "Figs. 1 and 2", "Figs. 1-3", etc.

Figure Legends

- Each figure legend should appear directly after the paragraph in which they are first cited or listed at the end of the manuscript.
- Do not include tables within legends.
- Use bold type for the figure titles.

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$$p^2 + 2pq + q^2 = 1 \quad (1)$$

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Display/Numbered Equation

- Format display equations in Mathtype or Equation Tools.
- Do not use Graphic Objects.

Inline Equation

- Format in regular text or as an inline equation in Mathtype or Equation Tools
- Do not use Symbol Font.
- Do not use Graphic Objects.

Genotyping

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Whole genome RFLP analysis

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Level 2 Heading

- Use Level 2 headings for sub-sections of major sections.
- Bold type, 16pt font.
- Only use italics and text formatting where needed.
- Do not use ALL CAPS.

Level 3 heading

- Use Level 3 headings for sub-sections within Level 2 headings.
- Bold type, 14pt font.
- Only use italics and text formatting where needed.
- Do not use ALL CAPS.

Results and Discussion

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Vestibulum adipiscing una ut lectus gravida, et bland **Table 1**. Donec tincidunt porta sem nec hendrerit. Vestibulum nec pharetra quam, vitae convalli. Fido nemo.

Table 1. This is the Table 1 Title.

	Chemical W	Chemical X	Chemical Y	Chemical Z
Chemical 1	Reaction 1W	Reaction 1X	Reaction 1Y	Reaction 1Z
Chemical 2	Reaction 2W	Reaction 2X	Reaction 2Y	Reaction 2Z
Chemical 3	Reaction 3W ^a	Reaction 3X	Reaction 3Y ^b	Reaction 3Z
Chemical 4	Reaction 4W	Reaction 4X	Reaction 4Y	Reaction 4Z
Chemical 5	Reaction 5W	Reaction 5X	Reaction 5Y	Reaction 5Z

This is the Table 1 legend.

^aTable footnotes belong here.

^bFootnotes should have corresponding symbols in the table.

Tables and Table Citations

- Tables should be cited as "Table 1", "Table 2", etc.
- Cite multiple tables as "Tables 1 and 2", "Tables 1-3", etc.
- Tables should be included directly after the paragraph in which they are first cited or listed at the end of the manuscript.
- Tables must be cell-based in Microsoft Word or embedded with Microsoft Excel
- No hard returns.
- Do not use empty rows to create spacing.
- Do not include graphic objects, images, colored text, or shading patterns.
- Typeset tables will be formatted to match PLOS ONE style.
- See [PLOS ONE Table Guidelines for more complete instructions](#)

Conclusions

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Reference Citations

- Cite references in brackets (for example, "[1]" or "[2-5]" or "[3,7,9]").
- References must be cited in order at first mention.

Supporting Information Citations

- Format Supporting Information Citations as "S1 Fig.", "S1 Table", etc
- Cite multiple files as "S1 and S2 Figs", "S1-S3 Figs", etc.
- It is not required to cite each supporting information file
- Supporting information should be uploaded separately as individual files.

Acknowledgments

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Acknowledgments

- Do not include funding or competing interests information in Acknowledgments.

References

1. Doe J, Data A, van Stats J, Testperson M, Ribosome D Jr, McBio GHT, et al. This is the article title. PLoS One 2014 Dec 18; 9(12).
2. Doe J, Data A, van Stats J, Testperson M, Ribosome D Jr, McBio, GHT et al. Bunny dynamics in cartoon landscapes. PLOS One. Forthcoming 2015.

References

- References should be listed after the main text, before the supporting information.
- References with more than six authors should list the first six author names, followed by "et al."
- Please see the PLOS ONE guide for References here: <http://www.plosone.org/static/guidelines#references>

Supporting Information

S1 Fig. This is the S1 Fig. Title. This is the S1 Fig. legend.

S2 Fig. This is the S2 Fig. Title. This is the S2 Fig. legend.

S1 Table. This is the S1 Table Title. This is the S1 Table legend.

S2 Table. This is the S2 Table Title. This is the S2 Table legend.

S1 File. This is the S1 File Title. This is the S1 File legend.

File Naming for Supporting Information

- Supporting Information files should be saved as "S1_Fig.tif", "S1_File.pdf", etc.
- Most file types are supported.

Supporting Information Legends

- List Supporting Information legends at the end of the manuscript in a section titled "Supporting Information"
- Use a Level 1 heading.
- Use bold type for the titles.
- Supporting Information files do not require full legends, only titles are required.

Please also see the PLOS ONE Guidelines for Figures, Tables, and Supporting Information, which can be found here: <http://www.plosone.org/static/figureGuidelines>

For assistance preparing figures, please contact figures@plos.org

For assistance with other formatting requirements, contact one_production@plos.org