Linkage to HIV care after discharge from an academic hospital in Johannesburg, South Africa

A master thesis at the programme in medicine

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1. Abstract

Background: Over the past decade the development and large-scale distribution of antiretroviral treatment has posed a shift in the challenges of the global HIV epidemic. Today, one of the biggest issues in the battle against HIV is to retain eligible patients in lifelong care. Most studies conducted in the area focus on linkage to care after arrival to a HIV clinic, while very few studies have been conducted on linkage to care after hospital discharge.

Aim: To assess the proportion of HIV positive, treatment naive patients that link to HIV care and treatment at a primary health care facility after discharge from Helen Joseph Hospital, Johannesburg, South Africa, and to identify risk factors for failed linkage to care.

Method: Outcome was determined by review of clinic files and by telephone interviews with patients. Patients were categorized as linked to care (no time cut-off), failed linkage to care, lost to follow-up or deceased.

Results: Among 62 included patients, 69.4% were found to link to HIV care after discharge, while only one (1.6%) reported failed linkage to care. Mortality and lost to follow-up in the group were both 14.5%. Median time between hospital discharge and first visit to a clinic for HIV care was 21 days (IQR 13-31.5). A possible correlation between having TB at discharge and better linkage to HIV care was observed.

Conclusions: Considering the moderate level of linkage to care and the high mortality found in the study, it is recommended that procedures to ensure counselling and a proper referral for this group of severely ill patients are implemented at Helen Joseph Hospital. If routine follow up of HIV patients is to be conducted in the future, there is a need for a computerized system at the hospital that can be used in the referral and follow-up process.

2. Background and literature review

The global fight against the epidemic of the Human immunodeficiency virus (HIV) has had enormous progress over the past decade. The development of antiretroviral drugs that can halt the progress of disease in infected individuals, resulting in a significant rise of life expectancy among people living with HIV, has had a powerful impact on the epidemic. Antiretroviral treatment (ART) also helps keeping viral loads down in infected individuals, there by reducing risk of transmission.[1] The challenge facing the world today is to enable access to HIV prevention, diagnosis and treatment for all in need, and to retain patients in lifelong HIV care. Expanded and improved HIV programmes have contributed to a 19% decline in the number of new HIV infections over the past decade.[2] Yet, the disease remains a unique threat to human development with a still rising global prevalence estimated to 35.3 million.[3]

Sub-Saharan Africa bears a disproportionate share of the global HIV-burden; 68% of people living with HIV reside in this area, although the area constitutes only 12% of the global population.[4] South Africa in particular has one of the highest HIV prevalences in the world estimated to 17.9% of the population, or 6.1 million people in 2012.[3] In line with the WHO strategy on HIV/AIDS, South Africa has implemented a policy of decentralization of HIV care to primary health care facilities, in order to ensure better access to treatment.[2,5] Important objectives in the South African policy on HIV are to ensure timely initiation of antiretroviral drugs, and to retain patients on lifelong therapy.[5] To link patients from HIV testing to HIV care is a complex task and losses have been shown to occur at all steps in the care pathway, but are most frequent prior to ART initiation.[6,7] Failed linkage to care as well as late presentation with low CD4 counts are associated with a large proportion of early deaths, and a worse prognosis after starting ART.[7-9]

Despite the remarkable expansion of access to HIV care that resource-constrained countries have seen over the past decade, problems with the linkage of patients to care lead to the fact that only a minority of people in need of ART are estimated to ever start treatment.[10] A meta-analysis on linkage to HIV care in Sub-Saharan Africa found that 66% of eligible patients initiate treatment, but the proportion ranged from 31% to 86% between different clinics and regions.[6] One clinic in Johannesburg found a linkage to ART of only 35%.[6] However, most of the studies in the area focus on linkage to care after arrival to the clinic where treatment is offered, while very few studies focus on discharge from one health facility with referral to another clinic. To carry out such a study is complicated since it requires tracking the patients through multiple records in different clinics.

Studies on linkage to care have previously been carried out at Helen Joseph Hospital (HJH), Johannesburg, among patients with newly diagnosed HIV-associated tuberculosis (TB). One study showed that after referral from the TB Focal Point hospital facility (TBFP), HJH, 61.7% of the patients linked to HIV care, but about one third of the patients who linked to care arrived late.[11] Another unpublished study on HIV/TB co-infected patients at HJH found a similar level of linkage to care, and proposed that a feedback system on linkage to HIV care should be considered. The South African guidelines underline the importance of communication between the local clinic and the referral point in order to ensure safe initiation of ART for eligible patients.[5] Such a system does not exist today, resulting in the patients being lost to follow up after initial HIV diagnosis and referral from the hospital to a local clinic. The rate of linkage to care among patients referred for ART from HJH needs to be monitored and evaluated in order to find evidence-based decisions on how to improve linkage to care among hospital patients suffering from HIV.

3. Objectives

Primary objectives:

- To determine the proportion of HIV- positive, ART-naive patients that link to HIV care and treatment after discharge from Helen Joseph Hospital.

- To identify risk factors associated with failed linkage to care.

- To assess the median time between hospital discharge and arrival at a clinic for follow-up of HIV care and treatment.

Secondary objectives:

- To suggest possible interventions that could lead to improved linkage to care for patients discharged from Helen Joseph Hospital.

4. Methods

4.1 Study setting

The study was carried out as a retrospective cohort study at Helen Joseph Hospital in Johannesburg, South Africa. Helen Joseph Hospital (HJH) is a large public hospital located in an urban environment. On site is also the Themba Lethu Clinic (TLC), a large facility that offers routine HIV care and treatment for thousands of outpatients every year. TLC is a governmental program run with the support of non-governmental organizations. Just like other governmental HIV clinics in South Africa its services are free of charge for the patients. Services include HIV testing, counseling, education, medical visits and treatment.

At HJH, all inpatients that are diagnosed with HIV and considered eligible for ART are seen by the infectious disease consult service at the hospital. This consult service determines the optimum timing for initiation of ART, and which antiretroviral drugs that should be used. Depending on what other conditions a patient is suffering from, it will be decided weather initiation will be done during the hospitalization or after discharge. On the day of discharge all patients are referred for follow-up and either continuation or initiation of ART at a primary health care facility. Referral can be done either to TLC or to a local clinic closer to the patient's home. According to the hospital guidelines, patients with more severe illness are to be referred to TLC. This includes patients that have a diagnosis of tuberculosis, CD4 count less than 200 cells per microliter, co-morbid conditions or pregnancy. Only stable patients are referred to a primary health care centre. Patients who initiate ART during the hospitalization are usually provided with antiretroviral medication for 30 days upon discharge. The hospital guidelines also state that patients should be counseled about their disease. This can be done either in the ward or upon discharge, when patients are referred to TLC. The counseling session aims to enhance the patient's understanding of the importance of adhering to medication, as well as the understanding of HIV as a chronic disease. If applicable, it will also be discussed which primary health care centre that is most convenient for the patient to attend for treatment and follow-up.

4.2 Eligibility criteria

All HIV-positive, ART-eligible and ART-naive adults (age 18 years or older) who were admitted to HJH between June 1 and August 31 2013, seen by the infectious disease consult service, and who survived to discharge were included in the study. Patients who had ever been on antiretroviral medication before or to whom no contact information was provided

were excluded from the study, as well as patients without a medical record that could confirm survival to discharge. ART eligibility was decided according to the South African guidelines for HIV and AIDS, which during the study period recommended ART initiation in patients with CD4 count <350 cells per microliter, WHO stage 4 disease or a diagnosis of TB. All HIV-positive women were eligible for ART during pregnancy and breastfeeding, regardless of CD4 cell count.[3]

4.3 Data collection

The records of the infectious disease consult service were entered by data capturers at HJH or by the study personnel into REDCap™ (Research Elecronic Data Capture), an electronic online system that allows users to print reports from entered data. Data that eventually could not be obtained by these records were extracted from hospital files at the Helen Joseph records department. This included information about HIV status, vital outcome (survived to discharge or deceased at the hospital), previous antiretroviral medication, initiation of ART during hospitalization, diagnoses at discharge, contact information and socio-economic data. Missing CD4 counts were obtained through the two online National Health Laboratory Systems (WWDISA and NHLS LABTRAK). In a few cases information was also obtained from the electronic medical record Therapy Edge™ (TE), a system used by TLC as well as many other HIV clinics in the City of Johanesburg (CoJ). Some data was also extracted from Focal Point Information System (FIS), a system used to register patients at TBFP. All obtained data were entered into REDCap™, from where eligible patients were extracted.

To ensure the capture of late presenters, outcome of linkage to care was measured about three months after the patients were discharged. For the behalf of the study access was given to medical records of the 13 clinics in CoJ that use TE as a tool of documentation. The biggest

five clinics, including TLC, were routinely searched for the included patients. Tracing of patients was done thoroughly with at least one search on the patient's name and one on the date of birth. For patients that were found to have arrived at a clinic, the date when the patient first collected ART was noted as the date of linkage to care. All patients were also double-checked for clinic visits prior to hospital admission, which could indicate that the patient was not ART naive at the time of hospitalization.

Patients that were not found on TE were contacted telephonically and interviewed about their situation during a short interview following a script (Appendices) by staff at TLC. The patients were asked questions about current HIV medication, clinic visits after discharge and, if applicable, reasons for not enrolling in HIV care. The general well being of the patient was enquired, and if the patient reported failed linkage to care the interviewer would counsel the patient about their situation, the importance of HIV treatment, and refer the patient for HIV treatment at the clinic most convenient. Patients were intensively traced on all phone numbers that could be found on any of the above mentioned record systems (records of the infectious disease consult, HJH hospital files, TE, FIS), including patient phone number and next of kin. Three attempts to contact the patient or next of kin were made for each provided number. For patients that could not be reached by telephone and who were registered with a South African ID number, the electronic South Africa's National Vital Registration system (SANVR) was used to verify the vital status (alive or deceased) of the patient. Patients that could not be contacted telephonically or did not want to take part in a telephonic interview, and who were not verified to be deceased on SANVR, were noted as lost to follow-up.

4.4 Data analysis

The primary outcome of the study was to estimate the ratio of patients that link to HIV care and treatment after discharge from HJH. Linkage to care was defined without time cut-off and patients were categorized as (i) linked to care, (ii) failed linkage to care, (iii) lost to follow-up or (iv) deceased. Both patients that were recorded on TE to have enrolled in HIV care and patients that self-reported ongoing HIV care on a telephonic interview were included in the group of patients that linked to care. Patients that self-reported failed initiation or continuation of ART after discharge were included in the group of failed linkage to care. The lost to follow-up group constituted of patients with no medical record of follow-up at any of the sought through clinics, and who could not be contacted by telephone. Both patients that were registered as dead in SANVR and those who were reported dead by next of kin were analyzed as deceased.

During the telephone interview, patients were asked about the date of their first visit to a clinic. If the patient could only tell in which month their first visit was, the 15th of this month was used as an assumption of the date for the patient's visit. The average time to enrollment in HIV care was calculated separately for the group of patients that had exact dates for clinic visits extracted from TE and for all patients, including both the group with recorded and the group with self-reported dates of visit. Reasons for failed or delayed linkage to care were obtained from telephone interviews and review of medical records and noted.

In the bivariate analysis of risk factors, patients were categorized as linked to care or failed linkage to care. The group of failed linkage to care included patients that reported no ongoing HIV care as well as patients that were lost to follow-up, assuming that these patients had not yet been enrolled in HIV care. Odds ratios (OR) were then used to respectively describe

patient and referral characteristics that can be associated with failed linkage to care. The results were presented with their 95% confidence intervals (CI).

5. Ethics

Before the study was commenced, ethical approval was obtained from University of the Witwatersrand Human Research Ethics Committee and the Helen Joseph Hospital. For confidentiality reasons, all patient identifiers were removed prior to analysis and replaced by a study ID, and data was analyzed anonymously. Telephone interviews were performed by multilingual interviewers with considerable experience of conducting interviews that touch on sensitive issues, making the interview as comfortable as possible for the patient. As a retrospective record study, the study posed minimal risk for the included patients. However, if improvements in the referral and discharge process can be made as a result of the study, future HIV patients admitted to HJH will benefit. Direct benefit of the study was also given to the patient that failed to link to HIV care, and who was counseled about his situation during the telephone interview.

6. Results

6.1 Patient characteristics

A total number of 200 patients that were admitted to HJH between June 1 and August 31 2013 were found in the records of the infectious disease consult service and analyzed for inclusion in the study. The inclusion criteria were met by 62 patients that were eventually included in the study (Figure 1). At the time of hospital admission the studied population hade a median age of 39 years (IQR 30.3-44.5). Fifty-three percent were female, 81% were of South African nationality and 53% were registered as employed or self-employed (Table 1).

Median CD4 cell count was 51 (IQR 20.8-140.8). One patient was excluded in the calculation of CD4 count due to an abnormal CD4 count of 9109 that was caused by a T-cell lymphoma. Almost half of the patients, 48%, were discharged with a diagnosis of TB that could either be pulmonary, extra pulmonary or combined pulmonary and extra pulmonary. Other confirmed diagnoses and clinical presentations that were frequent or characteristic in the population were community acquired pneumonia (n=15), pneumocystis pneumonia (n=5), acute or chronic kidney injury (n=11), hepatitis (all causes) (n=10), lymphoma (n=2) other cancers (n=2), immunogenic thrombocytopenic purpura or thrombotic thrombocytopenic purpura (n=3). Initiation of ART at the hospital was done in 61% of the cases while the rest were referred for initiation after discharge.

6.2 Linkage to HIV care

The review of medical records in TE resulted in a number of 22 patients that could be confirmed to have linked to care. Among the remaining 40 patients, 31 were successfully contacted by telephone, either by reaching the patient or next of kin. Of these patients, 21 reported to have linked to care, whilst only one person reported failed linkage to care (Figure 2). Nine patients (14.5%) were reported dead by next of kin. Out of the deceased patients, 6 were discharged with a diagnosis of TB. In total, 69.4% (n=43) of the included patients were found to link to HIV care (Table 2). Unsuccessful contact with 9 patients resulted in a group of patients that were recorded as lost to follow-up (LTFU) (14.5%). Four of these patients had a South African ID number and were traced in SANVR, but were not registered as deceased.

Out of the 22 patients that had a confirmed visit to a clinic on TE, 21 arrived at TLC and only one arrived at any of the other clinics included in the medical record review. The distribution of clinics visited by the patients that self-reported linkage to care were divided between 13

clinics in CoJ. Medical records for these primary health care clinics could not be accessed in the study to confirm the patients' arrival. However, 3 patients of the 21 that self-reported successful linkage to care reported enrollment in HIV care at one of the clinics with records on TE. Although extra intensive tracing of these patients was done, none of them were found to appear on the database. Furthermore, two patients self-reported initiation of ART at a hospital after being readmitted, and one patient reported follow-up in another country.

For patients with a recorded date of visit to a clinic, the median time between hospital discharge and first visit to a clinic for HIV care was 21 days (IQR 13-31.5) (Figure 3). For all patients, including both those with recorded and self-reported date of visit to a clinic, the median time of arrival to a clinic was 22 days (IQR 13.3-31.5). Of the patients with confirmed visit dates, 72.7% arrived to a clinic within 30 days, compared to 73.3% of all patients. One patient was excluded from the analysis due to missing discharge date, and 12 patients that self-reported linkage to care were excluded due to insufficient information about date of first visit to a clinic. Notable for the calculation of timing to HIV care was that one patient had a registered medical visit at the primary health care clinic prior to collecting ART. The time of linkage to care for this patient was therefore delayed by 35 days compared to the patient's first registered visit.

6.3 Factors associated with failed linkage to HIV care (Table 3)

No statistically significant correlations were found in the bivariate analysis of risk factors for failed linkage to HIV care. However, factors associated with failed linkage to care included being male (OR 2.08; 95% CI 0.51-8.47), having a CD4 count ≤50 (OR 1.94; 95% CI 0.47-7.99), and being a non South African (OR 1.88; 95% CI 0.40-8.88). The factor that showed the strongest correlation to failed linkage to care was not being diagnosed with TB (OR 3.82;

95% CI 0.73-20.10). There were no clear trends in association between employment status, initiation of ART at the hospital versus after discharge, or age and failed linkage to care. Since total numbers were small and none of the results proved to be statistically significant (p-value 0.11-0.93), a multiple logistic regression was not performed.

6.4 Observations and reasons for failed linkage to HIV care

Out of the 22 patients that were successfully contacted by telephone, only one claimed not to have linked to HIV care. Asked for the reasons for failed linkage to care, the patient stated not to have been informed about the antiretroviral treatment that was initiated at the hospital, or the follow-up of it. More information about delays to linkage to care could however be obtained through tracing patients in different medical records. For example, a 43 year old male diagnosed with disseminated TB and community acquired pneumonia, and who initiated ART at the hospital, delayed to visit a clinic and was readmitted to hospital. He was then discharged via TLC, collected antiretroviral medication and was noted to have linked to care 48 days after discharge. Another patient, a 30-year-old male with an unusual type of lymphoma refused hospital treatment, thereby ruling out possibilities for extensive investigation and start of treatment. The procedure of the patient being admitted to HJH but refusing treatment, except for antibiotics, was repeated a few times between July and November. In the same period the patient had several recorded visits to a HIV clinic, but was not initiated on ART, probably due to the doctor's lack of information about the patient's medical history, and possibly because the patient being reluctant to initiate. In November 2013 the patient was admitted to another hospital in CoJ where ART was initiated, about 4.5 months (140 days) after first hospital discharge.

7. Discussion

7.1 Significance of the results

The obtained data on linkage to care have several weaknesses. First of all, the small number of patients included in the study (n=62) result in wide confidence intervals. Secondly, as the study is based partly on results from telephone interviews, almost half of the patients that were analyzed in the group of linkage to care were not confirmed to have enrolled in HIV care by a medical record. Surprisingly, only one of the 31 patients that were successfully contacted by telephone claimed not to have linked to HIV care. This result stands in big contrast to Voss de Lima et al, who carried out a study of linkage to HIV care among 486 HIV and TB co-infected patients referred for care from TBFP, and found that 82 of 152 patients contacted by telephone (53.9%) reported failed linkage to HIV care.[10] It is difficult to tell why the results in the two studies differ, but the general difficulties with obtaining data from telephone interviews will be discussed later on. With 9 patients that were LTFU, it is also possible that mortality was actually higher in the group than the confirmed 14.5%. Furthermore, no data about weather the deceased patients had linked to care or not before they died could be obtained.

Following the fact that only one patient reported not to have linked to HIV care, the analysis of risk factors for failed linkage to care was done with the LTFU group categorized as failed linkage to care, constituting 90% of this group. Even though traced in medical records of five big HIV clinics in CoJ, it is a big chance that these people did arrive for treatment at another clinic and are incorrectly analyzed. Therefore, the results of risk factors for failed linkage to care are of little substance, but are anyways presented in the thesis. Furthermore, to analyze characteristics such as nationality and employment might be doubtful since it does not consider for example how long time the patient has spent in the country, and which conditions

he or she works under, factors that will probably influence the person's possibilities and likeliness to successfully link to treatment.

Another interesting observation made in the study was that 57% of the 200 patients that were initially analyzed for inclusion in the study had been on ART prior to admission, which is a higher number than expected. This might indicate that the infectious disease consult at HJH does actually not see all patients who are ART eligible as stated, but rather the patients with severe illness and complications. If this is the case, it contributes to inaccuracy of the selected population. Alternatively, the high number of patients on ART may indicate that the last ten years of treatment availability for HIV infected people in South Africa has resulted in a shift in the hospitalized population, from ART naive patients to patients failing medication due to resistance or failed adherence to treatment. It would be interesting to look closer at this subject.

7.2 Telephone interviews as a method

Considering the results of the study it is likely to believe that telephone interviews as a method makes it hard to achieve accurate study results. People might feel pressured to say what they believe the interviewer wants to hear, resulting in doubtful answers. In this study, three patients that were contacted by telephone claimed to have visited one of the clinics that had medical records accessible for the study personnel through TE. Even though extra attention was spent to find these patients on the database, none of them could be found. Many people in South Africa lack an ID number and registration in medical records is therefore generally done by date of birth combined with name. These details often differ between different databases, making the follow-up work very complicated. It can therefore not be excluded that these patients actually visited the clinic as they said. Another patient who

claimed to be taking ART at follow up and to have visited TLC was found on the system, but was only recorded to have attended an HIV class. Even though phoned a second time and asked about where she was getting her treatment from, the patient still claimed to pick up antiretroviral medication at TLC. However, since this patient was pregnant, it is likely that she got possible medication from an antenatal clinic, and might have misunderstood the question. All these examples demonstrate the difficulty with obtaining data from telephone interviews, sometimes due to doubtful truthfulness, sometimes due to misunderstandings, and probably sometimes due to people not understanding the treatment process. For example, it is likely to believe that people mix up TB and HIV treatment, and the respective clinics that treat these diseases.

The questionnaire used in the telephone interviews (Appendices) was made specifically to carry out routine follow-up of HIV patients at HJH and has not been validated. Even though questions were asked in as straightforward manner as possible, it was difficult to obtain data that was simple to interpret. For example, many people answered "after discharge" to the question of which date their first visit to the clinic was. Even the name of the medical clinic the patient had visited, or if the patient had actually picked up HIV medication somewhere, was sometimes doubtfully answered. For example, one patient answered "I went to Malawi from where I was taking the medication" to the question of which clinic he had visited.

7.3 Hospital procedures at Helen Joseph Hospital

At Helen Joseph Hospital there is currently no system in place to ensure that patients with HIV who are ART eligible link to an appropriate clinic facility upon discharge. However, a system to facilitate follow-up of TB care has been implemented at the hospital through the establishment of TBFP. All inpatients at HJH with newly diagnosed TB are routinely taken to

TBFP on the day of discharge where patients are registered, counseled, investigated and referred for treatment at a primary health care clinic for TB and, if necessary, HIV treatment. Even though the result is not significant, this study showed a correlation between having a diagnosis of TB at discharge and successful linkage to care. Considering the way the analysis was done, this can partly be described by the lower number of LTFU patients in the group of patients with TB. This in its turn is probably an effect of the work done at TBFP, where accurate telephone numbers to patient and relatives are obtained and entered into an electronic database. The proposed correlation might also indicate that the discharge procedure at TBFP has a positive influence on linkage to HIV care. Another possible explanation for better to the correlation is that the local clinics for TB treatment successfully ensure initiation and continuation of ART among TB and HIV co-infected patients, as the South African guidelines assign.[12]

During the implementation of the study it was observed that the patients were handled differently considering counseling and discharge procedures. Some patients were documented to have been counseled in the ward while others were not, and only some patients were documented to have been discharged through TLC. The decisions seemed to be made by individual doctors. To decide upon and strengthen procedures for counseling and discharge is probably an important intervention for successful linkage to HIV care at HJH. Considering that this is a vulnerable group of patients, usually suffering from a high degree of immunosuppression and severe infections, it is extra important that the hospital ensures that information about HIV and its treatment is communicated properly to everyone. To implement routines at all levels of the hospital work is therefore of great importance.

As of today, there is no database where information about HIV positive, ART eligible patients treated at HJH is routinely collected for the purpose of follow-up. In this study, an attempt to use REDCap as a database for this purpose was done. However, many problems with the

captured data were discovered, including a lot of missing information in the records of the infectious disease consult forms and many data-entry errors on REDCap™. Furthermore, many of the records of the infectious disease consult had initially not been entered on REDCap™, but were entered for the purpose of the study. Collecting the data of the included patients without a proper database for registration of HIV patients at the hospital was very time-consuming, indicating how hard it would be to carry out routine follow up of patients discharged with HIV from HJH at this stage.

8. Conclusions

The rate of linkage to HIV care after hospital discharge found in this study was higher than expected, but the results are unreliable due to a lot of the data being self-reported by patients. Observations were done about hospital procedures where many improvements can be made to ensure better communication and integration in the treatment process for patients. It is important that procedures for counseling and referral of discharged HIV-positive, ART-eligible patients are implemented. Information about the treatment and the referral needs to be adapted to the patient's level, and to include family members in the counseling session might also be an important tool for improved communication. If follow-up of HIV patients discharged from the hospital is to be done routinely in the future, there is a big need for the hospital to establish a database where information and contact details can be collected. Structurally, one way to carry out these changes is to establish a focal point for newly diagnosed HIV patients where counseling, referral and registration for follow-up can be done. To ensure good quality on such a facility, and to ensure that all patients in question are routinely referred there on discharge, would be one way for the hospital to better understand, and hopefully improve, the number of patients that link to care after discharge.

9. Populärvetenskaplig sammanfattning

Sydafrika är ett av de länder som är hårdast drabbat av världens HIV-epidemi. Av landets drygt 50 miljoner invånare räknar man med att 17.9% är smittade, alltså nästan var femte person. HIV orsakas av ett virus och obehandlad leder sjukdomen till att man inom loppet av några år utvecklar AIDS. AIDS är ett tillstånd då kroppens immunförsvar är kraftigt försvagat och man lätt drabbas av infektioner. Under många år stod världen handfallen inför HIV-epidemin och människor över hela världen dog utan att några mediciner kunde erbjudas. Sedan ett drygt årtionde tillbaka har det dock funnits bromsmediciner mot sjukdomens förlopp. Dessa kan inte bota en smittad person, men kan förhindra att immunförsvaret försvagas och därigenom göra att HIV-smittade personer kan förväntas leva ett så gott som fullångt liv. De senaste åren har man arbetat globalt för att kunna distribuera bromsmediciner till länder med många HIV-smittade. Detta har varit framgångsrikt och bromsmediciner kan idag erbjudas till en stor andel av dem som behöver, även i världens fattigare länder. Idag är istället en av de stora utmaningarna med HIV-epidemin att knyta patienter till vården och att öka följsamheten i den livslånga behandling som bromsmedicinering innebär.

Studien genomfördes på ett sjukhus i Johannesburg, Sydafrika, med syftet att undersöka hur många av de HIV-positiva patienter som skrivs ut från sjukhuset som följer upp sin behandling med bromsmediciner efter utskrivningen. Med god följsamhet i behandling menas att man regelbundet tar sina mediciner i rätt dos, och att man regelbundet besöker en klinik för vård och för att hämta ut nya mediciner. I studien inkluderades 62 patienter som aldrig tidigare stått på bromsmediciner. Vissa startade sin behandling på sjukhuset och remitterades för fortsatt uppföljning på en primärvårdsklinik medan andra remitterades för att starta sin behandling på en annan klinik efter utskrivningen. Det konstaterades att 69,4% av de inkluderade patienterna följde upp sin HIV-behandling efter sjukhusvistelsen. Siffran var högre än förväntat, och högre än i många andra studier från området. Uppföljningen gjordes

dels genom att journaler för primärvårdskliniker genomsöktes, och dels genom telefonintervjuer där patienterna själva fick svara på om de för närvarande tog medicin mot HIV. Bara en person uppgav sig under telefonintervjun inte ta bromsmediciner, detta då patienten enligt egen utsago inte fått information om sjukdomen och dess behandling på sjukhuset. Dödligheten i gruppen var också stor, 14,5% av patienterna hade avlidit vid uppföljningen. Lika stor var gruppen av patienter som inte kunde nås trots att både patient och anhöriga kontaktades flera gånger.

För att öka följsamheten i HIV-behandling efter att patienter skrivs ut föreslogs som åtgärd bättre rutiner för remittering och rådgivning till HIV-positiva patienter på sjukhuset. Vikten av ett bättre journalsystem konstaterades också, då det i dagsläget är väldigt svårt att göra forsknings- eller vårdrelaterad uppföljning av patienter. Forskning kring följsamhet i HIV-behandling är väldigt viktig för att förstå vilka förbättringar som kan göras i vård och samhälle för att fler HIV-smittade i världen ska bli framgångsrikt behandlade med bromsmediciner.

Acknowledgments

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Figures and tables

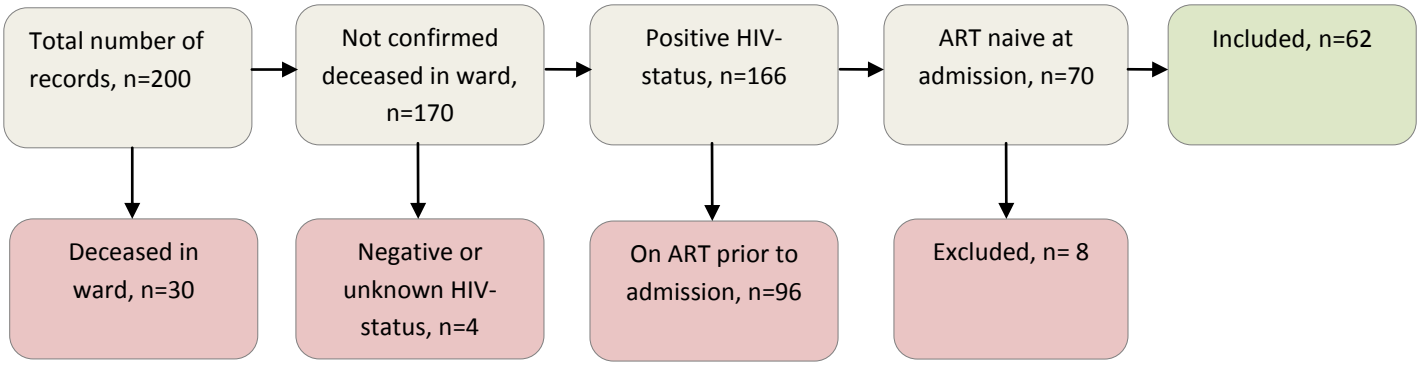

Figure 1. Flow chart of patients included/excluded in the study. A total number of 200 patients had been seen by the infectious disease consult service at Helen Joseph Hospital between June 1 and August 31 2013. Their records were retrospectively analysed for inclusion in the study. Reasons for exclusion are demonstrated in the figure above. As shown, the majority of patients were excluded due to not being ART naive at admission (n=96). Reasons for exclusion in the last step were missing contact information (n=2), age <18 (n=1), no medical record that could confirm survival to discharge (n=3), not ART eligible (n=1) and ordination of palliative care due to other medical condition (n=1).

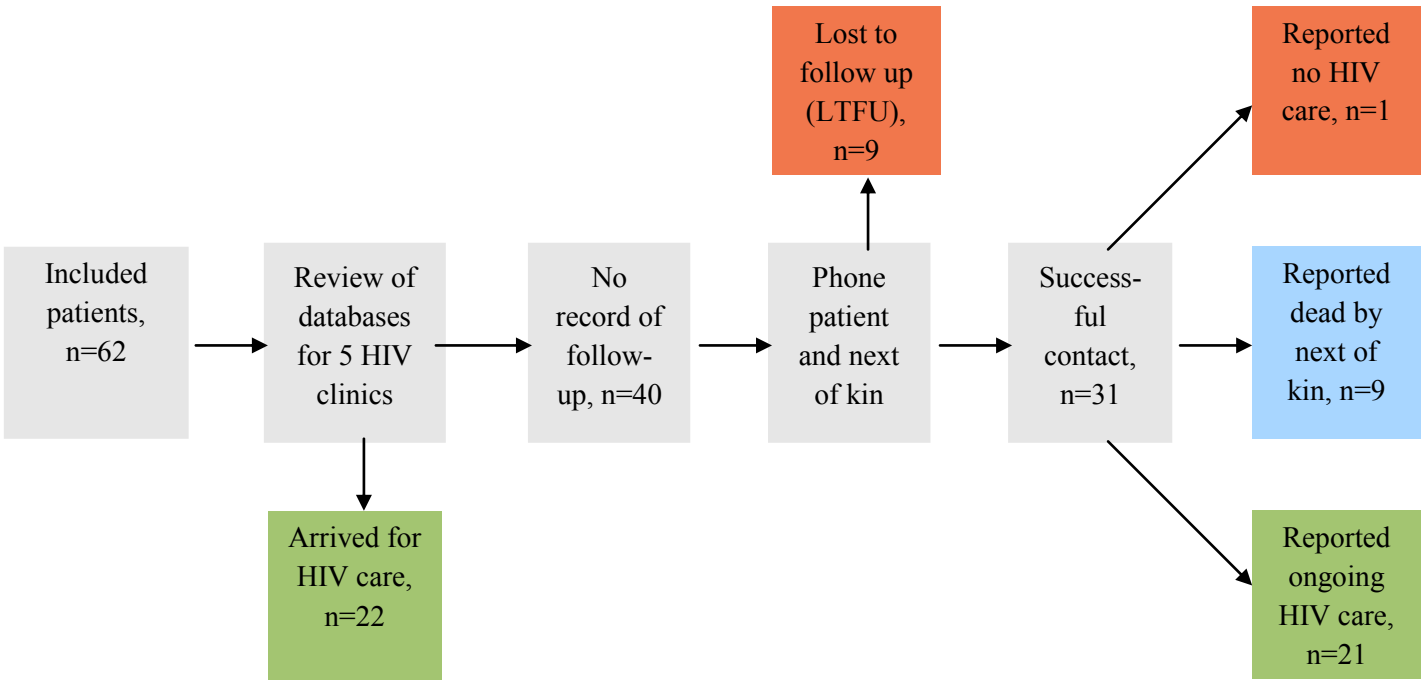

Figure 2. Flow chart representing the assessment of linkage to HIV care after discharge from Helen Joseph Hospital. The flow chart details the data collection that was done to determine the rate of linkage to HIV care for 62 HIV-positive, ART-naive patients that were referred from Helen Joseph Hospital for initiation or continuation of ART at primary care level. Data was collected about three months after hospital discharge to ensure the capture of late presenters.

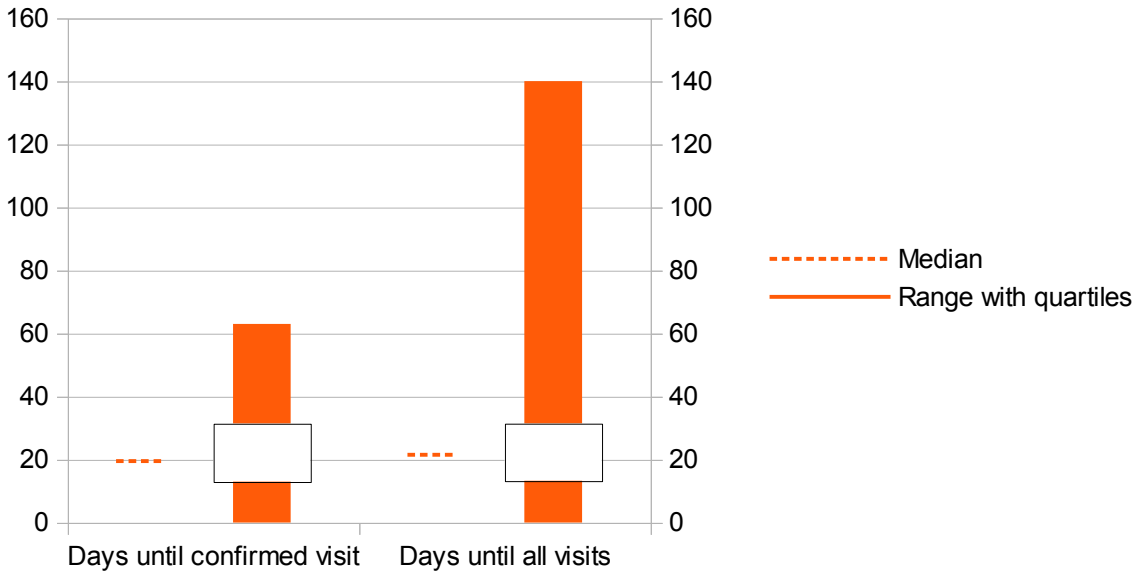

Figure 3. Boxplot demonstrating the distribution of time to arrival at a facility for HIV care for 30 HIV-positive, ART-naive patients discharged from Helen Joseph Hospital (days). The boxplot visualizes median time and inter quartile range (IQR) until first arrival at a facility for HIV care. The first bar represents patients with recorded dates of visit (n=22) and the second bar represents all patients, including both recorded and self-reported dates of visit (n=30).

Table 1. Baseline socio-demographics and clinical characteristic of 62 HIV-positive, ART-naive patients discharged form Helen Joseph Hospital, Johannesburg.

Patient characteristic		*N or median*	*% or IQR*
Gender (n,%)	Female	33	53.2
	Male	29	46.8
Age at admission (years) (n=62)	Median (IQR)	39	30.25-44.50
Nationality (n, %)	South African	50	80.6
	Other	12	19.4
Employment status (n, %)	Employed	33	53.2
	Unemployed	27	43.5
	Student	2	3.2
CD4 cell count (cell/mm3)	Median (IQR)	51	20.8-140.8
	≤50	29	50.0
	51-100	9	15.5
	100-200	9	15.5
	>200	11	19.0
TB diagnosis at discharge	Yes	30	48.4
	No	32	51.6
ART initiation at hospital	Yes	36	39.0
	No	23	61.0

Table 2. Outcome of linkage to HIV care among 62 HIV-positive, ART-naive patients discharged from Helen Joseph Hospital and referred for HIV care at a primary health care facility.

		N	Linked to HIV care, %	Did not link to HIV care, %	Lost to follow-up, %	Deceased, %
All patients		62	69.4	1.6	14.5	14.5
Gender	Female	33	75.8	0	12.1	12.1
	Male	29	62.1	3.4	17.2	17.2
Employment status	Employed	33	66.7	3.0	15.2	15.2
	Unemployed	27	70.4	0	14.8	14.8
Nationality	South African	50	70.0	2.0	12.0	16.0
	Other	12	66.7	0	25.0	8.3
Age	≤39	32	75.0	0	18.8	6.3
	>39	30	63.3	3.3	10.0	23.3
CD4 cell count	≤50	29	75.9	0	13.8	10.3
	51-100	9	44.4	0	33.3	22.2
	101-200	9	55.6	0	22.2	22.2
	>200	11	72.7	9.1	0	18.2
TB diagnosis	Yes	30	70.0	0	10.0	20.0
	No	32	68.8	3.1	18.8	9.4
Initiated ART at hospital	Yes	36	66.7	2.8	13.9	16.7
	No	23	73.9	0	17.4	8.7

Data was collected about 3 months after discharge and linkage to HIV care was defined without time cut-off.

Table 3. Factors associated with failed linkage to HIV care among 53 HIV-positive patients discharged from Helen Joseph Hospital and referred for care at a primary health care facility.

		N	Odds ratio (95% CI)	P value
Gender	Women	29	Reference	
	Men	24	2.08 (0.51-8.47)	0.31
Age	>39	23	Reference	
	≤39	30	1.19 (0.29-4.82)	0.81
Nationality	South African	42	Reference	
	Other	11	1.88 (0.40-8.88)	0.43
Employed	No	23	Reference	
	Yes	28	1.30 (0.32-5.29)	0.72
TB	Yes	23	Reference	
	No	30	3.82 (0.73-20.10)	0.11
ART initiation at hospital	No	21	Reference	
	Yes	30	1.06 (0.26-4.35)	0.93
CD4 cell count	≤ 50	26	Reference	
	51-100	7	4.13 (0.66-25.91)	0.13
	101-200	7	2.20 (0.31-15.55)	0.43
	>200	9	0.69 (0.07-7.11)	0.75
CD4 cell count ≤50	No	23	Reference	
	Yes	26	1.94 (0.47-7.99)	0.36

CI = confidence interval.

Appendices

Script used for telephone interviews

Name: _____

Date when telephoned: 1._____ 2._____3._____

1. How are you feeling now?

   ☐ Well ☐ Sick

   Comments:_____

   _____

2. a) Are you currently taking ARVs, which is the medication for HIV?

   ☐ Yes ☐ No If yes go straight to question 3.

   b) Why are you not taking ARVs?

   _____

3. a) Have you visited a clinic for follow up of your HIV treatment since you were discharged from hospital?

   ☐ Yes ☐ No If yes answer question 3b + 3c.
   If no answer question 3d.

   b) Which clinic did you go to? _____

   c) Which date was your first visit to the clinic? _____

   d) What are the reason/reasons that you have not visited a HIV clinic yet?

   _____

4. Have you been readmitted to hospital since you were discharged?

   ☐ Yes ☐ No