

FACTORS ASSOCIATED WITH ATTENDANCE AT
FIRST CLINIC APPOINTMENT IN HIV POSITIVE
PSYCHIATRIC PATIENTS INITIATED ON
ANTIRETROVIRAL THERAPY (ART) AS IN-PATIENTS

Dr Yvette M Nel

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fulfilment of the requirements for the degree of Master of
Medicine in the branch of Psychiatry

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DECLARATION

I, Dr Yvette Nel, declare that this research report is my own work. It is being submitted in partial fulfilment of the requirements for the degree of Master of Medicine in the branch of Psychiatry. It has not been submitted before for any degree or examination at this or any other University

.....

May 2014

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Date May 2014

PRESENTATIONS ARISING FROM THIS STUDY

Oral Presentation - University of the Witwatersrand, Department of Psychiatry, Annual
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ABSTRACT

The Luthando Neuropsychiatric HIV clinic was set up at Chris Hani Baragwanath Academic Hospital as an anti-retroviral roll out centre, specifically designed to provide anti-retroviral therapy to HIV positive patients with a psychiatric illness. Adherence to HIV treatment is essential for virological suppression, and non-adherence is a key factor in treatment failure. Research has suggested that psychiatric illness may negatively influence adherence to ART. Importantly, negative perceptions with regards to adherence may affect the decision to initiate ART in psychiatric patients.

Attendance at clinic appointments is the first step in adherence, and has been found to be one of the most important predictors of medication adherence. Attendance at first clinic appointment is easily measurable in a limited resource setting, such as South Africa. The aim of this study was to examine the rate of attendance at the first clinic appointment post discharge from psychiatric hospitalization in HIV positive psychiatric patients initiated on ART as in-patients, and to determine which factors, if any may be related to clinic attendance.

This study was a retrospective record review, conducted at Chris Hani Baragwanath Academic Hospital, at the Luthando clinic. Patients that were initiated on ART as psychiatric in-patients, 18 years to 65 years of age from 1st July 2009 to 31st December 2010 and then discharged for follow up as out-patients at Luthando clinic were included in the sample. The primary outcome was attendance at the clinic post discharge from hospital. Socioeconomic and clinical data were also recorded and analysed, comparing attendant and non-attendant

groups. The rate of attendance was 79.59%. There were a number of similarities between the attendant and non-attendant patients in terms of demographic and clinical data. The only significant difference between the attendant and non-attendant groups was disclosure of HIV status, and significantly fewer non-attendant patients had disclosed their HIV status to their treatment supporter ($p = .01$). Further research needs to quantify the significance of in-patient vs. out-patient initiation of ART, as well as to investigate the impact of a psychiatric diagnosis on attendance at ART clinics. Non-disclosure of HIV status needs to be further investigated and addressed in HIV treatment facilities in order to improve attendance.

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral Therapy
BD	Bipolar disorder
CD4	CD4 T helper cells (cells/mm ³)
CHBAH	Chris Hani Baragwanath Academic Hospital
CNS	Central nervous system
DSM IV	Diagnostic and statistical manual IV TR
GMC	General medical condition
HAART	Highly active antiretroviral therapy
HAD	HIV dementia
HAND	HIV associated neurocognitive disorder
HIV	Human immunodeficiency Virus
IHDS	International HIV Dementia Scale
LTFU	Loss to follow up
MMSE	Folstein's mini mental state exam
PHRU	Perinatal HIV research unit
SD	Standard deviation
SMI	Serious mental illness
Viral Load	HIV viral load (copies/mL)
WHO	World Health Organization

CHAPTER ONE: INTRODUCTION

1.1 Background

The Luthando Neuropsychiatric HIV clinic (“Luthando clinic”) was set up at Chris Hani Baragwanath Academic Hospital (CHBAH) as an anti-retroviral roll-out centre, specifically designed to provide anti-retroviral therapy (ART) to HIV positive psychiatric patients. Prior to the release of the 2010 National Department of Health guidelines, HIV positive patients, with a psychiatric diagnosis, with CD4 counts below 200 cells/mm³, or an AIDS defining illness, were initiated as in-patients or out-patients on ART at the Luthando clinic. The Luthando clinic also provides support groups, counselling sessions, volunteer groups and occupational therapy groups.

The Luthando clinic is situated within the psychiatry department at the CHBAH. Patients are referred to the Luthando clinic from the male and female acute psychiatric wards in the hospital, as well as from some medical wards within the hospital. Patients are also referred from the psychiatric outpatient department as well as other local community clinics for specialist management. Initially, the Luthando clinic also received referrals from other psychiatric hospitals such as Sterkfontein hospital, and Tara hospital, but these centres have now set up their own ART roll out programmes. Occasionally, patients are transferred in from another ART roll out site, such as the Peri-Natal HIV Research Unit (PHRU), or CHBAH’s adult ART treatment centre, Nthabiseng, for continuation of ART, combining HIV and specialist psychiatric care. In addition to this, the Luthando clinic also provides care to some patients in hospice residential placements such as Mother Theresa.

Prior to initiation of ART, patients undergo an extensive medical workup, to exclude other treatable medical causes of the psychiatric presentation, including common opportunistic central nervous system (CNS) infections. What is a unique feature at the Luthando clinic is the tendency to initiate hospitalised psychiatric patients on ART, whilst still in hospital. If hospitalised psychiatric patients meet criteria for initiation of ART, they are sent to the Luthando clinic for review and are initiated on ART whilst in the ward. They are subsequently discharged from hospital when mentally and physically stable, with an appointment date to follow up at the Luthando clinic within a month of discharge. There has been a general understanding that patients initiated on ART as in-patients have poorer outcomes than those initiated as out-patients. This has been supported by two South African studies showing high rates of loss to follow up (LTFU) in patients initiated on ART as in-patients (1,2). This perception is further evidenced by common practise in the medical wards at CHBAH, whereby in-patients are usually only initiated on ART as in-patients if their hospital stay is estimated to be prolonged, or if urgent treatment is thought to be lifesaving. Furthermore, there is some evidence to suggest that the presence of a mental illness is associated with poorer adherence to treatment regimens (3,4,5,6,7,8).

Consequently, negative perceptions with regards to rates of adherence, future clinic attendance and long term outcome may affect the decision to initiate ART in HIV positive psychiatric patients, especially in patients requiring hospitalisation. Attendance at the first clinic appointment post discharge from hospitalisation can be considered the first step in terms of long term retention in care and positive overall outcome of treatment. A larger evidence base will help guide future research and tailor treatment programs and guidelines to better serve this potentially vulnerable population.

1.2 Aim

To examine the rate of attendance at the first clinic appointment post discharge from hospital in HIV positive psychiatric patients who were recently admitted to a psychiatric ward at CHBAH and initiated on ART as in-patients, and to determine which factors, if any, may be associated with clinic attendance.

1.3 Study Objectives

- To describe the demographic and clinical details of the sample population, including the age, gender, marital status, employment status, disability grant, level of education, psychiatric diagnosis and treatment, length of admission and time to follow up appointment, distance of residence from the clinic, substance use history, and the HIV stage, including the international HIV dementia scale (IHDS) score.
- To determine the rate of attendance at the first clinic appointment after discharge from hospital of patients initiated on ART as in-patients in the psychiatric wards at CHBAH
- To compare attendant versus non-attendant patients, determining which factors if any may be associated with attendance or non-attendance at the first clinic appointment.

1.4 Hypothesis

HIV positive psychiatric patients who are initiated on ART as in-patients will return for the first follow-up appointment after discharge from hospital.

CHAPTER TWO: LITERATURE REVIEW

2.1 HIV and Psychiatry in South Africa

The HIV epidemic has changed the face of psychiatry in South Africa, bringing with it a multitude of challenges for the mental health care professional. HIV is known to have a causative role in mental illness. This can be due to the direct effects of the virus on the central nervous system; the effects of opportunistic infections; the psychological effects of the virus, largely related to the stigma and social consequences of HIV infection; as well as psychiatric side effects of treatment (9,10). Mentally ill patients may be co-morbidly infected with HIV, with some authors suggesting an increased risk of HIV infection in mentally ill patients (11).

With the advent of ART and the widespread introduction of ART into resource poor environments including the South African public sector, there is a need to examine factors affecting long term outcome in all patients infected with HIV. This includes those who are HIV positive who present to psychiatric services.

The issue of non-adherence is particularly important in HIV medicine, as well as in psychiatry and impacts directly on long term outcomes. Non adherence to ART has been associated with decreased CD4 count, increased viral load, higher mortality and morbidity and overall poorer quality of life (3,12). What is uniquely challenging in managing HIV as a chronic illness is the direct relationship between poor virological suppression and the development of resistant strains of HIV. Adherence to ART is vital for successful virological suppression in HIV infected individuals (13). In a Ugandan study in 2004, Richard *et al* (13)

found that “rapid emergence” of resistance to ART was directly associated with decreased compliance to medication. The development of resistance to first line ART necessitates second line therapy which may be expensive and less readily available in a resource poor environment (3,14).

It is not only in the field of HIV medicine that adherence to treatment has been shown to be a vital determinant of long term outcome. In psychiatry, the importance of adherence to treatment is made clear when examining the effects of non-compliance to psychiatric treatment, in terms of patient morbidity, mortality as well as the increased cost of treatment (15,16). Bearing in mind the impact of poor adherence on HIV outcomes and on psychiatric prognosis, improved adherence is a crucial target in the management of the psychiatrically unwell HIV positive patient.

2.2 Adherence to ART in the Mentally Ill

Negative perceptions regarding the ability of the mentally unwell to adhere to treatment regimens may impact on access to lifesaving ART treatment in this population group (17). However, in a study from the United States (US), Heimelhoch *et al* (18) found that patients with a psychiatric disorder were 37% more likely to receive ART than controls without a psychiatric disorder in an integrated HIV and psychiatric treatment centre. To my knowledge, this relationship has not been studied in a resource limited setting and findings may significantly differ with challenges such as unemployment, poverty, understaffing at clinics and resultant difficulties with follow-up services and individual patient monitoring. In practice there is a general perception that psychiatrically unwell patients in the South African setting would have difficulty adhering to ART treatment (19).

The evidence with regards to adherence in the psychiatrically unwell HIV positive population is currently limited, with most research emerging from the (US), and no significant contributions from resource poor environments. In their review of common mental health problems and ART adherence, Nel and Kagee, (3) found overall a reciprocal relationship between the severity of the psychiatric presentation and ART adherence. A similar relationship has been shown between adherence and HIV associated neurocognitive disorder (HAND) (4). While depression seems to be a risk factor for poor adherence, studies examining serious mental illness and adherence have been inconsistent (3,8,20,21,22).

2.2.1 HIV related neurocognitive disorder

HIV dementia (HAD) specifically has important implications when looking at adherence, as dementia has been shown to be a negative predictor for adherence in a clinical setting (4,5). Ettenhofer *et al* (4) found a reciprocal relationship between antiretroviral adherence and cognitive ability. Specifically, they found the most important predictors of medication adherence to be executive function, learning and memory (4). Similarly, Hinkin *et al* (6) found an association between executive function, memory and attention and poor adherence in HIV positive individuals in Los Angeles. It would be expected that a diagnosis of HAND would negatively affect clinic attendance, largely related to memory deficits in terms of keeping appointments, although to my knowledge there are no studies examining clinic attendance in patients with a diagnosis of HAND in a South African setting.

In a resource poor environment, an important tool used to screen for HIV associated dementia is the International HIV dementia scale (IHDS) (23). This has been validated in Uganda and the USA as an appropriate screening tool for HAD with a cut off value of 10 (23). Recently, Joska *et al* (24), in a South African study published in 2011, found the IHDS to be less sensitive in the South African sample group than the earlier results from 2005 when using the cut off value of 10, and suggested a cut off of 11 in the South African population. In clinical practice, the IHDS is used as a screening tool for HAND, and a cut off value of 10 continues to be used in the South African setting.

2.2.2 Serious mental illness and ART adherence

Serious mental illness (SMI) is a term usually referring to the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) diagnoses of schizophrenia, bipolar disorder, and major depressive disorder with psychotic features (21). Factors inherent to the diagnosis of a serious mental illness may negatively influence adherence. Schizophrenia, for example, is characterised by positive features such as delusions and hallucinations, disorganised speech and behaviour; as well as negative features including cognitive slowing and avolition (5). These features associated with schizophrenia, if not controlled, may negatively influence a patient's ability to adhere to a treatment regime (21). It is also possible that these factors would affect clinic attendance.

Heimelhoch *et al* (20) examined a cohort of HIV infected individuals in the US and focused in on the relationship between having a serious mental illness and discontinuation of highly active combined antiretroviral therapy (HAART). They found that patients with a SMI were significantly "less likely to discontinue HAART" in the first 2 years of treatment compared

with patients with no history of mental illness. Also, among the patients with a psychiatric diagnosis, those who had more mental health care visits were “less likely to discontinue HAART”, suggesting that successful treatment of SMI improves adherence, and that more vigilant follow-up of those with a mental illness may be needed to ensure retention in care (20). Although these findings seem to suggest a favourable outcome in terms of adherence in a first world setting for HIV positive patients with a SMI, Wagner *et al* (21) investigated ART adherence in patients with HIV and a SMI and found a mean adherence of only 66% using electronic monitoring caps. They recommended that further research should continue to investigate issues relating to adherence in HIV positive patients with a SMI (21).

There have been several studies specifically examining the relationship between bipolar disorder and adherence to ART. Walkup *et al* (22) examined the relationship between ART adherence and bipolar medication adherence and found that patients with bipolar disorder were more likely to be adherent to ART in the month after filling their bipolar medication scripts, suggesting that better control of bipolar disorder increases adherence to ART. Moore *et al* (8) compared HIV positive patients with bipolar (HIV+/BD+) and HIV positive patients without bipolar (HIV+/BD-) and found that those with a dual diagnosis were significantly less likely to be adherent. Evidence thus far suggests a significant negative impact of bipolar diagnosis on adherence, but also suggests that successful treatment of bipolar disorder may be associated with improved adherence.

2.2.3 Depression and ART adherence

Depression has been consistently reported as important in ART adherence. Factors associated with depression, which are important in determining patient adherence to treatment, include poor memory, anhedonia and decreased concentration (3,5). In a meta-analysis of the available literature, DiMatteo *et al* (25) examined adherence to treatment of a medical condition and found that depressed patients were three times more likely to be non-compliant than non-depressed patients. Similar values have been reported for HIV specific adherence and depression (3). Do *et al* (7) found the presence of depression to be significantly related to non-adherence in an HIV treatment setting in Botswana. Depression would most likely affect the ability to adhere to appointments in an ART treatment program, with Kunutsor *et al* (26) citing depression as a reason given by patients for missing appointments at an ART clinic.

2.2.4 Substance abuse and ART adherence

Uldall *et al* (5) reviewed the literature on mental illness, chemical dependency and HIV adherence and found that substance use was common among HIV positive individuals, and that substance use has been associated with poorer adherence to HIV medication. Do *et al* (7) found an association between on-going alcohol use and non-adherence in a Botswanan population. In their review of common mental health problems and ART adherence, Nel *et al* (3) recognised the importance of substance abuse, often co-morbid with other mental health care problems and the shared impact on adherence to ART. They also listed factors associated with substance abuse that negatively influence adherence, such as problems with memory and concentration (3).

2.2.5. Dual stigma - HIV and mental illness

Stigma has been consistently cited as a reason for non-disclosure of HIV positive status by HIV positive individuals to friends or family members (27,28). MacQuarrie *et al* (29) summarized their findings on review of the literature with regards to HIV related stigma and discrimination. They found that HIV related stigma is highly prevalent and negatively influences testing, treatment and adherence (29). Rintamaki *et al* (30) found that non adherence to medication was significantly more likely in people with high HIV “stigma concerns”. (30)

Added to this, stigma is overwhelmingly present in psychiatry and has also been found to be associated with non-adherence. Gray (31) summarises the issue of stigma in psychiatry in her article published in 2002, where the consequences of stigma are far reaching, including concealing of mental illness and delays in treatment, social rejection as well as hopelessness. Sirey *et al* (32) found that perceived stigma was associated with treatment discontinuation in elderly adults with depression. They defined perceived stigma as the “belief that most people will devalue and discriminate against individuals who use mental health services and/or have a mental illness”. (32, p.479) A further issue and area of concern especially in the HIV positive mentally unwell, is that of discrimination in terms of access to health care for physical conditions as a result of stigma (31).

2.3 Other Factors Related to Adherence in HIV Management

2.3.1 Disclosure of HIV status

Do *et al* (7) found a significant association between failure to disclose HIV positive status to a partner and non-adherence to ART in a HIV positive cohort in Botswana. In line with this Charurat *et al* (33) in a large Nigerian study found an association between increased adherence and disclosure of HIV status to a family or friend. Also, in related research, Ramadhani *et al* (34) examined “incomplete adherence” and “virological failure” in an HIV positive sample in Tanzania and found disclosure to friends or family to protect against virological failure.

2.3.2 Treatment supporter

A Ugandan study in 2001 looked at improving clinic attendance and treatment adherence through the presence of a treatment supporter (35). They measured clinic attendance for refills and measured adherence using monthly pill counts. Participants with a treatment supporter had a greater likelihood of being treatment adherent, and being on time for their clinic appointments. A major limitation of this study was the lack of objective measures such as repeat viral loads in support of monthly pill count as a measure of adherence (35).

2.3.3 In-patient initiation of ART in the mentally ill

To my knowledge, there are no studies examining out-patient adherence or retention in care after in-patient initiation of ART in mentally ill patients. Two South African studies have linked in-patient initiation of ART with increased LTFU in non-psychiatric HIV positive individuals. Eshun-Wilson *et al* (2) found a high rate of loss to follow up of 35% in hospitalised patients initiated on ART, defining LTFU as no OPD clinic attendance for three months. In line with this, Boyles *et al* (1) found that initiating ART as an in-patient was an independent predictor of loss to follow up, with an overall loss to follow up of 6.5%, which was defined in their study as no patient contact for more than six months at the end of the study period.

De Socio *et al* (36) reported a good overall treatment response in Psychiatric HIV positive patients initiated on ART in hospital in an Italian setting, however, this study was conducted in a long term residential placement setting for the mentally unwell with very close supervision of treatment and does not address long term adherence, particularly in the out-patient setting.

2.4 Measures of Adherence

Adherence to ART can be evaluated by a number of methods, some more reliable than others including self-report, electronic monitoring caps, biological markers (viral load and CD4 count), pill counts and clinic attendance (5). Practically, in a clinic setting, an important marker of adherence to medication is attendance at clinic follow up appointments (21).

Attendance is the first step in adherence and without attendance a patient cannot actually take medication. Wagner *et al* (21) used electronic monitoring caps and found that attendance at clinic follow-up appointments was strongly associated with adherence to medication, and was easily measurable. Similarly, Kunutsor *et al* (26) found a strong association between clinic attendance and adherence to ART, examining patients who had defaulted one clinic appointment. The authors suggested that monitoring clinic attendance in a resource-poor environment may be a useful tool to assist in early identification of those at risk of non-adherence (26).

2.5 Medication Adherence and Clinic Attendance

Although it has been found that medication adherence and clinic attendance are intricately linked, it should be remembered that a patient may attend the clinic but not be adherent to medication, for example a patient who regularly attends the clinic but does not take the medication on a daily basis at home (21,26). Any record of patients who are non-attendant at clinic appointments includes those who have defaulted treatment, but may also include those patients who have died, or transferred to an alternative treatment site (37). Geng *et al* (37) investigated the outcome of a sample of patients who were lost to follow up in an ART clinic in Uganda. Of the sample of 128, 111 were traced and 48 directly interviewed. Of those traced, 23 were found to have died, mostly due to HIV related illness. Of those still alive, who were successfully traced and interviewed, 83% reported they were attending another clinic, while 71 % reported that they were currently receiving ART from another clinic (37). In line with this, transfer to another clinic site was found to be an important reason for non-attendance in a follow up of patients recorded as “lost to follow up” (38). Peltzer *et al* (39) prospectively examined the characteristics of HIV positive patients in Kwa Zulu Natal who

were lost to follow up 6 - 12 months after initiation of ART. Of those that were initially categorised as lost to follow up, 46% were found to be deceased (39).

In their review of psychiatric clinic appointment non-attendance, Mitchell and Selmes (16) report that psychiatric appointment non-attendance is closely related to non-adherence to medication. Sparr *et al* (40) conducted a follow up of psychiatric clinic non-attendant patients and found that 73% of missed appointments were rescheduled within two weeks of initial appointment date, and that reasons given for non-attendance included patient error, forgetfulness, or confusion regarding the date of the appointment. Reports of death as a reason for psychiatric clinic non-attendance seem far less frequent than what is reported in follow-up investigations of HIV clinic non-attendance. Pang *et al* (15) reported that 6% of patients missing psychiatric out-patient clinic appointments who had been successfully traced had subsequently died and thus missed appointments. There was also a high rate of re-admission for psychiatric reasons among non-attendant, leading to missed appointments (15).

Most research focusing on clinic non-attendance is limited to populations with either HIV or mental illness, with no literature to my knowledge examining clinic attendance in those patients who have both an HIV diagnosis and a mental illness.

2.6 Measuring Non-Attendance in the Research Setting

The term LTFU is commonly used in HIV related research; however there is no universal definition of the term. Non-attendance is often recorded as LTFU, meaning anything from

failure to attend the next scheduled appointment, to failure to attend the clinic within a certain time frame, which can range from 30 days to 36 months (41). Chi *et al* (42) aimed to provide evidence based universal definition of the term LTFU for HIV-related research, in their multisite study published in 2011 (42). Loss to follow up usually refers to a time interval, which varies between centres, from the last appointment in which period there is no follow up (42). This time interval was examined in the study by Chi *et al* (42), keeping in mind that a short time interval, would yield a high level of sensitivity but a low specificity, in that patients who do not attend early may still attend at a later stage, and a long time interval may miss patients who become non-attendant at a later stage, so have a lower sensitivity but a higher specificity. They examined data across 111 ART treatment facilities in Asia, Africa and Latin America to determine a time interval for which there was optimal sensitivity and specificity, and found a period of 180 days to be most reliable, with the least number of “misclassifications” when compared to 12 month follow up (42). This is in contrast to prior recommendations by Chi *et al* (41) in an earlier study involving a smaller cohort in Uganda, where the authors suggested a cut-off point of 60 days in defining LTFU (41). While there has been an attempt to standardise definitions of LTFU, in his editors summary of the article published by Chi *et al* in 2011, Bartlett (42, see editors summary) suggested that in certain contexts, “national, regional and local definitions of LTFU may be more appropriate” when taking into consideration “the wide range of best performing definitions among facilities”. (42, p.12)

The rate of non-attendance at the first clinic follow-up appointment post discharge from psychiatric hospitalisation has been investigated by several authors. Kruse *et al* (43) examined factors associated with attendance at the first clinic appointment post psychiatric hospitalisation. Similarly, Crompton *et al* (44) examined predictors of missed first clinic

appointment at community mental health care centres after psychiatric hospitalisation. In both of these US based studies; attendance at the first clinic appointment post discharge from hospitalisation was the primary outcome measure. To my knowledge, there are no similar studies in HIV positive patients, with a focus on the first clinic appointment post discharge from hospitalization, in patients with or without mental illness.

2.7 Importance of Attendance at HIV Clinic Appointments

Non-attendance at HIV clinic appointments has been found to be associated with poor CD4 response, failure to achieve virological suppression, increased risk of death and increased risk of loss to follow up (45). Appointment non-attendance, including interrupted care, has also been found to be a significant predictor of higher viral loads and lower CD4 counts (46,47). Mugavero *et al* (48) found a significant increase in mortality rate in HIV positive patients missing appointments in the first year of treatment. “Timely” clinic attendance has recently been shown to be associated with decreased viral loads and lower levels of viral resistance (49).

2.8 Rate of Non-Attendance at HIV Clinics

In the South African context, examining attendance at out-patient ART clinics, Brennan *et al* (45) found that 35% of patients missed at least one visit in the first six months of treatment. There are no South African studies examining the rate of clinic attendance at the first out-patient clinic appointment in patients initiated on ART as in-patients. However there are several studies reporting longer term LTFU, with variable definitions of the term LTFU.

Eshun-Wilson *et al* (2) found that 35% of patients initiated on ART as in-patients did not return to the clinic for a three month period and were therefore LTFU. In line with this, Boyles *et al* (1) reported an overall loss to follow up of 6.5%, which was defined in their study as no patient contact for more than six months at the end of the study period.

Bofill *et al* (50) investigated the demographic and psychosocial factors associated with appointment attendance among HIV-positive out-patients in Miami, Florida, and found that during the study period 27.9% of scheduled appointments were missed. Mugavero *et al* (48) examined missed visits and mortality in out-patient care in HIV positive individuals, and found that within the first year of treatment, 60% of patients had missed a clinic visit.

2.9 Factors Associated with Non-Attendance at HIV Related Appointments

Catz *et al* (51) looked at HIV medical appointment attendance in the USA and showed that out-patient appointment non-attendance was associated with “younger age, minority status, less severe illness and lower perceived social support”. (51, p.361). Pregnancy was associated with increased risk of loss to follow up in the South African setting, and HIV positive women have been “found to miss more medical appointments than men” (1) (52, p.473). Isrealiski *et al* (52) also found that increased age and increased income were associated with increased attendance of medical out-patient appointments. Other factors reported as reasons for non-attendance include work and child care related problems, financial difficulties, lack of transport to the clinic, family and religious beliefs regarding treatment as well as feeling too

sick to return to the clinic (37). In line with this, food assistance programs as well as “free” treatment programs have been associated with greater attendance (38,53).

In their letter to the editor published in *Psychiatric Services* in 2007 by Breen *et al* (54) examined adherence to treatment in poorer countries and mention factors unique to low and middle income countries, often associated with “rapid urbanisation”. Breen *et al* (54) interviewed families of patients living with mental disorders in poor South African communities. They found that reasons given for poor adherence included logistical problems such as queuing in the dark from early in the morning outside the clinics and long queues to collect medication. Some of the patients that were interviewed reported taking incorrect doses in order to decrease the frequency of clinic visits for this reason. There was also a reported fear of mugging and physical attack associated with queuing and waiting for clinic appointments in the dark (54). This would lead to a decrease in clinic attendance in this population.

2.10 Importance of Attendance at Psychiatric Clinic Appointments

In a prospective outcome study examining psychiatric patients who regularly missed out-patient appointments, Pang *et al* (15) found that there was a significant increase in hospitalisation and death among patients who dropped out of treatment. It is not clear if these patients were hospitalised or died before or after their recorded missed appointments. Killaspy *et al* (55) prospectively followed a cohort of patients attending an out-patient psychiatric clinic. They found that in follow up patients, non-attenders were more likely to

have subsequently been admitted to hospital than attenders, but were also more likely to default further appointments and to drop out from treatment. Non-attenders were more psychiatrically unwell and had poorer social functioning (55). Essentially, evidence has shown a need for increased vigilance regarding follow-up of those who miss psychiatric out-patient appointments.

2.11 Rate of Non-Attendance at Psychiatric Clinic Appointments

In a retrospective review published in 2002, Kruse *et al* (43) measured rates of attendance at the first clinic appointment after discharge from a psychiatric hospital in the United States, and found that 18% of their sample did not attend the follow up appointment. This was in line with a finding by Thapar and Ghosh in 1991 (56), who studied rates of non-attendance at a psychiatric clinic in Wales and defined non-attendance as any new or follow-up patients who did not arrive for a clinic appointment without making a cancellation. The overall non-attendance rate for the study period was 17.5 % (56). However, Crompton *et al* (44) found a high rate of 64% non-attendance at the first scheduled clinic appointment post discharge from psychiatric hospitalisation.

2.12 Factors Associated with Non-Attendance at Psychiatric Clinic Appointments

In psychiatric appointment attendance, young age, race, area of residence and limited family support have all been found to be associated with non-attendance (43,50,57). Non-attendance was also previously associated with more severe mental illness (55). Centorrino *et al* (58) found personality disorder diagnosis, acute stage of illness, and higher level of education to be associated with attendance.

Kruse *et al* (43) found that appointments less than 2 weeks after discharge from hospital were more likely to be attended in patients discharged from psychiatric hospitalisation. Reliance on public transport was found to be associated with non-attendance in a first world setting (56).

Gonzalez *et al* (59) found that attendance at mental health appointments improved when there was a perception of a collaborative relationship with the physician. Other factors predicting missed appointments in the mental health care setting include not having a regular outpatient doctor and leaving hospital against advice of the treating team (44). Level of satisfaction with the clinic and perceived need for treatment were associated with appointment attendance (56). Attendance was also found to be higher if the visit was for psychotherapy as opposed to psycho-pharmacotherapy (58).

2.13 Summary of Literature Review

Adherence to ART is vital for successful treatment of HIV infected patients. Psychiatric comorbidity raises concerns with regards to a patient's ability to adhere to ART. Evidence has shown a link between psychiatric conditions and poorer overall adherence to ART. Psychosocial factors such as dual stigma have also been shown to influence adherence behaviours. Clinic attendance has previously been shown to be significantly associated with medication adherence and has been easily measured in a resource poor setting. A number of factors have been linked over the years with clinic attendance, but factors have varied from study to study, between conditions and with each population studied.

Although the issue of adherence in HIV positive mentally unwell patients has been previously examined, and there have been several studies looking at attendance at both psychiatric and HIV out-patient clinics, there were no studies examining attendance in the dual diagnosis population, those with HIV and a psychiatric presentation. While there are a few American studies focussing on out-patient first clinic appointment attendance post psychiatric hospitalisation, there are no similar South African studies. There are also no studies looking at out-patient first clinic appointment attendance after in-patient initiation of ART in psychiatric patients.

CHAPTER THREE: METHODOLOGY

3.1 Study Design, Sample Size and Population

This study was a retrospective record review, conducted at Chris Hani Baragwanath Academic Hospital, at the Luthando clinic. The study group included all HIV positive (ART naïve) mentally ill patients between the ages of 18 and 65, that were initiated on ART as in-patients, while admitted to a psychiatric ward at CHBAH and subsequently discharged from CHBAH, to follow up for continued ART and psychiatric treatment at the Luthando clinic.

A list was obtained of all the new patients attending the Luthando Neuropsychiatric clinic during the period 1 June 2009 – 31 December 2010, including the date of the first appointment at the Luthando clinic. The total number of new patients in this period was 388. This study period was chosen as it was felt there would be a significant number of patients initiated on ART as in-patients in this period. The clinic had been increasingly initiating in-patients on ART since its inception in 2008. Data collection began in early 2011. The Medicom Database is the computer system at CHBAH which holds the records of patient registration details, date of admission and discharge as well as hospital number. This database was scanned to determine admission and discharge dates for each patient. All 388 Luthando clinic files were obtained and examined to determine the date of initiation of ART. This information was examined together with the admission and discharge details obtained from the Medicom database, and it was determined if a patient was an in-patient or an out-patient at the time of their first clinic appointment and at the time of initiation of ART.

There were 98 patients included in the final data analysis. This sample size was determined after reviewing all new appointments at the clinic between 1 July 2009 and 31 December 2010, and determining which patients met inclusion and exclusion criteria. The sample was much smaller than initially anticipated as it was believed that there was a higher percentage of the total 388 new appointments that were in-patients and would fulfil study inclusion criteria.

3.2 Inclusion Criteria

Patients were included in the study if they met all of the following criteria:

- They were HIV positive and ART naive prior to referral to Luthando Neuropsychiatric Clinic
- They were seen for a first appointment at the Luthando clinic during the period 1 June 2009 – 31 December 2010 and subsequently initiated on ART during this same period
- They were in-patients at CHBAH at the time of initiation of ART, admitted in a psychiatric ward
- They were discharged from a psychiatric ward at CHBAH with recommendations to follow up at the Luthando Neuropsychiatric clinic
- They were between the ages of 18 and 65

3.3 Exclusion Criteria

Patients were excluded from the study if:

- They were seen at the clinic but not initiated on ART

- They were discharged with instructions to follow up at a clinic other than Luthando clinic
- They were seen as in-patients during the study period but initiated on ART as out-patients
- They were transferred to another hospital and not discharged from CHBAH directly.
- They had been initiated on ART elsewhere and were subsequently admitted, or had defaulted treatment and were admitted, and were thus re-commenced on treatment whilst admitted
- They were lost to follow up whilst in hospital, and therefore not discharged with a Luthando appointment. This would have occurred, for example, if a medically unwell patient who deteriorated physically whilst in the psychiatric ward was then transferred to the medical department for further management. The reason for exclusion was that the patient was most likely subsequently discharged from the medical department of the hospital without a Luthando appointment and so no follow up was arranged.
- They were transferred to a Life Esidemeni placement facility with no recorded follow up appointment scheduled. Life Esidemeni facilities are contracted by the government to provide long term residential care to public sector psychiatric patients who are unable to be managed within the community.

3.4 Data Collection

All data for the study were recorded on a specific data source sheet, numbered in order of collection, not including the patient's name or hospital number. Information was manually recorded from each relevant Luthando Neuropsychiatric clinic file, after determining if the patient met inclusion and exclusion criteria as stated above, specifically that the patient was

an in-patient in a psychiatric ward at CHBAH at time of initiation of ART. If information was incompletely recorded in the Luthando Neuropsychiatric clinic file, then the general psychiatric clinic file was obtained, and if this was not sufficient, then the CHBAH official admission record was obtained to fill in the missing data.

At times, on review of the Luthando file, it was clear that the patient was admitted to hospital, but this information did not correlate with the Medicom Database movement register, likely due to input error in the database or incorrectly recorded hospital number. In these cases, the hospital file was requested from patient registry. The manual admission and discharge dates recorded on the front of the hospital file were used to confirm that the patient met the criteria for the study and to calculate the length of admission.

Demographic data was obtained from the Luthando clinic file. The Luthando clinic file contains a basic data sheet which is completed at the initial visit including information on age, gender, address, marital status, employment status, disability grant status, presence of a treatment supporter and alcohol unit consumption. There is a separate sheet, containing HIV related data such as stage of infection and previous exposure to HAART. In addition to this, on each visit to the clinic, an appointment sheet is completed, with variable data depending on the treating doctor's clinical notes, usually including the date of the visit, admission to hospital, diagnosis, treatment, and complications. The follow-up appointment date is also recorded on this sheet. In addition to this, a referral sheet is often found in the file with basic information from the treating ward doctor referring the patient to the Luthando clinic for initiation of ART

3.4.1 Primary outcome - attendance

The primary outcome was attendance at first clinic appointment after discharge from hospital. This appointment date was recorded on the last appointment sheet completed during the in-patient management of the patient, or on the discharge summary, usually found in the psychiatric file or the CHBAH file. The appointment sheet for the next appointment after discharge was located.

The patient was classified as attendant (attending their appointment) if the date given before discharge and the next recorded visit were the same, partially attendant if the next visit was within one month of the appointment date, and non-attendant if there was no follow up within one month of appointment date. For all future analysis, attendant and partially attendant are grouped together as “attendant”. This grouping was decided on because patients are usually discharged from hospital with one month supply of their medication, and so if attending within one month of the given date, then it is still possible that they are adherent to medication. Also, some patients were discharged just before the next follow up appointment date recorded in the Luthando file, and it is possible they were told by the discharging doctor or ward to follow up “in a month” at the Luthando clinic, and not given the specific date in the file. On several discharge summaries, it was stated that the patient should follow up at Luthando, but the date was not specified, suggesting that the patient may not have been aware of the appointment date.

3.4.2 Secondary outcomes

3.4.2.1 Length of admission and time to follow up appointment

The data source sheet also recorded the date of admission and discharge, which was used to calculate the length of admission and time from discharge to follow up appointment.

3.4.2.2 Socio-demographic variables

Data was collected on demographic details; age (at the time of the first appointment), gender, marital status, employment status and level of education. Distance from the CHBAH to the furthest point of each major Soweto area was measured “as the crow flies” using Google maps, and areas were grouped together by estimated distance. It was usually documented in which area the patient lived, but not necessarily the exact address.

3.4.2.3 Psychiatric diagnosis

Data on psychiatric diagnosis was recorded from the clinical notes in the Luthando file, or if not recorded in the Luthando file, then from the CHBAH file or the psychiatric out-patient clinic file. No validated diagnostic scales were used as the diagnosis was always a clinical diagnosis and this was a retrospective review. Diagnoses were categorised based on the DSM IV TR, although often no differentiation was made in terms of bipolar disorder I and II in the clinical notes, and so a diagnosis of bipolar was recorded. For statistical analysis, diagnoses

were loosely grouped into two groups due to the small numbers involved; “Primary psychiatric illness” (schizophrenia, schizoaffective disorder, bipolar disorder, not specified I or II, major depressive disorder, and substance induced psychotic disorder), and “psychiatric illness due to general medical condition” (HIV or other). The psychiatric diagnosis most often included a differential diagnosis, and all of the differentials were recorded on the data sheet, in no particular order.

3.4.2.4 Current psychiatric treatment

Current in-hospital treatment for the psychiatric symptoms was recorded from the Luthando file and simplified into mono-therapy vs. poly-therapy, depending on the number of psychotropic used. Benzodiazepines were not included as treatment as most patients receive short term benzodiazepines whilst in the ward regardless of diagnosis.

3.4.2.5 Substance use history

Substance use history was seldom recorded in the Luthando file, and this information was taken from the discharge summary or from the initial clerk of the patient in the CHBAH file, relying on the patients self-report of substance use, or the collateral information reporting substance abuse/use, with no additional screening done for substances, and no validation in terms of categorising use, abuse or dependence.

3.4.2.6 IHDS score and stage of HIV infection

The cut off value for IHDS for screening for HIV associated dementia was taken as 10 as that is the currently accepted value (23). The IHDS was not routinely recorded in the clinic file but was done at the first clinic visit, or follow up visits, if a neurocognitive deficit was clinically suspected, or in the ward if clinically deemed to be necessary. The World Health Organization (WHO) stage of HIV infection was recorded in the initial Luthando record for each patient.

3.4.2.7 Disclosure of HIV status

Disclosure of HIV status was also difficult to measure, as all patients had a treatment supporter, but, on review of the clinic file, had not necessarily disclosed their HIV status to the treatment supporter. The treatment supporter is chosen by the patient prior to initiation of ART. The treatment supporter is usually a family member or close friend who will assist with reminders to attend the clinic and encouragement to continue with treatment. At the Luthando clinic the presence of a treatment supporter was enquired about at first visit, prior to initiation of ART. Often, the clinician had recorded in the file “disclosed” or “not yet disclosed”, however, it was often not recorded if the treatment supporter was aware of the diagnosis and this was then recorded as unknown. This additional clinical note regarding disclosure could suggest that while the patient may have had someone (the treatment supporter) who was aware that the patient was attending a clinic for a medical condition, the treatment supporter may not have been aware of the diagnosis of HIV. Alternatively, it could have meant that the patient had identified someone to be a “treatment supporter” but had not yet disclosed their

HIV positive status to that identified person. ART was commenced whether or not disclosure of HIV status to the treatment supporter was confirmed.

3.5 Statistical Analysis

Data was recorded in Microsoft Excel and statistical analysis performed using the GraphPad InStat3 program, which was downloaded off the internet. Two by two contingency tables were constructed for categorical variables, comparing each categorical variable with attendance at follow up appointment. Categorical data were analysed using Fisher's exact test in order to obtain a *p*-value for statistical significance. Fisher's exact test was used as the sample size was small and the chi squared test would have generated incorrect *p*-values. Continuous variables were described using means and standard deviations, and statistical significance was calculated using the unpaired t-Test for the "age" variable, and the Mann-Whitney test for the three non-parametric continuous variables. A significance level of 5% was used for all tests. Variables were grouped for analysis in the categories "marital status", "psychiatric diagnosis" and "disclosure of HIV" status due to the small number in each specific sub-category.

3.6 Postgraduate Committee and Ethics Committee Approval

The study was submitted to the University of the Witwatersrand's Human Research Ethics Committee (HREC), and approval was granted unconditionally. Due to the retrospective nature of the study direct informed consent was not necessary. The names and personal identifying details of all the patients in the study remain anonymous and were not recorded on the data sheets.

Permission from the head of the Department of Psychiatry at CHBAH and the management at CHBAH was obtained to conduct research and access the Medicom database of the wards and at Luthando Clinic.

Postgraduate research committee approval of the initial research protocol was obtained and all corrections to the initial research proposal were reviewed by the research supervisor and approved by the Postgraduate research committee. The Post graduate research committee also recommended a change of title, which was subsequently submitted and approved.

CHAPTER FOUR: RESULTS

4.1 Sample Characteristics

Of the 388 new patients seen at the clinic from 1 July 2009 to 31 December 2010, 155 were in-patients at the time of the first clinic appointment, and of that number 131 were initiated on ART as in-patients. The 24 in-patients who were not initiated on ART as in-patients were not eligible for inclusion in the study: two patients refused ART, and had capacity to make that decision; two patients were found to be HIV negative and had been inappropriately referred to the clinic; one patient had a high CD4 count and so did not qualify for ART initiation; a further 19 patients were not initiated on ART whilst admitted to hospital, but rather discharged with a plan to initiate ART as out-patients.

Of the 131 patients initiated on ART as in-patients, 33 were excluded from further analysis: one patient was transferred to another hospital and not discharged from CHBAH directly; five patients were discharged to follow up at a community clinic or in a separate province; 22 patients had been initiated on ART elsewhere and were subsequently admitted, or had defaulted treatment and were admitted, and were thus recommenced on treatment whilst admitted; four patients were also excluded as they were lost to follow up whilst in hospital after transfer to the medical department for further management and were therefore not discharged with a Luthando appointment; and one patient was transferred to a Life Esidemeni placement facility with no recorded follow up appointment scheduled.

The final sample consisted of 98 HIV positive, ART naïve patients, presenting with psychiatric symptoms, admitted to hospital and initiated on ART whilst in hospital, then subsequently discharged to follow up at the Luthando clinic as out-patients. (Fig 4.1)

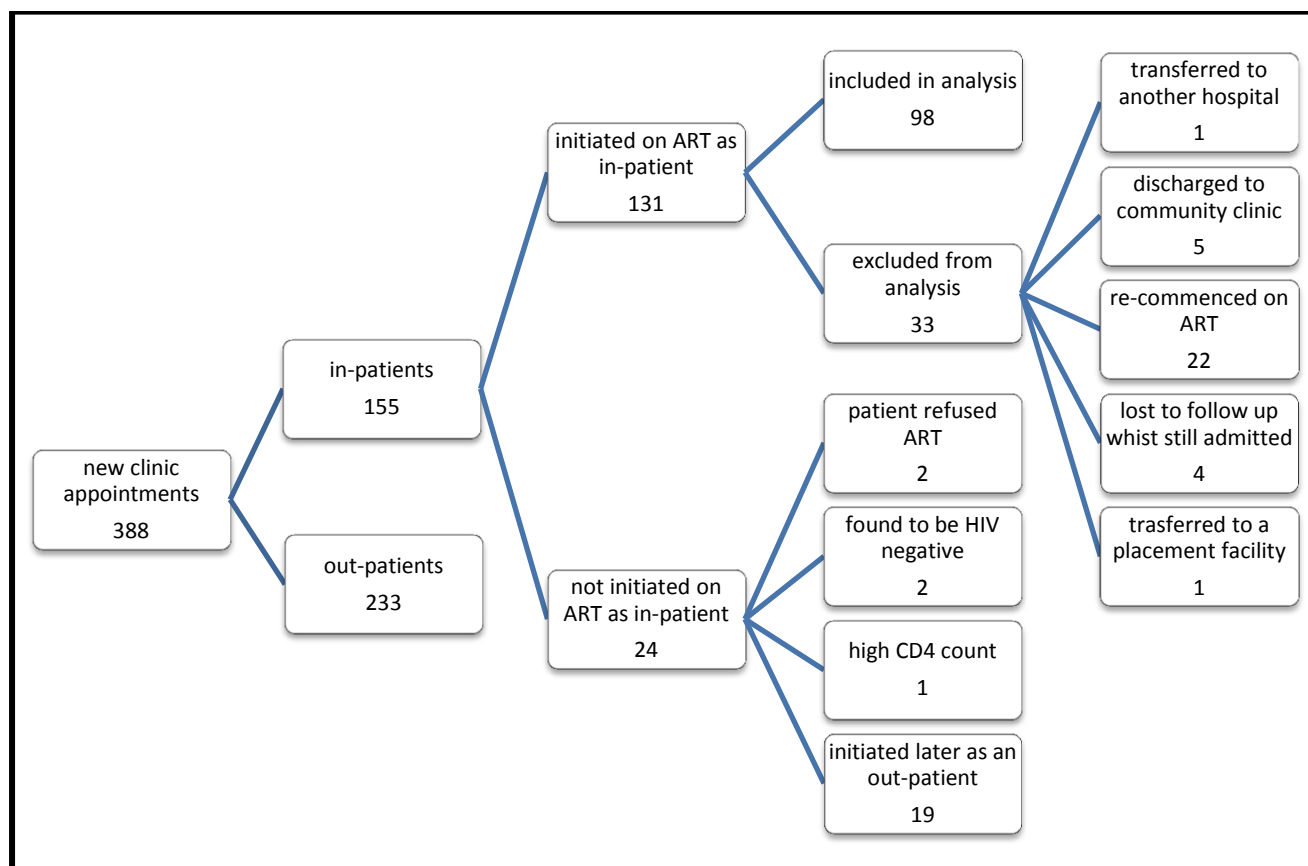


Figure 4.1 Flow chart outlining all new patient clinic appointments at the Luthando Neuropsychiatric clinic for the period 1 July 2009 – 31 December 2010

4.1.1 Demographic data of the sample

Of the total sample of 98, the majority of the patients were female (76.53%) ($n = 75$). The mean age \pm standard deviation of the sample was 34.85 ± 8.89 years, with males being slightly older than females (37.07 ± 10.55 years vs. 34.04 ± 8.23 years) (unpaired t test, $t = 1.63$, 96 d.f., $p = 0.11$). The oldest patient was 62, and the youngest 18 years old.

Most of the sample were unemployed, accounting for 88.78% ($n = 87$) of the sample. However, only 23.47% ($n = 23$) of the sample were on a disability grant. The majority (66.36%) ($n = 65$) of the sample were single, with 28.57% ($n = 28$) being married or having a life partner, and thus described as being in a current relationship. The mean \pm standard deviation for the number of years of schooling for the sample was 9.76 ± 2.49 years. There were three patients with a tertiary level of education. Of the total sample, 62.24% lived within 15km of the clinic.

4.2 Rate of Attendance

The rate of attendance was 79.59% ($n = 78$), including full attendance and partial attendance on follow up appointment date. The rate of partial appointment attendance (attending within one month of appointment) was 26.53% of the total sample ($n = 26$) and full attendance was 53.06% ($n = 52$). Non-attendance was recorded in 20.41% of the total sample ($n = 20$) (fig 4.2)

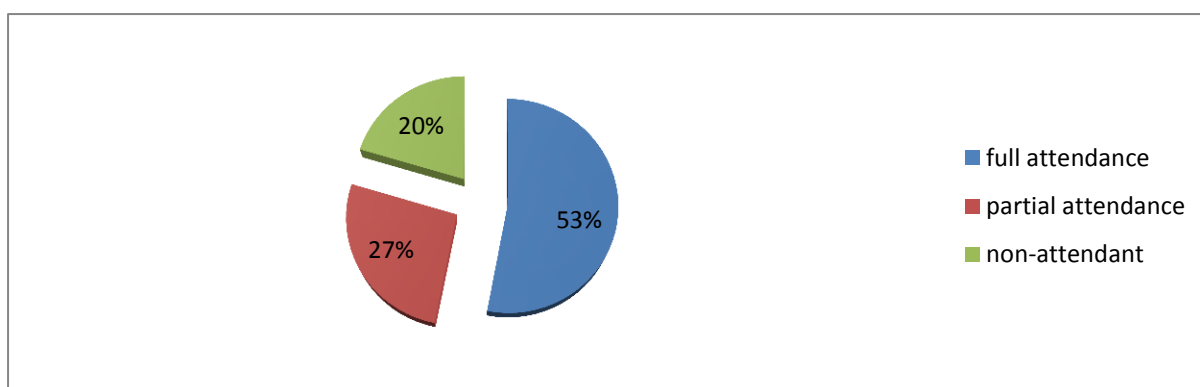


Figure 4.2 Rate of attendance

4.3 Comparison of Data: Attendant vs. Non-Attendant Groups

The comparison between the two groups, attendant vs. non-attendant revealed that the groups were fairly similar in terms of demographic data and clinical data. The groups did not differ significantly, in terms of gender, employment status, disability grant, poly-therapy/mono-therapy, stage of HIV diagnosis, length of hospitalisation as well as time from discharge to follow up appointment. Both groups were predominantly female (Fisher's exact, RR 1.12, 95% CI 0.81-1.52, $p = 0.55$), unemployed (Fisher's exact, RR 1.15, 95% CI 0.27-4.93, $p = 1$) and not on a disability grant (Fisher's exact, RR 0.74, 96% CI 0.33-1.62, $p = 0.56$). Most of the patients in each group had WHO stage four illness (Fisher's exact, RR 0.97, 95% CI 0.76-1.25, $p = 1$). There was also no difference in patients prescribed mono-therapy vs. poly-therapy psychotropic medication (Fisher's exact, RR 1.14, 95% CI 0.93-1.39, $p = 0.31$). (Table 4.1)

The (n) values are stated in table 4.1 and where they differ from the total number of attendant and non-attendant, the difference can be accounted for by missing data. All (n) values have been clearly stated exactly as they were used for statistical analysis.

Table 4.1 Comparison of demographic and clinical data of attendant vs. non-attendant groups

Data	Attendant (n=78)	%	Non-attendant (n=20)	%	p-value
Age (years)- mean \pm SD	35.65 \pm 9.04		31.7 \pm 7.7		0.08 ^b
Female	61	78.21%	14	70.00%	0.55
Unemployed	69	88%	18	90%	1.00
Disability grant	17 (n=77)	22.08%	6	30%	0.56
School Education (years) – mean \pm SD	9.51 \pm 2.65 (n=64)		10.8 \pm 1.21 (n=15)		0.08 ^a
Poly-therapy	42 (n=77)	54.54%	14	70%	0.31
Substance use history	16 (n=72)	22.22%	7 (n=16)	43.75%	0.11
HIV status not disclosed	6 (n=40)	15%	6 (n=11)	54.55%	0.01 [*]
WHO stage four	49	71.01% (n=69)	13	68.42% (n=19)	1.00
Current partner	26	33.33%	2	10%	0.05
Length of hospitalisation (days) –mean \pm SD	37.95 \pm 23.75		40.4 \pm 20.9		0.42 ^a
Time from discharge to follow up (days)- mean \pm SD	14.86 \pm 8.53		13 \pm 6.88		0.45 ^a

p-values calculated using Fisher's exact unless otherwise stated; a= Mann-Whitney test; b=unpaired t-test; * =significant.

4.3.1 Psychiatric diagnosis

Completion of data on psychiatric diagnosis was complicated by the presence of differential diagnosis in 51% of the sample. It was not clearly stated in any of these files which diagnosis the clinician considered to be the most likely of the differential diagnosis. Only 49% of the sample was labelled with one clear diagnosis, while 36.72% were given two differential

diagnoses, and 14.28% had three differential diagnoses stated. The average number of diagnoses/patient was 1.65. There were no differences between the two groups in terms of being given only one vs. more than one diagnosis. (Fisher's exact, RR 0.99, 95% CI 0.81-1.21, $p = 1$) The average number of differential diagnosis in the attendant group was 1.30 diagnoses/person, compared to 1.75 diagnoses/person in the non-attendant group.

The most common differential diagnosis overall was psychotic disorder due to HIV (68 patients), followed by mood disorder due to HIV (31 patients), followed by bipolar disorder (not specified I or II) (20 patients). In the 49% labelled with only one diagnosis, the most common diagnosis was still psychotic disorder due to HIV (19 patients), however, the second most common diagnosis was bipolar disorder (14 patients) followed by schizophrenia and major depressive disorder (five patients). The most common diagnosis in both groups, attendant and non-attendant, was psychotic disorder due to HIV. There was no difference between the two groups in terms of differential diagnosis when divided into two categories; "Primary psychiatric diagnosis" and "Psychiatric diagnosis due to general medical condition (HIV or medical illness). (Fischer's exact, RR 0.88, 95% CI 0.72-1.07, $p = 0.21$). The data was analysed in two categories as there were a number of small values in the specific diagnosis categories which made a statistical analysis invalid. The distribution of diagnoses is shown in table 4.2.

Table 4.2 Outline of attendant vs. non-attendant groups by psychiatric diagnosis

Diagnosis		Total	%	Attendant	%	Non-attendant	%
Primary Psychiatric diagnosis		49	30.25%	35	27.56%	14	40%
	<i>Schizophrenia</i>	8	4.94%	5	3.94%	3	8.57%
	<i>Schizoaffective disorder</i>	1	0.62%	0	0	1	2.86%
	<i>Bipolar disorder</i>	20	12.34%	15	11.81%	5	14.29%
	<i>Major depressive disorder</i>	9	5.56%	8	6.30%	1	2.86%
	<i>Substance induced Psychotic disorder</i>	11	6.79%	7	5.51%	4	11.43%
Psychiatric diagnosis due to HIV /medical illness		113	69.75%	92	72.44%	21	60%
	<i>HIV associated neurocognitive disorder</i>	7	4.32%	5	3.94%	2	5.71%
	<i>Psychotic Disorder Due to GMC-HIV</i>	68	41.98%	55	43.31%	13	37.14%
	<i>Psychotic Disorder Due to GMC-other</i>	7	4.32%	6	4.72%	1	2.86%
	<i>Mood disorder due to GMC-HIV</i>	31	19.14%	26	20.47%	5	14.29%
Total		162		127		35	

4.3.2 IHDS score

The variable which was missing most often on review of the files was the IHDS score. In those with recorded IHDS score, there was no difference between attendant and non-attendant (Fisher's exact, RR 0.91, 95% CI 0.57-1.45, $p = 1$). Towards the end of the period under review, the IHDS score was being routinely recorded in the Luthando file, but prior to

this, was recorded only if the clinician felt it was significant with regards to current management issues. The IHDS score was missing in 77.56% of the total sample. (Table 4.3)

Table 4.3 Comparison of IHDS score in attendant vs. non-attendant groups

IHDS score	Attendant (n=19)	Non-attendant (n=3)	<i>p</i> value (Fischer's exact)
<10	4	1	<i>p</i> =1
>9	15	2	

4.3.3 Age

The mean age of the attendant group (35.65 ± 9.04) was slightly older than the non-attendant group (31.7 ± 7.7) although not significant (Unpaired t test, $t = 1.79$, 96 d.f., $p = 0.08$).

4.3.4 Level of education

The non-attendant group (mean $10.80 \pm$ SD 1.21) had a higher mean level of school education than the attendant group (mean $9.51 \pm$ SD 2.56) (Mann-Whitney, $p = 0.08$) (Table 4.1) There were only three patients in the entire sample with a tertiary level of education, one attendant ($n = 69$) and two non-attendant ($n = 16$) (Fisher's exact, RR 2.49, 95% CI 0.50-12.37, $p = 0.09$)

4.3.5 Substance use history

A history of substance use was recorded in 23.47% of the overall sample. In 10.20% of files reviewed, a substance use history had not been documented by any of the treating clinicians, suggesting there had been no enquiry into substance use during hospitalization in these patients. A history of substance use was more common in the non-attendant group (43.75%) vs. the attendant group (22.22%) although not significant (Fisher's exact, RR1.24, 95% CI 0.93-1.65, $p = 0.11$). (Fig 4.3)

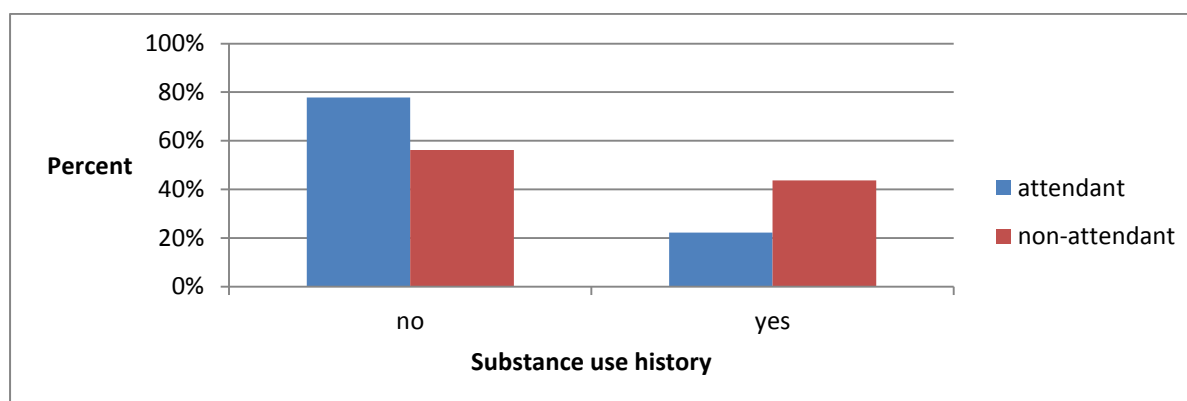


Figure 4.3 Percentage of attendant (n=72) vs. non-attendant (n=16) patients with a history of substance use ($p = 0.11$)

4.3.6 Disclosure of HIV status

The only factor in the bivariate analysis that was statistically significant was disclosure of HIV status (Fisher's exact, RR 0.28, 95% CI 0.11-0.69, $p = 0.01$). This category was recorded as "disclosed" if the patient's treatment supporter was aware of the HIV diagnosis. The category "disclosure of HIV status" relied on an additional note from the treating clinician stating of the patient had disclosed their HIV status to the treatment supporter. Each

patient had a documented treatment supporter in order to be considered for ART. However, it was not mandatory that the treatment supporter knew the details of the “treatment” and the “diagnosis”. In certain files it was clearly stated “not disclosed” and in others, “disclosed to...” However in 47.96% of the sample, it was not stated clearly if the diagnosis had been disclosed to the treatment supporter. (48% of attendant vs. 45% of non-attendant patients). The remainder of the files specified “disclosed” vs. “non-disclosed” next to the name of the treatment supporter, indicating that the treatment supporter was aware of the HIV diagnosis. Significantly fewer of the non-attendant group (15%) had disclosed their HIV positive status to the treatment supporter than the attendant group (54.55%).

Within the category “disclosure”, data was further divided into sub-categories based on who the patient had disclosed their HIV status to, family or friend. (Fig 4.4). There was no significant difference between the two groups in terms of disclosure to friend or family. (Fisher’s exact, RR 1.78, 95% CI 0.44-7.17, $p = 0.24$)

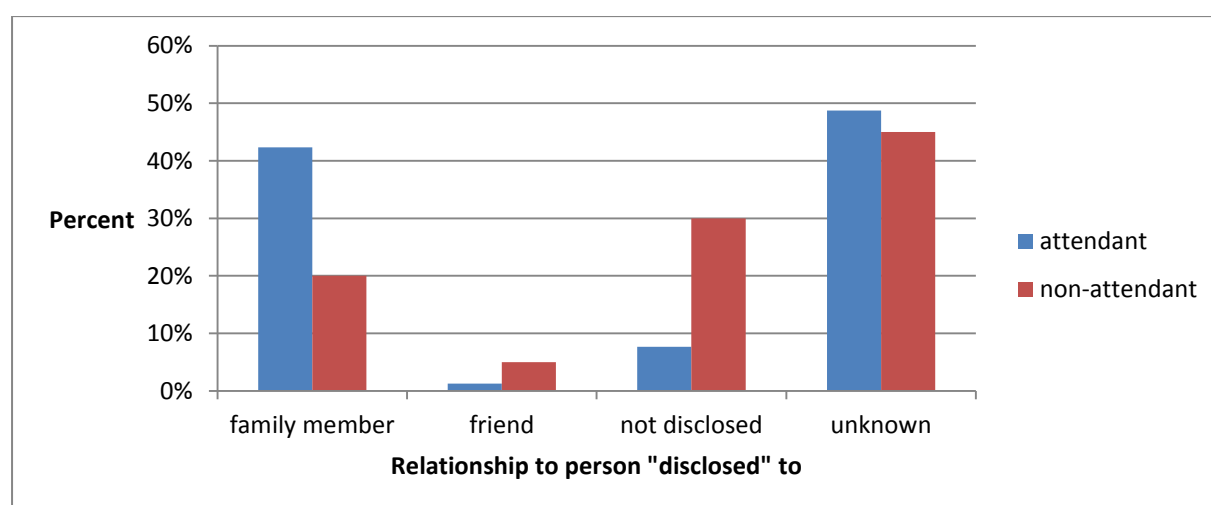


Figure 4.4 Percentage of attendant vs. non-attendant patients who had disclosed HIV seropositive status to friend or family

4.3.7 Marital status

The data collected with regard to Marital status was grouped for analysis into two groups, “Current Partner”, including the patients who were married or had a life partner, and “No Current Partner”, which consisted of patients who were single, or widowed, or divorced. Less non-attendant patients had a current partner (10%) than attendant patients (33.33%), although not statistically significant (Fisher’s exact, RR 3.33, 95% CI 0.86-12.89, $p = 0.05$). Data was grouped for final analysis as the numbers were too small to perform a valid analysis on each subcategory independently. (Table 4.4)

There was no association between being in a current relationship and disclosure of HIV status. (Fisher’s exact, RR 0.99, 95% CI 0.67-1.41, $p = 1$)

Table 4.4 Comparison of marital status in attendant vs. non-attendant groups

Marital status	Attendant (n=78)	%	Non-attendant (n=20)	%
Divorced/widowed	4	5.13%	1	5%
life partner	6	7.69%	1	5%
Married	20	25.64%	1	5%
Single	48	61.53%	17	85%

4.3.8 Length of hospitalisation

The average length of hospitalisation was 39.89 days. There was no significant difference in the length of admission to hospital between attendant (mean $37.95 \pm \text{SD } 23.75$) and non-attendant groups (mean $40.40 \pm \text{SD } 20.90$). (Mann-Whitney test, $p = 0.42$) The maximum length of stay in the attendant group was 93 days vs. 127 days in the non-attendant group. (Table 4.1)

4.3.9 Time from discharge to follow up appointment

There was no significant difference between the attendant (mean $14.86 \pm \text{SD } 8.53$) and non-attendant groups (mean $13 \pm \text{SD } 6.88$) in terms of time from discharge to follow up appointment date. (Mann-Whitney test, $p = 0.45$) (Table 4.1) The average length of time from discharge to follow up appointment date was 14.48 days, indicating that on average, patients were scheduled for a follow up appointment approximately two weeks after discharge from hospital.

4.3.10 Distance from clinic

There was no significant difference between attendant and non-attendant patients in a grouped analysis of those living within 10km of the clinic. (Fisher's exact, RR 1.58, 95% CI 0.66-3.78, $p = 0.37$) (Table 4.5)

Table 4.5 Comparison of distance from clinic in attendant vs. non attendant groups

Distance	Attendant (n=62)	%	Non attendant (n=14)	%	Fisher's exact
< 10 km	34	54.84%	10	71.43%	<i>P</i> = 0.37
≥ 10 Km	28	45.16%	4	28.57%	

4.4 Summary of Results

The rate of attendance for the sample at the clinic post discharge from hospital was 79.59%.

The sample was predominantly female. There were a number of similarities between the attendant and non-attendant groups in terms of demographic and clinical data. The only statistically significant variable was disclosure of HIV status, and attenders were significantly more likely to have disclosed their HIV status to the treatment supporter.

CHAPTER FIVE: DISCUSSION

5.1 Rate of Attendance

The rate of attendance at the first clinic appointment post discharge from hospital was 79.59%. The reason for non-attendance (20.41%) was not ascertained in this study, and most likely included those that had discontinued ART treatment, were too unwell to return for follow up appointments, moved to a different area and therefore changed clinics, as well as those that died within the time from discharge to follow up appointment (2,37,38,39). To my knowledge, there are no similar figures for attendance at other neuropsychiatric clinics after in-patient initiation of ART, following psychiatric hospitalisation with which to compare this rate from South African or international data. A possible explanation for the lack of similar data, representing HIV positive psychiatrically unwell patients is the nature of the Luthando Neuropsychiatric clinic, in that it provides a unique combination of in-patient and out-patient treatment for HIV as well as psychiatric treatment.

International studies examining first clinic appointment attendance post discharge from psychiatric hospitalisation have not been consistent, with figures of attendance varying from 82% to 36% in studies conducted in the USA (43,44). The rate of attendance in the current study fell within this large range. Crompton *et al* (44) commented that their exceptionally high rate of non-attendance was out of keeping with previous similar studies, but not out of keeping with what they expected in their clinical setting based on prior observation. They suggested several reasons for their high rate of non-attendance including the severity of psychiatric presentations and high rates of unemployment in their sample (44). In the current study, in addition to the psychiatric presentation it is important to remember the significance

of the HIV diagnosis with regards to outcome after hospitalisation. HIV positive patients may be physically more unwell than the general psychiatric patient described in the studies by Kruse *et al* (43) and Crompton *et al* (44), which might impact on attendance.

Boyles *et al* (1), in their study examining an ART initiation program designed for a low resource setting in the Eastern Cape, estimated their four year loss to follow up rate at 11.4%. They suggested that this represents a low rate of loss to follow up and might have been the result of some of the strengths of their program, including integrated in-patient care (1). Boyes *et al* (1) found a higher rate of LTFU specifically after in-patient initiation on ART as well as in pregnant women, and suggested three possible reasons for this finding. Firstly, they suggested the possibility that a decreased time before initiation of treatment and a decreased number of preparation sessions could be associated with high rates of LTFU (1). Time from diagnosis to initiation of ART was not examined in the current study, but it is possible that some patients had a longer pre-initiation period, with more extensive pre-initiation adherence counselling. Secondly, Boyes *et al* (1) suggested that patients who present with HIV due to illness and not because of a concern regarding exposure may be more likely to be LTFU. They support this hypothesis by referencing Maqutu *et al* (60) who found an increased rate of “optimal adherence” in those patients who presented for HIV testing due to feared exposure compared to those who were tested because they were unwell (1). There may be links between illness awareness, insight into risk of infection, insight into need for treatment and subsequent adherence to treatment (60). This may have been a relevant factor influencing the rate of attendance in the current study as all the patients presented primarily with a psychiatric diagnosis and not for HIV testing due to feared exposure. It is possible that hospitalization due to a psychiatric presentation may suggest that a patient’s primary focus was not on HIV testing and need for ART treatment, which may impact on attendance and

subsequent adherence. Thirdly, Boyes *et al* (1) postulated that peri-partum depression may have accounted for some of the increased rate of LTFU in the pregnant group. Boyes *et al* (1) quoted several previous studies which have linked depression to non-adherence to ART, and postulated that there might have been a possible high overall prevalence of post-partum depression in their study, in the pregnant group. Notably, it does not seem that depression was screened for in their study, and no comment on the level of peri-partum depression was reported, thus this direct link was not supported by the data presented in the article reviewed (1). However, there is some evidence linking depression to non-adherence and non-attendance in the literature and this will be discussed separately (3,5,7,25,26). Although there was a female predominance overall in the current study, and depression was independently examined as a possible association with attendance, it was not recorded if a patient presented in the peri-partum period and thus no link was investigated between peri-partum depression and attendance.

Eshun-Wilson *et al* (2) found a higher rate of loss to follow up, over a 6 month period of 35% in their case control sample of HIV positive patients, hospitalised for a medical illness, initiated on ART in South Africa. They hypothesised that this high rate of LTFU might have in part been due to death, and suggested that unrecorded death accounts for a significant proportion of patients classified as lost to follow up in HIV treatment centres (2). They found that hospitalised patients initiated on ART were more likely to die or be lost to follow up than out-patient controls. They defined loss to follow up for their study as failure to return to clinic for a period of three months or more. Their study was limited by a small sample size (2). It is possible that the current study sample was not as medically unwell as the sample in the study by Eshun-Wilson *et al* (2), as in general, frail medically unwell patients are not admitted to the psychiatric wards at CHBAH, although, medical co-morbidity was not recorded in this

study. It should also be noted that four medically unwell patients who were initially admitted to the psychiatric wards and attended the Luthando clinic for ART assessment, subsequently deteriorated physically and were transferred to a general medical ward and lost to follow up and excluded from analysis. (Fig 4.1) It is therefore possible that the incidence of death in the first month post discharge from hospital in the current study population might have been lower than that recorded in general HIV clinics if patients LTFU were traced to determine reason for LTFU.

5.2 Gender

There was no significant difference between the attendant and non-attendant groups in terms of gender, however the majority of the sample were female (76.53%), with a ratio of female to male in the sample of 3.3. The mid-year South Africa national statistics for 2011 (61) estimated a female to male HIV prevalence ratio at 1.5 in South Africans between the ages of 15-49. The ratio found in this study was notably greater than the estimated ratio for the population of South Africa. The reason for the female predominance in this study is unclear; however other studies at ART centres in South Africa have found a female predominance ranging from 62.8% to 71% in similar regions within South Africa (45,62). This is in contrast to a previous report from a random sample of psychiatric admissions at CHBAH in 1996, where there was a distinct male predominance with females only representing 35.6% of the sample (63).

In their review article, Akerman and de Klerk (64) outlined the variables thought to play an important role in increasing the risk of HIV infection in females in the South African context.

These factors include biological factors, related to the female anatomy, as well as a number of psycho-social factors which have been shown to impact rates of transmission and vulnerability to HIV infection (64). With regards to societal factors, in a technical report to the Australian agency for international development, Dunkle *et al* (65) investigated rates of “gender based violence” among women attending an antenatal clinic in Soweto. The authors suggested a link between exposure to gender based violence and HIV infection in women (65). The study found high rates of reported physical abuse (50.4%) and sexual abuse (20.1%) among respondents, with 55.5% of respondents reporting a lifetime history of physical or sexual assault by a male partner (65). Furthermore they found an association between partner violence, perception of control in a relationship and HIV status (65). Dunkle *et al* (65) made reference to a review article by Campbell *et al* (66) examining “intimate partner violence” and HIV infection. In this review, Campbell *et al* (66) summarised factors thought to play a role in the link between gender based violence and increased susceptibility to HIV infection; firstly, the biology around forced sex, with “traumatic penetration” further increasing the risk of transmission to females, secondly, the influence of violence towards women on sexual decision making, such as safe sex practices like condom usage; thirdly, an association between sexual abuse and subsequent high risk sexual behaviour increasing risk of HIV infection including substance use; and fourthly, the long term effect of chronic abuse on physical and psychological well-being possibly increasing susceptibility to HIV infection, citing high levels of depression and anxiety among those exposed to chronic gender based violence (65,66,67). High rates of “transactional sex” may also increase female vulnerability to HIV infection in Soweto, and thus might have influenced the predominantly female presentation in the current study (67).

In a review of the issues around mental illness in people living with HIV/AIDS, Brandt (68) suggested an increase in risk for psychiatric conditions in females with HIV, compared to males with HIV, which may have played a role in the female predominance in the current study. Brandt (68), however, did not explore the reasons for this discrepancy.

It is also possible that in general there may be fewer men who agree to test for HIV. Venkatesh *et al* (69) reported that 64.8% of women compared with 28.9% of men in a sample surveyed in Soweto had ever been tested for HIV. Similarly, Mhlongo *et al* (70) found that 71% of men in a cross sectional sample in Soweto had never tested for HIV. It is possible that fewer men in the psychiatric wards are referred for, or agree to, HIV testing at CHBAH. This might have played a role in the female predominance noted in the current study.

5.3 Employment

There was a high rate of unemployment in the sample with 88% of the sample being unemployed. This rate was much higher than previously reported unemployment rates in non-psychiatric ART roll out sites in Soweto of 41% (62). However, the rate of unemployment was closer to that reported for a psychiatric population in Soweto of 93%, with rates of employment previously found to be 17.8% in psychiatric admissions at CHBAH (63,71). The unemployment rate in Soweto was estimated by the Soweto Development Plan to be around 53% (72). It is possible that the psychiatric diagnosis in the sample impacted on ability to sustain employment.

Only 23% of the sample had access to a disability grant, suggesting the possibility of financial barriers to attendance in a significant proportion of the sample. This was slightly higher than a previous report of disability grant access in psychiatric admissions at CHBAH of 17.8% in 1996 (63). Although there was no significant difference in unemployment rates or disability grant status between attendant and non-attendant groups, the high rate of unemployment overall and possible resultant financial constraints might still impact on outcome, as has been previously suggested, and should be investigated at each clinic visit (73).

5.4 Disclosure of HIV Status

The only significant difference between the attendant and non-attendant groups was disclosure of HIV status, with non-attendance being associated with non-disclosure of HIV status. It was a requirement prior to initiation of ART that patients had a treatment supporter, and the intake history sheet contained the name of a treatment supporter. It was not standard however that the treatment supporter was aware of the diagnosis at the time of initiation of ART. The finding in this study that disclosure of HIV status is significantly associated with clinic attendance is consistent with the findings in several previous African studies examining adherence to ART (7,33,34).

It has been recommended that patients should have disclosed to one significant friend or family member or joined a support group prior to initiation of ART (27). The Luthando clinic has several support groups running and patients are actively encouraged to attend support

groups and adherence counselling sessions prior to initiation of ART. Consequently disclosure is not always insisted on by the treating team.

Reasons for non-disclosure were not examined in this study, but have been previously extensively studied. A qualitative South African study in 2006 investigated patient and provider perceptions of support strategies influencing ART adherence, with participants recognising stigma related to disclosure of HIV status as a significant barrier to adherence (27). Key concepts which emerged from the patients in the qualitative South African study included concepts around safe disclosure. Participants felt safe disclosing to someone ““who will not reject you”, “will not discriminate against you”, will “help you cope with the disease” and will help “take HIV medication at the right times””. (27, p.130). Other patients mentioned fear of being “outed” to the community as being HIV positive by the person disclosed to as a reason for non-disclosure (27). Furthermore, gender based violence and subsequent disempowerment of women may influence behaviour related to disclosure of HIV status among women in Soweto (65,66).

Calin *et al* (28) examined disclosure among HIV positive black African patients in London. Disclosure was prompted by a close trusting relationship, associated with the belief that there would be a supportive outcome (28). The most common reason for non-disclosure was ““not wanting to cause worry”” (28, p.388) followed by the idea that the diagnosis would be seen as a death sentence by those disclosed to. Interestingly, the mostly immigrant population cited commonly held beliefs around being HIV positive in Africa as a reason for non-disclosure, with one participant stating ““if you live at home, you are dead already””. (28,

p.388). There was also a fear of rejection, and a fear that the person they disclosed to would tell others (28).

The patients in the current study not only had the stigma associated with HIV infection to bear, but also that of having a “mental illness” diagnosis. Therefore, rates of non-disclosure would have been expected to have been higher in this population than in a general HIV infected sample. Stigma has been reported extensively in psychiatric populations (31,32). Although to my knowledge there are no studies examining disclosure of psychiatric diagnosis by patient to family or friends and relationship to adherence, stigma regarding psychiatric illness may influence an individual decision to disclose a psychiatric diagnosis. Subsequent lack of support and encouragement may influence clinic attendance.

It seems from previous research that disclosure of HIV status, if not met by rejection, serves the purpose of providing the patient with emotional and physical support, as well as someone to remind the patient to attend the clinic and to encourage adherence to the treatment regime (27). It is therefore important that non-disclosure of HIV status proved to be the only significant association with non-attendance at clinic.

5.5 Marital Status

Overall, the majority of the sample was currently single, with only 28.57% of the sample being in a current relationship. This was in keeping with previously reported figures from a selection of Psychiatric clinics in Soweto of 21.6% (71).

There were a larger percentage of attendant patients who were in a current relationship than non-attendant patients although this was not quite significant. There was no statistical association between being in a current relationship and disclosure of HIV status in the current study, but this may have been influenced by the small sample size. The previously described link between being in a current relationship and improved attendance may be related to the level of support, rather than being in a relationship, based on findings in previous studies (50,51). Bofill *et al* (50) found poor attendance at psychiatric out-patient clinics to be associated with limited family support. Similarly, in HIV clinic attendance, Catz *et al* (51) found non-attendance to be associated with lower perceived social support.

5.6 Substance Use

Although a history of substance use was more common in the non-attendant group this finding was not statistically significant. The current study did not look at substance use in detail in terms of which drugs were being used. There was also no objective evidence for substance use, and the study relied on a self-report history of substance use. Self report may lead to lower estimates of substance use within the sample due to patients wanting to impress clinicians with reports of abstinence (5). Overall, substance use was recorded in 23.5% of patients. In her review of the mental health of people living with HIV in Africa, Brandt (68) suggested that 7-16% of HIV positive patients in the research reviewed either abused or were dependent on substances, including alcohol. The South African Stress and Health study found a lifetime prevalence of substance use disorders in Gauteng of 13.3%, but 38.7% of people surveyed overall reported alcohol use (74,75). Furthermore, in a study of Psychiatric

admissions to Stikland hospital in the Western Cape, 51% of admissions were diagnosed with a co-morbid substance use disorder (76). In the current study, it is interesting to note that in addition to a low rate of substance use reported, a substance use history was not obtained at all in 10.2% of patient's records. This may suggest that not all clinicians view substance use as a potential problem worth screening for in the HIV positive psychiatric patient and are thus potentially under-diagnosing substance use disorders. This is especially significant as previously it has been shown that current substance abuse is associated with poorer adherence to ART and thus poorer overall long-term outcome (5,77).

5.7 Age

The attendant group were slightly older than the non-attendant group although not statistically significant. Previously, older age was found to be associated with ART clinic attendance (50,51). Catz *et al* (51) hypothesised that non-attendance and age may be related because of inexperience or lack of previous medical contact, as well as a feeling of invulnerability to death.

5.8 Education Level

The current study showed a non-significant, slightly higher mean level of school education in the non-attendant group. This is out of keeping with what has been found in previous studies, showing lower levels of education in non-adherent patients in ART treatment settings, as well as lower "health literacy" levels (78). Lower health literacy was also previously associated

with fewer years of education (78). The significance of education level in this study may have been limited by the small sample size.

5.9 Psychiatric Diagnosis

Previous literature has shown a significant association between poor adherence and depression, bipolar disorder and HAND (3,4,5,7,8). It was hypothesised that there would be an association between these diagnoses and poor attendance. However, it was not possible to demonstrate any associations with individual psychiatric conditions and adherence in the current study due to the small numbers involved in each psychiatric condition, particularly in the non-attendant group. Overall there were a high proportion of patients with a psychotic presentation with relatively fewer patients overall diagnosed with a major depressive episode. A possible explanation of this finding is the bias created by selecting hospitalized psychiatric patients for the study, which would already suggest a psychiatric presentation which is severe enough to warrant hospitalisation. A report on psychiatric admissions to CHBAH in 1996, which was before the national “roll-out” of antiretroviral therapy, suggested the most common diagnoses in their sample were schizophrenia and bipolar disorder (63). In their study, Behr *et al* (63) found 48.3% of patients presented with a psychotic illness namely schizophrenia or “other psychotic disorder”, with only 7.8% presenting with a major depressive episode. It should be noted that in 1996, psychotic disorder due to HIV was an emerging concept and did not appear among the listed diagnoses of their sample.

As the IHDS score was not routinely performed in this sample, it is possible that screening for HAND may not have been adequate, thus underestimating the prevalence of HAND in the

sample, and possibly influencing the findings in terms of lack of association of HAND with attendance.

5.10 Length of Admission and Time from Discharge to Follow-up Appointment

The average length of stay was 39.89 days, which is similar to the finding by Behr *et al* (63) of an average length of admission to a psychiatric ward at CHBAH in 1996 at 37 days. In 1996 however, the impact of HIV on psychiatric admissions was yet to be seen, and it is not clear what the average length of admission was in a psychiatric ward at CHBAH in 2009/2010. There was no difference between attendant and non-attendant groups in terms of length of admission. This was in contrast to the finding by Crompton *et al* (44) in their psychiatric population followed up after psychiatric hospitalisation, where a shorter duration of hospitalisation was associated with non-attendance.

The mean time from discharge to follow up appointment was 14.48 days. There was no difference between attendant and non-attendant groups. Kruse *et al* (43) found that patients were more likely to attend appointments scheduled within two weeks after psychiatric hospitalisation. Similarly, Crompton *et al* (44) found that non-attendant psychiatric out-patients had a longer mean time from hospital discharge to follow up appointment.

5.11 Distance to the Clinic

Although there was no reported difference between attendant and non-attendant groups in terms of distance to the clinic, Adulefosi *et al* (73) previously found that a higher proportion of schizophrenic patients who missed clinic appointments in Nigeria lived more than 20km away from the clinic. In a first world setting, reliance on public transport and lack of transportation to the clinic impacted on clinic attendance (37,56). One possible explanation as to why the current study found no association between distance from the clinic and attendance could have been that the majority of the sample (62.24%) actually lived within 15km of the clinic. However, there is mixed evidence that distance from the clinic is important in attendance. Eschun-Wilson *et al* (2) found no association between distance from the clinic and subsequent risk of loss to follow up.

5.12 Limitations

Although nearly 400 files were reviewed, only 98 were relevant for the current study. This figure was smaller than expected, and the percentage of non-attendant patients was even smaller. The small size of the non-attendant group provided difficulty in terms of the size of the sample and statistical analysis. Several variables might have possibly been significant in line with previous studies given a larger sample size

Due to the retrospective nature of this study, completeness of data was dependent on physician record keeping at the time of initial contact with the patient. Several variables proved to be poorly recorded in the Luthando, CHBAH as well as out-patient psychiatric

files. The most noticeable of these was the data on IHDS score, which was missing in 77.56% of the sample. From review of the files, it seems that IHDS score was only recorded if a physician felt that there was neurocognitive impairment. However, this has possibly lead to an underestimation of neuro-cognitive deficits in the sample group. Towards the end of the study period, IHDS score was being routinely recorded.

There were also no objective tools used to make psychiatric diagnosis, or to diagnose substance abuse, and the data was purely recorded from clinician's notes reporting substance use, or clinical diagnosis which was felt by the treating doctor to be most likely. Most patients had a differential diagnosis. It seems that clinicians were reluctant to commit to one diagnosis based on the clinical presentation. This made it difficult to compare groups based on psychiatric diagnosis. In terms of substance abuse, self-report may not be reliable, especially if current abuse may influence the clinician's decision to initiate ART and the patient is aware of this (5). Also, details regarding substance use were not recorded for this study, including duration of substance use, type of substance, route of administration, previous rehabilitation or impact on social and occupational function.

There was no control group in this study with which to compare rate of attendance. This made it impossible to comment if the rate of attendance was high, low or average. There are no studies examining rates of out-patient clinic attendance in HIV positive mentally ill patients with which to compare the rates found in the current study.

However, taking into account financial and time constraints, this research report provided vital information with regards to the demographic profile of the psychiatric in-patients initiated on ART, highlighting high unemployment levels and suggesting a female predominance. The study has also highlighted system difficulties, reinforced the need for meticulous record keeping and brings to the fore potential targets for improvement in daily operations at the clinic, including treatment supporter interventions aimed at improving clinic attendance.

CHAPTER SIX: CONCLUSION

HIV positive mentally ill patients initiated on ART as in-patients are capable of returning for out-patient follow up and continued out-patient ART. Non-disclosure of HIV status has been shown to be significantly associated with non-attendance and is likely a significant barrier to long term treatment adherence in this vulnerable mentally unwell, HIV positive population. This finding adds to the body of evidence linking disclosure of HIV status with adherence to ART, and now links non-disclosure specifically to out-patient clinic non-attendance in this population.

Although this study did not examine the reasons for non-disclosure, stigma and fear of rejection are still a reality in the context of the HIV epidemic in South Africa, and likely influence the patient's decision not to disclose their HIV status. Psychosocial factors are often ignored by clinicians in favour of biological, or disease related barriers to adherence. This study once again highlights the importance of these psychosocial factors.

CHAPTER SEVEN: FURTHER RECOMMENDATIONS

7.1 Clinical Implications and Recommendations

Clinic protocols should encourage disclosure of HIV status within a safe environment, with adequate clinic as well as community support, recognising the potential for stigma and rejection within the community. This recommendation should be carried out within a broader public health framework aimed at de-stigmatising HIV within the community.

The high female predominance in the sample population suggests a need to focus on women's health issues at the clinic including peri-natal input. From a public health perspective, interventions aimed at decreasing HIV transmission among women should be investigated. The HIV counselling and testing procedure for males admitted to psychiatric wards may need to be reviewed to ensure early diagnosis and access to care in this sub-group.

There should be a re-emphasis on good clinical record keeping by doctors working in the clinic, documenting screening done at each encounter with a patient. Given the previous literature linking substance use and HAND with poor adherence and long term outcomes, screening for co-morbid diagnoses of HAND as well as substance use disorders should be routine. Objective measures such as urine multidrug testing as a screening tool for substance use, and the IHDS as a screening tool for HAND might be useful and increase sensitivity over clinical judgement and self-report. Even though these co-morbidities were not found to be significantly associated with attendance in this study, it should be noted that screening was

low and it is possible that the prevalence of HAND and substance use disorders was therefore underestimated.

The high level of unemployment and relatively low level of access to social disability grants may suggest a need for increased involvement of allied disciplines such as occupational therapists in long term care of these patients. At a public health level, it may be useful to increase awareness of the occupational needs of this specific population, those with HIV and a psychiatric illness, at non-governmental workshops and sheltered employment centres.

7.2 Recommendations for Future Research

Future research arising from this study could focus on investigating reasons for non-disclosure, subsequently leading to development and implementation of strategies to encourage disclosure. Tracing patients lost to follow up at the clinic, with face to face interviews might aid in determining patients rationale for non-attendance. This would obviously need to take into account ethical considerations with regards to confidentiality and patient willingness to participate in research.

Research could also further investigate the role of psychiatric illness in attendance, by prospectively comparing rates of clinic attendance and loss to follow up in HIV positive patients with and without a psychiatric diagnosis.

Another area of concern, and target for further research is the perception that ART should not be initiated in hospitalized “in-patients”. Future research would be useful to add to the evidence regarding rates of loss to follow up and attendance in patients initiated on ART as in-patients vs. those initiated as out-patients.

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APPENDIX ONE: DATA SOURCE SHEET

Demographic Data

Subject Number: _____

Age

18 - 30	0
30 - 50	1
50 -65	2
unknown	3

Gender

Male	Female	Unknown
0	1	2

Marital Status

Single	Widowed	Divorced	Married	Life partner	Unknown
0	1	2	3	4	5

Employment

Yes	No	Unknown
0	1	2

Disability grant

Yes	No	Unknown
0	1	2

Education: _____ years

Primary	Secondary	Tertiary	Unknown
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0	1	2	3
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Approximate Distance from CHBAH, by area

<5km	Including: Diepkloof, Orlando east, Orlando west, Devland, Klipspruit, Naturena	0	
5-10km	Including: Klipriviersoog Olifansvlei Eldorado Park Chiawelo Mfolo Meadowlands Jabulani Molapo Moletsani	Eldorado estate Nancefield Pimville Dhlamini Dube Klipspruit west Dobsonville Jabavu Moroka Orlando	1
10>15km	Including: Mapetla Protea South Naledi Tladi Thulani Bram Fischerville	Lenasia Protea North Protea Glen Zola Emdeni Doornkop	2
15≤20	Including: Lenasia South Finetown	Lawley	3
>20	Including Orange Farm		4
Other			5
Unknown			6

Admission details and clinic attendance

Date of Admission: _____

Date of Discharge: _____

Length of admission

<2 weeks	2 weeks-1 month	1-2months	>2months	Unknown
0	1	2	3	4

Appointment Date: _____

Time from discharge to follow up appointment date

≤1 week	1week<2weeks	2weeks≤1month	>1month	Unknown
0	1	2	3	4

Adherent (Attendance at clinic on appointment date)?

Yes	No	Unknown
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0	1	2
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Partially adherent (Attendance at another date within 1 month)?

Yes	No	Unknown
0	1	2

Non Adherent (Did not attend clinic within 1 month)?

Yes	No	Unknown
0	1	2

Past psychiatric and medical history**Current Psychiatric diagnosis**

Schizophrenia	0
Substance induced psychotic disorder	1
Psychotic disorder not otherwise specified	2
Major depressive disorder	3
Bipolar mood disorder	4
HIV associated neurocognitive disorder	5
Psychotic disorder secondary to GMC (HIV)	6
Psychotic disorder secondary to GMC (other)	7
Mood disorder secondary to GMC (HIV)	8
Mood disorder secondary to GMC (Other)	9
Diagnosis unclear	10
Unknown	11

Current psychotropic medication

Monotherapy	Polytherapy	Unknown
0	1	2

Substance abuse history

Yes	No	Unknown
0	1	2

HIV related data**Disclosure**

Family member	0
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Friend	1
Unknown	2
Not disclosed	3

WHO Stage of HIV infection:

Stage 1	0
Stage 2	1
Stage 3	2
Stage 4	3
Not recorded	4

IHDS Score

>10	0
<10	1
Unknown/NR	2

APPENDIX 2: PERMISSION TO CONDUCT RESEARCH AT CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

CHRIS HANI BARAGWANATH HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 25 March 2011

TITLE OF PROJECT:

Factors predicting adherence to clinic follow up in HIV positive psychiatric patients initiated on Anti-retroviral therapy (ART) as in-patients

UNIVERSITY: Witwatersrand

Principal Investigator Dr Yvette Nel

Department: Psychiatry

Supervisor (if relevant):. Dr Gregory Jonsson

Permission Head Department (where research conducted) Yes

Date of start of proposed study: April 2011

Date of completion of data collection July 2012

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

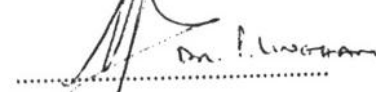
- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.


.....
CHIEF MEDICIAN

Recommended

(On behalf of the MAC)

Date: 25 March 2011


.....
Dr. P. Lwaram

Approved/Not Approved

Hospital Management

Date: 29 MAR 2011 .

APPENDIX 3: ETHICS CLEARANCE CERTIFICATE

M110502

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
 R14/49 Dr Yvette Nel

CLEARANCE CERTIFICATE

M110502

PROJECT

Factors Predicting Adherence to Clinic Follow-Up
 in HIV Positive Psychiatric Patients Initiated in Ant-
 Retroviral (ARV) Therapy as In-Patients

INVESTIGATORS

Dr Yvette Nel.

DEPARTMENT

Department of Psychiatry

DATE CONSIDERED

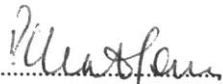
27/05/2011

DECISION OF THE COMMITTEE*

Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 27/05/2011

CHAIRPERSON 
 (Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
 cc: Supervisor : Dr Gregory Jonsson

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

