

Factors Influencing Adherence to Antiretroviral Therapy at a General Hospital in Mombasa, Kenya

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KEY WORDS

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Treatment



ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CCC	Comprehensive (HIV) Care Clinic
CPGH	Coast Provincial General Hospital
FGD	Focus Group Discussion
HAART	Highly Active Antiretroviral Therapy
HIS	Health Information System
HIV	Human Immunodeficiency Virus
MOH	Ministry of Health
NACC	National AIDS Control Council
PLHIV	People Living with HIV
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization



ABSTRACT

Sub-Saharan Africa is home to two thirds of the 33 million HIV infected individuals worldwide. In 2007 there were an estimated 1.5 million Kenyans infected with HIV, and 166 000 new infections in 2008. The introduction of antiretroviral therapy [ART] brought new hope to HIV patients. It has transformed a fatal disease to a chronic manageable condition. Kenya has made great strides in ensuring access to ART and by 2009, 308 610 patients in the country were receiving ART - which is the second highest number worldwide. The success of ART requires a sustained adherence rate to medication of more than 95% to prevent viral replication and the development of drug resistant HIV strains. Identifying the factors that influence adherence, is essential for the long-term success of public ART programmes.

The current study explored patient, socio-economic, cultural, and religious and health systems factors that influence adherence to ART at the Coast Provincial General Hospital [CPGH] in Mombasa, Kenya.

Methodology

An explorative qualitative study was conducted with ART patients and health care workers at the Comprehensive HIV Care Clinic [CCC] of the Coast Provincial General Hospital. Four focus group discussions [FGD] were conducted with 27 patients, and eight health care workers. Data was audio-recorded and transcribed verbatim. Thematic and content analysis of transcribed data was done.

Results

The facilitators to adherence of ART include: high individual commitment, high level of formal education, and having social support from family and friends. Alcohol abuse, HIV-related stigma and discrimination, none disclosure of HIV status, lack of partner support, travelling to attend funerals and the religious practises of faith healing and fasting during the month of Ramadhan, were noted barriers to adherence. Health system factors such as congestion in the clinic, negative staff attitudes and a lack of privacy for drug dispensing at the pharmacy were also identified as barriers to clinic attendance and keeping appointments. Interestingly, patients did not report pill burden or adverse drug reactions as barriers to adherence. Transportation did not influence treatment adherence due to the good transport network and close proximity of the clinic. Treatment success was reported as both a facilitator and a barrier to adherence.

Conclusion

HIV-related stigma and discrimination in the community need to be addressed through community outreaches to increase support to PLHIV and encourage disclosure of HIV status. Improvement of women's socio economic status needs to be addressed through increased educational opportunities and economic support by microfinance institutions so as to reduce male dependence and increase accessibility to health care. The health systems need to reduce clinic congestion and waiting times by increasing the number of health care workers, expansion of existing infrastructure and strengthening of satellite ART sites .



DECLARATION

I declare that “*Factors Influencing Adherence to Antiretroviral Therapy at a General Hospital in Mombasa, Kenya,*” is my own work and that it has not been submitted for any degree or examination in any other university and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full Name.....Dr. Anisa Abdalla Baghazal.....

Signed



... Date.....2nd March 2011.....



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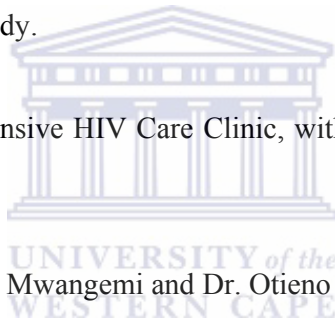


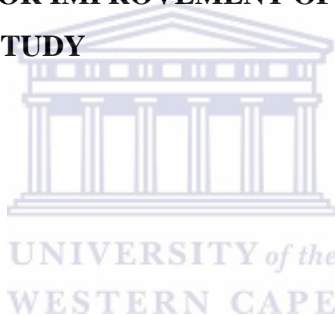
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CHAPTER ONE

INTRODUCTION

1.1 Background

An unprecedented public health crisis is facing the world at large, and more so sub-Saharan Africa in the form of the HIV pandemic (WHO, UNAIDS & UNICEF, 2009). In 2008 it was estimated that 33 million people were infected with HIV worldwide, with sub-Saharan Africa bearing the brunt of the disease burden, hosting 67% of HIV infected people globally. It is further estimated that there were 2.7 million people newly infected with HIV and 2 million HIV/AIDS related deaths in 2008 (WHO, UNAIDS & UNICEF, 2009).

Kenya, a resource limited country in East Africa, is grappling with the HIV/AIDS epidemic. The Kenya AIDS indicator survey, which was a population based survey conducted in 2007, reported a national HIV prevalence rate of 7.1%, translating to 1.5 million Kenyans living with HIV and AIDS (Ministry of Health, 2009). Further, the third Kenyan National HIV strategic plan in 2009 reported that an unacceptably high level of 166 000 new infections occurred in the year 2008 (National AIDS Control Council, 2009).

A high prevalence of HIV infection in the economically productive age group (25 to 35 years), decreases productivity and aggravates food insecurity, making HIV not just a health issue, but an economic and development challenge as well (UNAIDS, 2008). HIV has had a significant negative impact on development indices, with life expectancy in Kenya decreasing from 60 years in 1990, to 51 years in 2000, and then to 54 years in 2008. Similar trends were noted in the under-five mortality rate which rose from 68/100000 live births in 1990, to plateau at 81/100000 live births in 2000 and 2008 (WHO, 2010).

Significant progress has been made in the management and control of HIV through the introduction of antiretroviral therapy [ART] (WHO, UNAIDS & UNICEF, 2009). Global political commitment, backed by considerable financial support from partners such as the

Global Fund to Fight AIDS, Tuberculosis and Malaria, the United States President's Emergency Plan for AIDS Relief and other bilateral, national, non-governmental and private sources have made ART accessible to millions of people living with HIV in developing countries, leading to a significant reduction in HIV related infections, morbidity and mortality (WHO, UNAIDS & UNICEF, 2009). ART has brought new hope to HIV infected persons by transforming a fatal disease to a manageable, chronic condition (Ickovics & Meade, 2002). Challenges to access still exist, because 5 million out of an estimated 9.5 million people in need of treatment globally are still without access to ART (WHO, 2010).

1.2 Access to Antiretroviral therapy in Kenya

The Kenyan Ministry of Health [MOH], in conjunction with international partners, launched a nationwide program in 2003 to provide ART in public health facilities (Ministry of Health, 2007). A small user fee was initially charged, but has since 2005 been done away with in order to increase access to treatment. HIV treatment is now free in all public health facilities including the study site, Coast Provincial General Hospital (CPGH). This has had good results as the uptake of ART has seen exponential growth. In 2007, 38% of individuals with advanced HIV disease were receiving ART in Kenya (WHO, 2010). By the end of December 2009 there were 308,610 patients accessing ART from 943 health facilities nationwide; placing Kenya as the country having the second highest number of patients on ART worldwide (National AIDS Control Council, 2010; WHO, 2010).

These hard won gains are however fragile. The global economic crises, poor political commitment and stewardship, weak health systems and patient related factors have raised concerns for sustainability of funding for public ART programmes and their long-term success (WHO, UNAIDS & UNICEF, 2009). Additionally patient adherence to medication has been identified as an essential component of treatment success (WHO, 2006a).

1.3 Adherence and ART

Adherence to medication has been defined as “the extent to which patients take medications as prescribed by their health care providers” (Osterberg & Blaschke, 2005: 487). A sustained adherence rate of above 95% to correct medication intake has been determined as necessary for successful ART treatment response (Paterson, Swindells, Mohr, Brester, Vergis, Squier *et al.*, 2000).

It is evident that persons with sub-optimal adherence to antiretroviral medication have inadequate viral suppression and a higher incidence of opportunistic infections leading to increased morbidity, hospitalization and mortality (Paterson *et al.*, 2000). Recurrent hospitalization combined with the resultant increased medical expenses, loss of earnings for the patient and the caregivers, further aggravates poverty in the family, community and nation (Mills, Nachega, Buchan, Orbinski, Attaran, Singh *et al.*, 2006a). Patients’ with suboptimal adherence are also at a greater risk of developing drug-resistant HIV strains, a consequence of continuing viral replication in the face of selective antiviral pressure (Lima, Harrigan, Murray, Moore, Wood, Hogg *et al.*, 2008). This concern is particularly valid in resource limited settings where viral load measurement and drug resistance testing are not part of the routine care of patients on ART (WHO, 2006a).

Development of drug resistance virus would require second line drug regimens whose availability is still limited in resource limited settings as well as being significantly more costly compared to a first line regimen, thus escalating the cost for ART programmes (Eholie, Tanon, Polneau, Oiminga, Djadji, Kangah-Koffi *et al.*, 2007; Vervoot, Jan Borleff, Hoepelman & Grypdonck, 2006). Patients with suboptimal drug adherence who do not engage in safer-sex practices may infect others and spread antiretroviral drug-resistant virus (Harries *et al.*, 2001).

1.4 Setting

The Coast Provincial General Hospital (CPGH) is a public health facility with a bed capacity of 600 inpatients. It is managed by the Ministry of Medical Services, and is located in the city of Mombasa; the second largest city in Kenya. There are a number of other public and private

health facilities in Mombasa. CPGH serves as the referral hospital for the approximately 891,594 inhabitants of the Coast province of Kenya. It has been recognised as a training centre for different cadres of health service providers.

In 2003, CPGH pioneered the introduction of ART services in the Kenyan public sector (Population Council, 2004). HIV care and treatment for adults is provided in the Comprehensive HIV Care clinic (CCC), which is situated in the out-patient department of CPGH. By March 2010, CPGH was offering comprehensive HIV care to about 12, 000 registered patients and ART to 5,249.

Thanks to support from the United Nations Global Fund to fight AIDS, Tuberculosis and Malaria, and the President's Emergency Plan for AIDS Relief (PEPFAR), HIV care and treatment are provided at no cost to HIV patients at the CPGH. The facility offers comprehensive integrated HIV care and treatment including counselling and testing for HIV, provision of ART, nutritional assessment and therapy, sexually transmitted infections screening and treatment, basic care package, family planning services, cardiovascular risk assessment and community based follow up.

The above services are offered by a team comprising of two medical officers, (one of whom is the researcher), two clinical officers, seven nurse/counsellors, a nutritionist, two data clerks and four volunteer community health workers. It is a high capacity ART site with 130-190 adult patients attended to in a day, served Monday to Friday from 8am to 4:30 pm. At the time of the study all patients were managed in accordance with the Kenyan national guideline for antiretroviral therapy of 2007 which recommends initiation of ART for patients diagnosed as:

- WHO clinical stage IV irrespective of the blood CD4 cell count.
- WHO clinical stage III and having a blood CD4 cell count of ≤ 350 cells/mm³.
- WHO clinical stage I or II and having a blood CD4 cell count of ≤ 250 cells /mm³ (Ministry of Health, 2007a).

Patients eligible for ART undergo a minimum of three, one hour counselling sessions, which include information on the benefits of ART and co-trimoxazole, the importance of good treatment adherence, nutritional requirements as well as potential adverse drug effects. Counselling is ongoing at every visit by the adherence/nurse counsellor, clinician and the

pharmacist (CPGH- Standard Operating Procedure, 2005). The level of adherence to ART based on the patients self report is assessed at every visit by the health care worker. Adherence is rated as satisfactory if 95% or above, and unsatisfactory if below 95%. Patients with unsatisfactory adherence are referred to the nurse or lay counsellor who provides extra counselling session. If this is found to be inadequate the patients is then referred to the community health workers who links the patient to a community health worker who has the capacity to provide home visits and support.

This study setting was identified because, being the first public health facility in Kenya to offer ART and having a high patient load; it is a rich source of information. The clinic is also accessible to the researcher who is a health care provider at the hospital.

1.5 Problem Statement

The success of ART programmes is directly related to a sustained high level of adherence (compliance) to medication by patients and retention in treatment programme. There are concerns, amongst health care providers and program managers in Kenya, of a possible decline in the quality of HIV care (of which ART adherence is an integral part of) as we scale up on the ART programme.

It is important to explore factors that influence adherence to the prescribed regimen in this urban African setting. Such an understanding of the factors influencing ART adherence can provide guidance in developing interventions to increase adherence over the short, medium and long-term with improved treatment outcome, reduced infectivity and HIV transmission thus strengthening HIV prevention strategies.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Over the last fifty years major advances in pharmacotherapeutics have resulted in the development of new and potent drugs for the treatment of many acute as well as chronic medical conditions. These include the development of medications for hypertension, diabetes, psychiatric conditions and the Highly Active Antiretroviral Therapy (HAART) for HIV infection developed in the 1990's (Steiner & Earnest, 2000).

The benefits of these medications are however only achieved if prescribed treatment instructions are strictly observed by the patient. Studies have shown that for many chronic illnesses, adherence to medication averages between 50-60% (Steiner & Earnest, 2000). Whereas a good response to treatment is achieved with an adherence rate of 80% to antihypertensive medications and 60% for Helicobacter Pylori infection, HAART demands a sustained adherence rate of least 95% (Paterson, Swindells, Mohr, Brester, Vergis, Squier *et al.*, 2000; Ministry of Health, 2007a; WHO, 2006a). This challenging requirement, together with the consequences of poor adherence has resuscitated a renewed interest in medication adherence behaviour especially with regard to ART (Steiner & Earnest, 2000).

2.2 ADHERENCE

2.2.1 Definition of Key Concepts

The notion of adherence suggests that the treatment plan is a result of a joint decision making process culminating in an agreed therapeutic contract or alliance established between the patient and the clinician (Reynolds, 2009). The patient is involved in the decision making process and takes ownership of the prescribed treatment.

The notion of compliance suggests that the patient is passively following the doctor's orders and undermines any involvement of patients in treatment planning and decision making (Population Council, 2004).

Most health care workers prefer the term adherence and it is the term used in the current study (Osterberg & Blaschke, 2005). Studies using either terminology have been included in this review as long as they were used to refer to the extent to which patients take the prescribed medications as required.

2.2.2 Patterns of Adherence

Adherence behavior has been noted to be a dynamic and idiosyncratic process, with rates and patterns of adherence varying amongst individuals, and even in the same individual over time (Population Council, 2004; Reynolds, 2009). Patterns of variation that have been identified include:

- Schedule deviations
 - Failing to take the prescribed dose of medication or not taking it on time.
 - Taking medication more or less frequently than prescribed.
 - defaulting from treatment or taking a “drug holiday” (abruptly stopping medications for a few days or longer).
- Dosing deviations
 - Taking a smaller or larger amount than the prescribed dose.
 - Failing to take medications with required conditions, such as on an empty stomach or with food.
 - Selective nonadherence to a component of the regimen.
- Medication deviations
 - Taking the wrong antiretroviral medications (Reynolds, 2009).

2.3 FACTORS AFFECTING ADHERENCE TO ANTIRETROVIRAL THERAPY

In this section, the study will undertake a study of literature written on the following aspects: patient, treatment, socioeconomic, cultural, religious and health systems factors, and their reported influence on adherence to ART.

2.3.1 PATIENT FACTORS

Patient factors that influence adherence include: age and gender, education level, commitment to ART and daily routine schedule, alcohol abuse and previous opportunistic infections.

Age and gender

Although most studies show that age and gender do not influence adherence (Fong, Fung, Lee, Tse, Yuin, Sin *et al.*, 2003; Luszczynska, Sarkar & Knoll, 2007; Marc, Testa, Walker, Robbins, Shafer, Anderson & Berkman, 2007; Sarna, Pujari, Sengar, Garg, Gupta, van Dam *et al.*, 2008; Singh, Squier, Sivek, Wagener, Nguyen & Yu, 1998), Ozuchukwu, Onwujekwe, Onoka, Okoli, Uguru and Chukwuogo (2009) showed that being female and younger than 35 years in Nigeria were significantly associated with poor adherence. Godin, Cote, Naccache, Lambert and Trottier (2005) found that Canadian men were twice more likely to be adherent compared to women.

Education level

Several studies have shown that level of formal education is not a reliable predictor of adherence to ART (Reynolds, 2009; Sanjobo, Frich & Freithman, 2008; Watt, Maman, Earp, Eng, Setel, Golin *et al.*, 2009). However, Kip, Ehlers and Van der Wal (2009) demonstrated that patients in Botswana with low formal education had poorer adherence due to their inability to read and follow instructions, as well as a lack of understanding about the importance of chemotherapy regimens.

Studies by Waite, Paasche-Orlow, Rintamaki, Davis and Wolf (2008) and Marc, Testa, Walker, Robbins, Shafer, Anderson *et al.* (2007) show that in North America, low literacy is a significant risk factor for poor adherence. Waite *et al.* further highlighted that perceived social stigma is a possible mediator in this relationship.

However, studies in Botswana and Cote d'Ivoire reported a higher level of adherence amongst patients with low formal education (Eholie, Tanon, Polneau, Oiminga, Djadji, Kangah-Koffi *et al.*, 2007; Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema *et al.*, 2003). Eholie and colleagues suggest that patients with high education level were more likely to fear stigmatization, and drop out of HIV care and treatment once their health improved.

Commitment and psychological factors

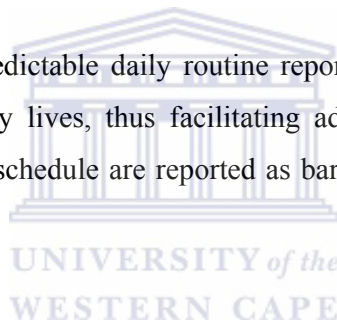
Psychological factors such as mental depression, anxiety, hopelessness and feeling overwhelmed by the disease, its prognosis and management have been shown to have negative effects on adherence in ART (Fong *et al.*, 2003; Godin *et al.*, 2005; Garcia, Badaro,

Netto, Silva, Amorin, Ramos *et al.*, 2006; Luszczynska *et al.*, 2007). Studies in India and Canada identified a high sense of ‘self efficacy’ - which refers to an individual’s strong optimistic belief in ability to cope with adversities-- as a strong predictor of adherence (Godin *et al.*, 2005; Luszczynska *et al.*, 2007). It has also been observed that acceptance of the disease and development of a positive attitude to ART are facilitators to ART adherence (Marc *et al.*, 2007).

One of the most common reported reasons for missing doses was that the patient “forgot” or was “too busy”, as found in Hong Kong, New York, and Soweto, South Africa (Fong *et al.*, 2003; Golub, Indyk & Wainberg, 2006; Nachega, Stein, Lehman, Hlatshwayo, Mothopeng, Chaisson *et al.*, 2004).

Daily schedule

Patients with consistent and predictable daily routine reported finding it easier to integrate daily pill taking into their daily lives, thus facilitating adherence, while an unstable life, shifting routine and busy work schedule are reported as barriers (Golin *et al.*, 2002; Fong *et al.*, 2003 Watt *et al.*, 2009).



Alcohol abuse

Alcohol use has been reported to be common amongst HIV-infected individuals, as exemplified by a study in Baltimore USA, where 45% of HIV-infected patients used alcohol with 10.7% classified as hazardous drinkers (Chander, Lau & Moore, 2006). A dose-response relationship between alcohol use and adherence has been identified with hazardous alcohol use being associated with poorer adherence. Alcohol use is often associated with substance abuse which has been independently identified as a significant barrier to adherence (Chander, Lau & Moore, 2006). Mills in a meta-analysis of adherence to ART in sub-Saharan Africa showed that alcohol abuse was the fourth most important factor that negatively affects adherence (Mills, Nachega, Bangsberg, Singh, Rachlis, Wu *et al.*, 2006a).

Previous opportunistic infections

The presence of opportunistic infections or poor health at the time of diagnosis may act to increase the perceived severity of the disease and the patient's vulnerability, which in turn leads to a faster acceptance of the disease by the patient and adherence to medication (Remien, Hirky, Johnson, Weinhardt, Whittier & Le, 2003; Nam, Fielding, Avalos, Dickinson, Gaolathe & Geissler, 2008). Asymptomatic individuals have been reported to feel less vulnerable and therefore less compliant to treatment recommendations (Singh *et al.*, 1996; Etard, Lanie`ce, Fall, Cilote, Blazejewski, Diop *et al.*, 2007).

2.3.2 TREATMENT RELATED FACTORS

The challenges of treating HIV are exacerbated by the lifelong nature and the complexity of the ART regimen. The regimen is often accompanied by other medications for prophylaxis or treatment of opportunistic infection and at times dietary restrictions (Population Council, 2004). The treatment of tuberculosis requires special mention as this is the most common significant opportunistic infection affecting up to half of PLHIV in Kenya (National AIDS Control Council, 2005). It is important to note that Kenya's national ART guideline which is in line with recommendations from WHO advises routine co-trimoxazole prevention therapy for all PLHIV (Ministry of Health, 2007a). In the subsequent section the effects of pill burden, adverse drug reaction, treatment success and fatigue on adherence by patients will be discussed.

Pill burden

Studies from Africa have documented that the number of pills a patient has to consume daily (pill burden) has not been identified as a major barrier to adherence (Beyene, Gedif, Gebre-Mariam & Engidawork, 2009; Gilbert & Walker, 2009). Weiser in Botswana documented that although 30% of patients thought the pills were too many to swallow; however, this interfered with adherence in only 5% of patients (Weiser *et al.*, 2003). This is in contrast with earlier studies from developed countries that reported pill burden to negatively influence adherence (Ickovics & Meade, 2002). The pill burden was reported to be physically taxing, confusing

and emotionally consuming (Fong *et al.*, 2003; Golub *et al.*, 2006). More recent reviews have found no association between pill burden and adherence (Garcia *et al.*, 2006; Mills, Nachega, Bangsberg, Singh, Rachlis & Wu, 2006b).

Adverse drug reaction

Concerns have been raised regarding adverse drug reactions (ADR) to ART such as peripheral neuropathy, lipodystrophy, diarrhoea, nausea, malaise, metabolic changes and liver toxicity as barriers to adherence (Mills *et al.*, 2006b). Studies have shown that despite ADR being experienced by a third to half of all patients on ART in Ethiopia, Tanzania and Botswana, it did not significantly influence adherence (Beyene *et al.*, 2009, Watt *et al.*, 2009; Weiser *et al.*, 2003). Weiser *et al.* (2003) documented that only 9% of patients in Botswana reported ADR as a barrier to adherence.

Studies from South Africa, Nigeria and USA have however reported that adverse drug reaction negatively influenced adherence (Malangu, 2008; Uzochukwu *et al.*, 2008). It is possible that patients with HIV tolerate side effects better than patients with “less severe” chronic diseases such as hypertension (Fong *et al.*, 2003; Golub *et al.*, 2006).



Treatment success

The reduction of HIV stigma that follow ART use such as weight gain and reduced episodes of illness have been identified as motivators for continuing adherence (Gilbert *et al.*, 2009; Nam *et al.*, 2008; Weiser *et al.*, 2003). Improvement in health has also been cited as a barrier as some patients perceive the improved health as meaning one is cured of HIV and does not need ART anymore thus discontinuing medication (Sanjobo *et al.*, 2008; Kip *et al.*, 2009).

Treatment fatigue

Some studies have reported that longer durations on treatment regimes are associated with weariness and treatment fatigue as the patients concerns regarding the long term consequences of lifelong drug dependency sets in (Eholie *et al.*, 2007). However studies in

Uganda and Zimbabwe did not identify any correlation between the two factors (Muyingo, Walker, Reid, Munderi, Gibb, Ssali *et al.*, 2008).

2.3.3 SOCIAL FACTORS

There is general consensus that the quality of inter-personal relationships plays a critical role in motivating people living with HIV in general terms and more specifically in relation to adherence of ART (Beyene *et al.*, 2009; Godin *et al.*, 2005). This applies to relationships within families, friends, community and even between patient and health care providers.

Social support

Strong social support has been identified as a source of strength that encourages a patient's commitment (Mills *et al.*, 2006b). It helps improve an individuals' psychological, nutritional and physical status, compensating for any negative attitude; thus facilitating adherence. Support can come in the form of reminders about hospital appointments and timing for medication, psychological support, economic support, and nutritional support (Luszczynska *et al.*, 2007; Marc *et al.*, 2007; Remien *et al.*, 2003). Several studies have demonstrated the presence of social support to be significantly higher amongst patients who were adherent compared to those who were non adherent to medication (Diabate', Alary & Kanga-Koffia, 2007; Gardenier, Andrews, Thomas, Bookhardt-Murray & Fitzpatrick, 2010).

Stigma and discrimination

UNAIDS defines HIV related stigma and discrimination as: “...*a process of devaluation of people either living with or associated with HIV and AIDS...discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status*” (UNAIDS, 2007:9). There is consensus that stigma and discrimination to PLHIV is widespread and a major barrier in many communities for people to access and continue care (Scrambler, 2009). The former director of UNAIDS, Peter Piot, in his keynote address to the XVI International AIDS Conference in Toronto noted that “*Since the beginning of the epidemic, stigma, discrimination, and gender inequality have been identified...as major obstacles to effective responses to HIV*” (UNAIDS, 2007:7). The fear of stigma and discrimination prevents disclosure to loved ones who could potentially fill the role of

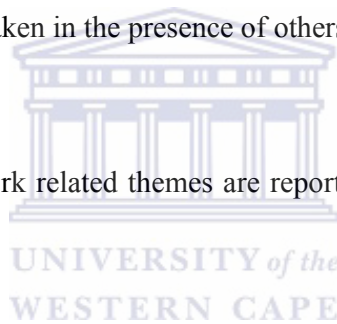
treatment supporters and causes patients to hide their antiretroviral drugs and skip doses in the presence of friends or family. The resultant social isolation predisposes to poor self esteem and mental depression which independently has been shown to negatively influence adherence (Nachega *et al.*, 2006).

Disclosure

Disclosure of one's HIV status to close ones is reported to aid adherence to ART as it is a crucial step towards mobilising social, psychological, economical or spiritual support from family and communities (Mills *et al.*, 2006b). Disclosure is also closely tied in with acceptance of one's status and commitment towards HIV care. Mills *et al.* (2006a) in a systemic review of 84 studies from both developed and developing nations reported that non disclosure was the most important barrier to adherence. Patients who had not disclosed their HIV status were more likely to suffer frequent treatment interruptions due to the fact that tablets must be hidden and not taken in the presence of others (Mills *et al.*, 2006a).

2.3.4 ECONOMIC FACTORS

Poverty, food insecurity and work related themes are reported to influence adherence. I will discuss these factors in turn.



Poverty

In resource poor countries like India, and in Kenya prior to the year 2005 when ART had to be purchased, the cost of ART had been identified as a major constraint to adherence (Kumarasamy, Safren, Raminani, Pickard, James, Sri Krishan *et al.*, 2005; Zachariah, van Engelgem, Massaquoi, Kocholla, Manzi, Suleh *et al.*, 2008). Despite ART being free of charge at point of delivery, the cost of transportation, child care and loss of earnings have been identified as barriers to adherence (WHO, 2010; WHO. 2006b). Considering that more than 50% of Kenya's population lives below the poverty line, these costs have to compete with other essential needs such as food and school fees.

Studies from areas such Botswana and rural Uganda where patients have to travel long distances to access care have revealed transport costs as a significant barrier (Hardon, Akurut, Comora, Ekezie, Irunde, Gerrits *et al.*, 2007; Thobias, 2008). These findings are at variance with other studies from both rural and urban Zambia where transport costs did not influence

adherence (Murray, Semrau, Mc Curley, Thea, Scott, Mwiya *et al.*, 2009; Carlucci, Kamanga, Sheneberger, Shepherd, Jenkins & Spurrier *et al.*, 2008).

Food Insecurity

Several studies from resource limited settings have identified lack of food as a factor responsible for patients neglecting their treatment (Hardon *et al.*, 2007; Nachega *et al.*, 2006). Patients report that it is hard to take pills when hungry as ART are often perceived to be strong and powerful and the body not strong enough to withstand potency of ART if hungry (Thobias, 2008). In Tanzania, patients reported taking their medication only once, in the evening when food was available, rather than twice as prescribed. Patients have also been reported to sell their ARVs in order to buy food. This implies that food scarcity can be a drawback to adherence (WHO, 2006b).

Work related factors

Lack of employer support and mobility due employment have been reported as barriers to adherence (WHO, 2006b). Patients have also reported not being allowed time off from work to attend hospital appointment and for drug refills thus compromising adherence. Abrupt dismissal from work on disclosure of their status has been reported making patients reluctant to disclose their status and compromising adherence (WHO, 2006b).

2.3.5 CULTURAL AND RELIGIOUS FACTORS

There is a paucity of studies addressing cultural, religious and spiritual interpretation of HIV and ART within the African context. Mills *et al.* (2006:688), in a meta-analysis of 58 studies on adherence to ART in sub-Saharan Africa and North America state that ‘understanding culturally specific barriers to adherence will be important in developing evidence-based interventions targeted at individuals with poor adherence.

Alternative therapy

In Africa the use of alternative and herbal therapy is deeply rooted and is intricately interwoven within the cultural, spiritual and social fabric. Reports of use of alternative therapy negatively influencing adherence have been reported from Uganda (Wanyama, Castelnuovo,

Wandera, Mwebaze, Kambugu, Bangsberg & Kanya, 2007). In Tanzania, beliefs that people have been bewitched, had a spell cast on them or been afflicted by an AIDS devil/spirit (a 'jinni') are commonplace and inhibit adherence to ART (WHO, 2006b). Globally, alternative therapy is gaining popularity and may influence more patients to be non adherent to ART in the future (Remien *et al.*, 2007).

Ramadhan

A few studies done in Nigeria have sought to identify the effect of Ramadhan, the Muslim month of fasting on ART adherence. During Ramadhan the Muslim faithful neither eat, drink, nor take oral medication, starting from dawn to dusk, an interval that lasts an average of 15 hours in Sub-Saharan Africa. Despite Islam exempting sick patients from fasting and allowing them to take medication, many patients with chronic illness, HIV included, insist on fasting and thus potentially compromise their treatment adherence (Aadil, Houti & Mousasamih, 2004). Habib (2008) reported a median ART dosing interval of 15.75 hours from the ideal of 12 hours. This is of concern in Mombasa where 40% of the population profess the Islamic faith. More studies are needed in order to increase our understanding of the above religious factors and long term drug adherence.

2.3.6 HEALTH SYSTEMS FACTORS

Sub-Saharan Africa is the epicentre of the HIV/AIDS pandemic. It is also the region least prepared for a pandemic of this magnitude. Decades of economic crises, structural adjustment programmes and declining public expenditure have severely undermined health care systems. This has diminished the capacity of these countries to provide even the most basic health care (McCoy, Chopra, Loewenson, Aitken, Ngulube, Muula *et al.*, 2005; Harries *et al.*, 2001).

In Kenya, an estimated 1.4 million HIV infected people will eventually require ART. This figure keeps escalating as 166 000 new infections occurred in 2009 (NACC, 2009). Provision of ART entails lifelong treatment and labour intensive assessment, monitoring and support of patients. Despite the vision of universal access to ART, concerns have been raised about the feasibility of providing and sustaining ART to these large numbers of people in resource limited settings such as Kenya and ensuring long term adherence. There are reports that the health care system is buckling under the load of ART with concerns focusing on the limited

human resources and inadequate infrastructure, components that are difficult to reverse in the short term (Boulle & Ford, 2007). Certain health systems factors have been identified to influence adherence to ART, namely human resource shortage, long waiting times in the clinics, the patient-provider relationship and the unavailability of ART drugs.

Human resource shortage

Numerous developing countries, Kenya included, are facing a severe shortage of skilled health care workers. In Kenya, the doctor-patient and nurse-patient ratio stands at 1:10000 and 12:10000 respectively, which are way short of the World Health Organisation's recommended doctor/patient ratio of 1:600 (WHO, 2010). This human resource crisis is now regarded as the key systems constraint to sustaining ART programmes (Schneider, Blaauw, Gilson, Chabikuli & Goudge, 2006). The aetiology of this crisis is multi factorial and includes inadequate supply, increased loss due to migration to resource rich countries for better monetary gains, and death due to HIV/AIDS. In addition to the inadequate numbers, is the demoralisation and demotivation of health care professionals. In many countries health care workers particularly of the lower cadre earn salaries below subsistence levels. Demotivated and underpaid staff are likely to be inefficient and to misuse the health care system to ensure their own survival rather than using it as an avenue for caring and service provision. This outlook has entrenched a culture of service delivery in public sector hospitals that is often described as harsh and unsympathetic. In the context of ART provision, which is more labour intensive than other primary care activities, and requires the establishment of a health care worker-patient partnership, these entrenched norms may undermine the ability to create the necessary partnership with patients and limit access to health care and adherence (Schneider *et al.*, 2006).

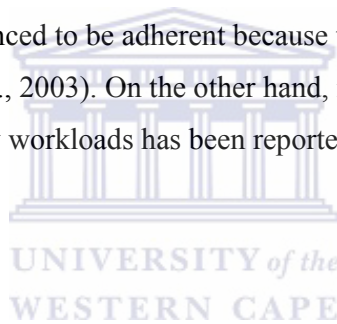
Long waiting times in clinics

Studies have identified congested clinics, long waiting time and confidentiality issues as barriers to accessibility of health care and adherence (Ickovics & Meade, 2002). Studies from Tanzania and Zambia have reported that congestion due to limited space and infrastructure

compromised confidentiality of clients as clinicians had to share rooms. In addition ART patients reported lengthy waiting time, spending up to ten hours in Tanzania, waiting to be attended to in the health care facility during their monthly visits. This was reported as a major barrier to both clinic attendance and adherence (WHO, 2006b).

Patient-provider relationship

Patient satisfaction with the interpersonal quality of the patient-provider relationship has been associated with significantly better patient adherence and outcomes; by contrast, patient distrust is associated with poorer adherence (Beyene *et al.*, 2009, Godin *et al.*, 2005). The patient-provider relationship has been recommended to be ideally characterised by continuity, trust, a shared decision making process with open communication about expectations, needs and experiences of patients (Reynolds, 2009; WHO, 2006b). A study from Botswana showed that 96% of patients were influenced to be adherent because the provider treated them with respect and dignity (Weiser *et al.*, 2003). On the other hand, negative staff attitude possibly due to low motivation and heavy workloads has been reported to be a barrier (WHO 2006b).



Unavailability of ART drugs

Unavailability of antiretroviral drugs at the hospital level due to poor drug procurement and supplies systems has been mentioned in studies as a barrier to adherence (Harries *et al.*, 2001). Fortunately, reported instances of drugs being out of stock in East Africa are reported to be uncommon and mainly affect individuals who opt to purchase ART (Byakika-Tusiime, Oyugi, Tumwikiriza, Katabira & Mungenyi, 2005; Zachariah, van Engelgem, Massaquoi, Kocholla, Manzi, Suleh *et al.*, 2008).

Other factors

Other unforeseen events can also hamper adherence. This is exemplified by the post election violence of early 2008 in Kenya, which led to an estimated 250 000 internally displaced persons, including individuals on ART. Many fled from their homes without medication or

supporting documents and were forced by circumstances to live in squalid camps. This severely disrupted the immature and fragile system of ART service delivery in various regions (Mwaura, 2008). It is estimated that up to 5% of displaced patients on ART may have interrupted their ART (MOH, 2008).

SUMMARY

The literature review to date has revealed a diverse range of facilitators and barriers to adherence of ART from patient related, treatment related, socio-economic, cultural, and religious to health systems factors.



CHAPTER THREE

METHODOLOGY

This chapter describes the methodology used in this study. It details the aims and objectives of the study, the study setting, study design, sampling procedure, participants' characteristics, data collection and data analysis. Measures taken to improve the rigour of the study and ethical considerations affecting the study are also highlighted.

3.1 AIM AND OBJECTIVES

This study aimed to explore the barriers and facilitators of medication adherence amongst patients on ART at the Coast Provincial General Hospital, in Mombasa, Kenya.

Specific Objectives

- To explore the influence of individual, treatment related, socio-economic, culture, religion and health systems factors on medication adherence amongst HIV infected patients on ART.



3.2 STUDY DESIGN

Given the complexity of the subject being studied and the need for a comprehensive exploration of all factors affecting the study, a qualitative approach was chosen. This approach has been proven to be effective in gathering rich in-depth information about human experiences that helps us understand mechanisms that generate behavioural pattern such as ART adherence (Meyer, 2000; Sankar, Golin, Simoni, Luborsky & Pearson, 2006). In a systematic review of facilitators and barriers to adherence from developed and developing nations, Mills *et al.* (2006b) lament a lack of studies on ART adherence using qualitative methods from Africa.

The qualitative approach allowed patients and health care providers to relate their experiences and observations in their own words, within their cultural and social context and allowed me

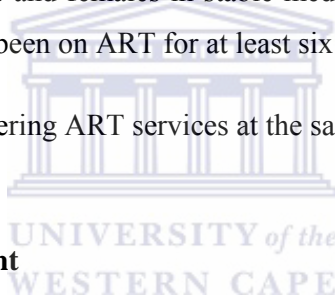
(as a researcher) to probe and uncover values, beliefs and experiences associated with medication adherence that would otherwise be inaccessible through a quantitative approach (Meyer, 2005). Qualitative methodologies were effective in identifying social norms, socio-economic factors, gender roles, culture and religion, and allowed me to gain a rich understanding of medication adherence within the specific social context of patients attending a public health facility in an urban African setting (Pope & Mays, 1995).

3.3 POPULATION AND SAMPLE

3.3.1 Study Population

The study population consisted of:

1. HIV infected adult males and females in stable medical condition attending the CCC at CPGH and who have been on ART for at least six months.
2. Health care providers offering ART services at the same clinic.



3.3.2 Sampling and Recruitment

Purposive sampling was employed to enable the researcher to select patient participants who were rich sources of information and representatives from both the Christian and Islamic faith, to allow us to explore the effect of religion on adherence.

Patients attending the CCC for follow up care and fulfilling the eligibility criteria were identified and approached individually by a nurse at the reception. The recruiting nurse excluded patients who were medically unstable who would not be able to participate fully in the discussion. The FGD's for the patients were planned for Saturday mornings. Patients were recruited from the clinic days on Monday to Friday during the same week prior to the discussion.

A lay counsellor who is living with HIV explained to the eligible patients the details of the study and written consent was obtained from those who agreed to participate (Appendix 1 & 2). If a patient declined to participate the next suitable patient was approached. The researcher ensured that the recruitment criteria were strictly applied during the selection of participants. All consenting patients received a brief study information sheet in the local language (Kiswahili) to take home for reading at their leisure (Appendix 5). They were then notified of the date and time to return for the planned FGD which were to be conducted the following Saturday.

The focus group discussion for the health care workers targeted the entire ART clinical team that was available, which comprised of two clinical officers and six nurse counsellors. The doctors did not participate since one was the researcher and the other was on leave. A signed written consent form was obtained from all participants and an information sheet given for further information (Appendix 3 & 4).

3.3.3 Sample size

A total of four FGDs were conducted, between 25th July and 21st August 2009 with 27 patients and eight health care workers.

The participants of the FGD were as below:

1. Female Patients aged 25-35 years.
2. Female Patients aged 30-45 years.
3. Male Patients.
4. Health care workers providing care at the CCC.

Two FGD's were conducted for female patients as two thirds of the patients attending CCC are females. Separate FGDs were conducted for male and female patients to ensure that each group was homogenous, and to facilitate group interaction without potential gender role barriers.

3.4 DESCRIPTION OF STUDY PARTICIPANTS

Female nurse counsellors constituted the majority of participants. Most of the nurses were highly experienced in the provision of HIV care and treatment, with two of them having worked at the CPGH CCC since its inception eight years ago.

Table 1: Characteristics of Health Care workers Participants

Description	Male	Female
Number of nurses	1	5
Number of Clinical officers	1	1
Nurses-Age range in years	36	35-54
Clinical Officers Age (years)	29	28
Nurses- Median years worked at CCC	6	6.4
Clinical Officers- Median years worked at CCC	3	3

Table 2: Characteristics of Patient Participants

Characteristics	Males	Females
Ages range in years	35-44	22-46
Median age in years	38	33
1-2 yrs years on ART	1	7
3-5yrs years on ART	6	10
6-9 years on ART	1	2
Median duration in years on ART	3.5	2.5
Range no of children	0-5	0-6
Mean no of children	2.5	3
Median no of children	2.5	3
Married	7	9
Separated	0	2
Widowed	1	0
Single	0	8

All the participants were residents of Mombasa district and spoke the Kiswahili language.

3.5 DATA COLLECTION

Data collection instruments

Standard discussion guides for patient and health care workers were developed by the researcher together with her research team and reviewed by the research supervisors in order to ensure uniformity and consistency across discussions groups. The discussion guide comprised of a variety of semi-structured open-ended questions to explore various patient, treatment, cultural, socio economic and health system factors affecting adherence to ART. Probes were inserted within each key question in order to gather further clarification when the

issue was not well understood or to get a different view (Appendix 6; Appendix 7; Kitzinger, 1995).

Focus group discussion

FGDs for the patient participants were conducted at the hospital support centre for HIV while the one for health care workers was conducted in the hospitals conference room. The rooms were appropriately furnished so that all the participants and research team members were in full view of each other. Prior to the interview and in order to put the participants at ease, they were engaged in small talk. This created a warm and friendly environment. Anonymous identification codes written on cards were placed in front of each participant for easy reference by other respondents during the discussions.

A graduate in social science with five years experience in conducting qualitative research served as the FGD moderator. She had a good rapport with the participants and encouraged in-depth discussions and contributions by all the members by probing while exploring emerging views. The FGDs for patient participants were conducted in the local language of Kiswahili while the FGD for health care workers was conducted in English. A research assistant recorded the discussions on audio tapes and summarized notes of all discussions including facial expressions and gestures on paper. The moderator also took additional short notes to track emerging issues that would define future questions. All discussions lasted between one and one and half hours. The researcher being a medical doctor and an ART provider in the hospital was not present during any of the discussions so as to allow participants to give their views freely. She closely monitored the outputs and had debriefing sessions with the moderator immediately after each FGD to ensure compliance with the study protocol.

3.6 DATA ANALYSIS

Within a week of each discussion, the audio tapes and hand written notes were translated and transcribed verbatim into English by the moderator and submitted to the supervisors. All proper names and identifiers were replaced with pseudo names. The transcripts were then entered into a Microsoft word processor and analysed manually. This method was chosen as it

was a small study with limited themes and also allowed the researcher to gain hands on experience as a first time qualitative researcher.

The five stages of thematic analysis, as described in Pope, Ziebland and Mays (2000) were used for analysis. The researcher took the lead during data analysis with two supervisors actively involved in validating and interpretation of the results. In order to ensure rigour, the researcher controlled for bias by constantly searching for negative instances (Bryman & Burgess, 1993).

Familiarization stage

This involved repeatedly listening to the tapes and reading the transcript carefully. Emerging key issues and themes were identified and certain words and phrases were noted down.

Identification stage

At this stage the researcher aimed to discover trends and establish relationships between emerging concepts and themes. By using content analysis the researcher looked for quotations and observations. Emerging key issues and themes were identified and certain words and phrases were noted down which were then de-contextualised to identify key codes, themes and subthemes. Key factors that influence adherence to ART were identified into five categories namely: patient and treatment related, socio-cultural, religious and economic and health systems factors. Differences in response between the genders and between patients and health Care Workers were noted. The data was labelled into manageable chunks for subsequent retrieval and exploration and labelled numerically producing a detailed index of the data.

Indexing stage

This stage focused on comparing concepts and subthemes. The transcript was systematically annotated with numerical codes from the index, supported by short text for elaboration.

Charting stage

The data was rearranged; similar topics were then grouped together according to the appropriate framework to which they related.

Mapping and interpretation

Finally, the identified themes were grouped. Similarities and contrasts between the groups were noted and interpreted meaningfully. This was influenced by the research objectives by the themes that have emerged and supplemented with additional literature (Mays & Pope, 2000).

The other members of the research team who have been actively involved since the beginning of the study constantly reviewed this process.

3.7 QUALITY AND CREDIBILITY OF THE RESEARCH

The following were applied to this study in order to make it credible, namely: triangulation, trustworthiness, credibility, clear exposition of methods of data collection and analysis, reflexivity and fair Dealing.

Triangulation

Triangulation involves comparing results from two or more data collection methods or two or more data sources. We collected data from two different interest groups; patients and health care workers. Weakness from one group was compensated by strength in another.

Trustworthiness

This is the extent to which a measurement yields the same answer each time it is used. To achieve this all the FGD's were conducted by the same moderator and team using the same discussion guide to reduce inter-investigator bias.

Credibility

The entire process of data analysis was validated by two supervisors who were involved in the entire analytic process.

Clear exposition of methods of data collection and analysis

A clear account of the data collection and analysis is provided. The methodology was rigorous, appropriate and systematic throughout the research process. The audio tapes and transcripts have been kept for accountability at a later stage. Conducting the interviews in the local language of Kiswahili and later translating to English may have introduced a bias. The moderator cum transcriber is a person fully conversant with both languages and is also skilled and experienced in conducting FGD's.

Reflexivity

Reflexivity is the process of realization that the researcher is part of the social world during research. The researcher was always sensitive of her role as a doctor in the CCC. She was not present during data collection so as to allow participants to discuss their experiences freely. She was always reflective of her prior assumptions and experiences during the process of data analysis.

Fair Dealing

Scientific and professional integrity was maintained throughout the process. Immediately after the group discussions, there was a debriefing session with the team to reconstruct the contents while the session was still fresh in their minds. All these strategies helped in reducing error and increasing rigour (Pope & Mays, 1995).

3.8 ETHICAL CONSIDERATIONS

All the participants had individual as well as group face to face explanation of the purpose of the study. Informed written consent was obtained from the participants in English or

Kiswahili language prior to interviewing and audio recording. Participants were assured of confidentiality and that the activity was purely for research purposes. Participation was entirely voluntary and participants were informed that they could withdraw at any point without suffering any consequences. Anonymity was ensured by removing all identifiers in the tapes and transcripts and names substituted with codes. The data is stored in a secure room with a lockable cabinet and is accessed only by the researcher and her team. The data entered in the computer had password-protection. Participants were requested not to divulge any confidential information outside the discussion.

The participants did not view the research as a threat as it was conducted in a teaching hospital, which had other ongoing researches in HIV. A professional counsellor from the hospital was available, should any of the participants have required emotional support or counselling as a result of the research process. At the end of the session, each participant, was given Kenya shillings 300 (US\$ 4) as transport reimbursement.

Written consent was granted from the ethical committees of the University of the Western Cape, the University of Nairobi and from the Coast provincial General hospital administration. The results of the research will be available to participants at the completion of the study.

CHAPTER FOUR

RESULTS

The analysis of data from the focus group discussions yielded the following: i) Patient/ individual factors; ii) Treatment related factors; iii) Cultural and socio-economic factors; iv) Health systems related factors.

Table 3: Classification of results

THEMES	SUB THEMES	CODES
1. Patient/ individual factors	1.1 Commitment	<ul style="list-style-type: none"> • Acceptance of disease • Self-motivation
	1.2 Treatment Literacy	<ul style="list-style-type: none"> • Knowledge of the consequences of poor-adherence • Formal education
	1.3 Alcohol abuse	<ul style="list-style-type: none"> • Hazardous alcohol use
2. Treatment Factors	2.1 Treatment Success	<ul style="list-style-type: none"> • Improvement in health as a facilitator to adherence • Normalization of life and forgetting medication
	2.2 Pill Burden	<ul style="list-style-type: none"> • Too many pills
	2.3 Adverse Drug Effects	<ul style="list-style-type: none"> • Side effects
3. Cultural and socio-economic Factors	3.1 Disclosure of one's HIV status	<ul style="list-style-type: none"> • Assistance when unwell
	3.2 Family and Partner support	<ul style="list-style-type: none"> • Reminder of drug intake and appointment • Drug pick – up • Encouragement

THEMES	SUB THEMES	CODES
	3.3 Non Disclosure	<ul style="list-style-type: none"> • Lack of social support • Inability to take ART in presence of others
	3.4 Stigma & discrimination in the family	<ul style="list-style-type: none"> • Mental abuse
	3.5 Stigma & discrimination in the community	<ul style="list-style-type: none"> • Patients seeking care in distant clinics
	3.6 Religion	<ul style="list-style-type: none"> • Ramadhan • Faith Healing
	3.7 Traditions	<ul style="list-style-type: none"> • Alternative therapies • Unplanned travel for funerals
	3.8 Poverty	<ul style="list-style-type: none"> • Lack of food • Transport Cost
	3.9 Employment	<ul style="list-style-type: none"> • Time away from work
4. Health Systems Related Factors	4.1 Counselling	<ul style="list-style-type: none"> • Group counselling • Informative counselling • Trained lay counsellors
	4.2 Quality of care	<ul style="list-style-type: none"> • Positive staff attitude
	4.3 Congestion	<ul style="list-style-type: none"> • Long waiting time • Inadequate clinic space • Increase in number of patients • Poor patient flow
	4.4 Poor Health Information System	<ul style="list-style-type: none"> • Poor filing
	4.5 Stand-alone pharmacy	<ul style="list-style-type: none"> • Lack of confidentiality
	4.6 Substandard care	<ul style="list-style-type: none"> • Staff harsh and unsympathetic • Stigma from health care worker

THEMES	SUB THEMES	CODES
		<ul style="list-style-type: none"> • Discontinuation of home visits • Poor monitoring of adherence

4.1 PATIENT FACTORS

This study found that patient-related factors such as commitment and treatment literacy facilitated adherence, while alcohol abuse hindered adherence.

4.1.1 Commitment

Acceptance of one's HIV status and self-motivation emerged as important facilitators of adherence.

- *Acceptance of HIV-status*

The initial reactions to the positive HIV test result varied from shock, disbelief and denial to relief with immediate acceptance. Participants who have been sick for a long period of time prior to testing reported to be relieved on knowing their diagnosis. This was reported to be an important step towards seeking and continuation of care and treatment for HIV.

I was not shocked when I tested and got positive results because I had so many problems before I decided to come and test. They found that I was positive and was counseled and told that I would be taking this medicine for the rest of my life. So I started medication and did not have a lot of thoughts about it. (Male, 38yrs)

Other participants reported initial hesitancy and difficulty in accepting the HIV diagnosis. Over time and with support this was overcome and patient accepted treatment.

First of all it really disturbed my mind. I did not imagine myself being able to take medicine everyday for the rest of my life. When I was told to take them, I refused and took off for 7 months. (Laughs)... I was really disturbed. But I sat down and thought, I got some counseling that diabetic people take medicine or inject themselves everyday and cancer patients too. Even women who take pills take them every day, therefore I

accepted... I said if that is where my survival will come from, then I accepted to take the medicine. At first it was very difficult. (Female, 36yrs)

After receiving counselling sessions, she recognized that her survival depended on her taking the medication and that she was not alone as there are other chronic conditions that require daily medication.

There is acceptance of one's status because you could have been given the medicine but do not remember the times well because you still do not want to believe that you have the virus. But once you accept, then you will remember that there is some medicine I am supposed to take every day and the reasons for taking them. (Female, 39yrs)

You will remember that you have medicines to take. If you have not accepted [your HIV positive status], you will forget. (Male, 37yrs)

Acceptance of the diagnosis was seen as a crucial stepping stone towards adherence to ART.

- **Self-motivation**

A sustained high level of motivation was reported to be a facilitating factor for adherence to the lifelong treatment. A patient equated adherence to ART to taking an oath. Oath taking in an African setting is a grave and serious affair with dire consequences should one not adhere to it. Equating ART adherence to taking an oath thus demonstrated the motivation, steadfastness and even allegiance required in ART adherence.

This is like an oath, I call it an oath and when I come here I tell them I have come to get my oath (others laugh). (Female, 39yrs)

Patient participants stated that over time ART became integrated in their daily schedule and activities even when going out night clubbing thus ensuring adherence.

It is something that is already in you. (Male, 40yrs)

It is a habit. (Male, 37yrs)

Self motivation resulted in patients making certain adjustment to ensure adherence. Such as the long distance bus driver who reached a decision that the medicines should always be in his travelling bag.

At the beginning I would forget when I started because my phone alarm will go off when I am in town and I am told to take the bus as I was needed in Nairobi by 8.00. While at home getting ready I will have placed them on the table but because of the hurry I would leave them there... so I was forced to realize that this medicine is not supposed to be out of my bag [out of reach] I had bought a padlock for the back and it was always locked. (Male, 38yrs)

When asked why he locked up the medications, he responded:

When I started I had some self-stigma and did not want people to know that I was on medication and thought that maybe when I was away someone could come and open my bag and see what was inside it. (Male, 37yrs)

Several patients reported using different types of reminders to facilitate good adherence. These included alarms in the mobile phones, the five regular call of prayer from the nearby mosque and news hour on television.

I would watch or listen to news and know it is time to take medicine. (Male, 37 yrs)

Personally, on my dining table there was something that would show me the time or I would set my mobile phone and if the alarm went off I would know it was time for my medicine. If my mobile failed, I would tie anything on my finger which would remind me all the time that there is medicine to be taken. (Male, 35yrs).

4.1.2 Treatment Literacy

Participants cited being aware of the consequences of poor adherence and having formal education as facilitators towards adherence.

- ***Knowledge of consequences of poor adherence***

All the patients interviewed were aware of the consequences of poor adherence. They reported practising good adherence in order to avoid ill health especially contracting new opportunistic infections, with tuberculosis being cited as a particular concern. They were also aware that poor adherence is likely to lead to development of resistance to the drugs, a situation they wanted to avoid.

Your immune system goes down and can get opportunistic infections very easily than someone who is taking their medicine properly. (Male, 37yrs)

According to me and the way I was told that if I do not adhere to medication... if I give the virus time, the virus will increase. That will hurt me. Also if I do not follow the instructions well, my body could also develop resistance to the drugs. So I had to follow the instructions well so that my body could get used to the drugs. (Male, 37yrs)

- ***Formal education***

Education was identified as an enabler to adherence as it is associated with good patient literacy as well as facilitating acquisition of knowledge on ART. Patients reported reading the boxed in literature accompanying the medication to supplement the information provided in the counselling sessions. This led to a better understanding of the medication regimen and consequently improved adherence.

You know about our doctors. They did not have the time to really counsel us but would give us little information. As for the rest you had to plan for yourself...There are some you are told to swallow before eating, others after eating... I would read the literature which came with the drugs. (Male, 37yrs)

Health care workers observed that the understanding and the concept of strict timing that is necessary for ART adherence of ART is better in the educated patients.

You cannot compare those who are illiterate to those who have gone to school. Why am I saying so, because you will tell him/her that you should take your drugs at exactly 9.00am or she will chose the time to take the drugs, “that I will take the drugs

at 9.00am and 9.00pm?” Then you later realize that they depend on the radio to get that time, and maybe due to some circumstances at home the person did not hear the news and they later realize it is 10.00 o’clock or someone comes and tells them it is now 10.00pm. Basically adherence to those who are not educated is not very good.
(Nurse, 36 yrs)

4.1.3 Alcohol abuse

Participants mentioned the hazardous use of alcohol as being a major barrier to adherence.

- ***Hazardous alcohol use***

Hazardous alcohol use was seen as a significant factor by all the women patient participants and health care workers in being a major hindrance to adherence of ART. The majority of female patients reported having close associates, friends and spouses who defaulted from treatment due to alcohol abuse. It was observed that when patients were intoxicated they would ignore the times for treatment or forget to take the medication altogether.

There is an older husband of mine who died five months ago. He had the virus and was started on medications at the CPGH... What happened was he would take for a week, then the following week he will not take and go to Mangweni (local drinking den)...He forgets that there is medication...On the second month he died. We even buried him. (Female, 30yrs)

The male participants, in contrast, were very reluctant to engage in the discussion about alcohol. One male participant acknowledged that upon initiation of ART three years ago, he had a problem with alcohol use and ART adherence as he would forget or ignore the time when it was time to take drugs.

When I started, I used to have problems as it happened for about 3 months; later is when I came to tow the line...sometimes I would even forget to take, sometimes I will even ignore the time (laughs) so forgetting used to disturb me. (Male, 37yrs)

A male patient admitted that he still drinks alcohol but reports that it does not affect his adherence as he has incorporated his drug taking to his frequenting the bar. He reports visiting

the bar regularly and at 7 pm ensures he has taken his medication without fail while at the bar.

When I am from work, I pass by home and go to the 'maskan' [the joint] and take my alcohol. Once 7 O'clock reaches I take my medicine and continue with whatever I was doing. (Male, 37yrs)

4.2 TREATMENT RELATED FACTORS

Participants mentioned treatment success and normalization of their lives as a facilitator for good adherence. Treatment success was also discussed as a barrier to adherence as patients felt healthy and forgot to take their medication. The number of pills taken daily and the adverse drug reaction were mentioned not to influence adherence.

4.2.1 Treatment Success

Treatment success was reported as both a facilitator as well as a barrier to adherence of ART.

- ***Improvement in health as a facilitator to adherence***

As the patients' health improves with weight gain and reduction in opportunistic infections, the stigmata of HIV infection also declines thus increasing the motivation to continue medication as the benefits of ART are visible. This positive outcome of ART was mentioned to be a major motivator for adherence to ART. Mothers describe the joy of delivering babies who are HIV free while others are delighted when their sick babies start thriving. This has made them optimistic about ART which encourages their adherence.

I did not feel bad because when I saw my child walk and had been unable to, was eating well; I did not see the reason for me to refuse medicine. (Female, 46yrs)

Yes, when I came here the first time my CD4 was five (others are shocked) I was so sick until when being taken to the hospital I will be pushed on a wheel chair! ...and now my CD4 is up, I am so okay. There are those that I know now who used to laugh at me then and are wasting while I see myself as being well (laughs). (Female, 39yr)

The interrelated factors affecting adherence to ART show that treatment success has counteracted other negative contributors of adherence such as stigma and adverse drug effects of ART. Patients who initiated HIV care in public facilities before ART become widely available report they appreciate how the introduction of ART has given them a new lease of life whereas many of their friends died when ART was inaccessible. These sentiments are also shared by the health care workers.

- ***Normalization of life and forgetting medication***

Reduced levels of anxiety and vulnerability to ill health are reported to occur in patients who recover their physical health. Patients who reported having felt better became fully engrossed in their daily activities and subsequently forgot the need to fully adhere to their medication. Below are the comments from patient participants.

What makes him stop is when he is feeling better and sees he has become well, therefore he forgets; sometimes you will find that he does not even take them because he believes he is okay. (Female, 39yrs)

4.2.2 Pill Burden

- ***Too many pills***

In addition to ARV, patients' regimen often contains medication for prophylaxis and treatment of opportunistic infections thus increasing the number of pills one has to take. Patients made it known they would prefer fixed dose combinations of ART which result in a reduced number of pills that one has to take. This was reported to improve adherence especially amongst patients who are frequent travellers and those with low formal education. Despite the above sentiments all the patients reported that the number of pills taken was not a barrier to adherence.

Another thing about the medicine, I think they can now manufacture them so that they are three in one so that a person just carries three tablets for three days instead of having to take nine. It is easier for those who are always travelling. (Male, 37yrs)

A patient who has been on ART for over six years recalled the old regimens as being more complicated, with multiple doses, some of which had food restrictions had to be taken at odd times during the night.

Yes, but because sometimes getting up at night could be difficult you had to find a way and plan for yourself. There are some you are told to swallow before eating, others after eating... I would read the literature which came with the drug. (Male, 37yrs)

4.2.3 Adverse Drug Reaction

- *Side effects*

The diverse range of adverse drug effects reportedly experienced by the patient respondents included skin rash, mental confusion, nightmares, lack of sleep and lack of appetite. However no patient reported discontinuing medication as a result of them. Both patients and health care worker participants considered the adherence counselling sessions as vital for ensuring adherence. During the discussion, a female participant demonstrated to her colleague severe body image changes (lipodystrophy) she has developed following prolonged use of ART. Despite comparing her new body image to a computer, below is her quotation as she confidently reports good adherence in an effort to normalize her life.

Very, very same way. I did not stop even for a single day, because wanted my life back. (Female, 27yrs)

A repeated theme was unfounded rumours regarding adverse drug effects patients heard from community members prior to initiation of ART. Patients reported being warned not to start ART as this would bring serious and potentially fatal side effects such liver toxicity. Such rumours were reported to instil fright and dread at the thought of initiating ART and could negatively influence adherence.

Also there is a friend of mine who told me, “do not take them, they destroy the liver! Yes you will start, will look nice, will help you and will be healthy, but later your liver will burn.” When you hear that, it instils fear. (Female, 36yrs)

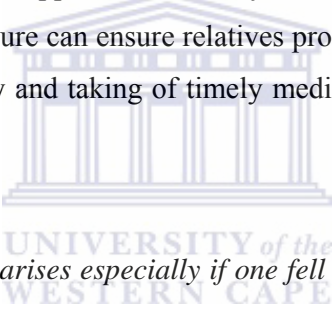
4.3 CULTURAL AND SOCIOECONOMIC FACTORS

Patients' experiences with family members and the community were identified to influence adherence. Factors identified that impacted positively on adherence to ART in this theme were disclosure of one's HIV status to close and loved ones and family and partner support. Factors identified which had a negative effect on adherence were: lack of disclosure of HIV status, stigma and discrimination in the family and community, some religious practises, some traditional practises, poverty and employment.

4.3.1 Disclosure of HIV status

- *Assistance when unwell*

Self-disclosure of one's HIV status to close and loved ones was reported to be a critical facilitator and directly linked to support from family members, especially during times of need. Patient discuss how disclosure can ensure relatives provide continuum of care when one is unwell by ensuring availability and taking of timely medication and appropriate utilization of health services.



It also helped when need arises especially if one fell ill and the only people around to help are family. Sometimes you can become overwhelmed, if none of your people knows that you are using medicine and maybe they are finished, it is that close person who will remind you of the follow-up; and if you are very sick they can pound it for you on a spoon and give it to you. (Female, 28yrs)

4.3.2 Family and Partner Support

Family support was identified to be crucial in reminding patients on drug intake, assisting in collection of medication from the pharmacy when the queues are long and also in giving mental encouragement to patients.

- *Drug reminders and pick up*

The nature of relationship with other persons at family level which in turn is linked to disclosure of one's HIV status was identified to influence adherence to ART. In families that are

open about the diagnosis, the whole family, children included are able to play a positive role in reminding parents to take drugs.

My whole family knows, even my last born knows because now even that last born reminds me, "mama, medicine." (Female, 38yrs)

Spouses reported of assistance from their partners in preparing for them nutritional meals and collecting their drugs for them when the queues were long.

If I came and if my time is over and have still not got any medication, I do not come here the next day. As long as I have the card and the prescription, I give my wife who comes to collect it on my behalf. (Male, 35yr)

- ***Encouragement***

A Participant shared his experience of encouragement and positive family support during the early stages of his ailment.

They are the ones who actually approached me and said it would be better to do the test and know my status. There is no problem, we shall support you whatever the outcome. (Male, 37yrs)

4.3.3 Non-disclosure

Non-disclosure of one's HIV status to close family members was linked with failure to optimally adhere to treatment as the vital social support was not forthcoming and they are unable to take medication in front of others.

- ***Lack of Social support***

Nurse Counsellors noted that, without disclosure when a patient gets unwell and is unable to attend the clinic in person, he may run out of medication as he cannot send anyone to collect it on his behalf.

Maybe they have fallen sick and time to come and collect medicine has reached but do not have someone to send to collect... (Nurse, 35yrs)

A nurse counsellor narrated a scenario where non-disclosure to children who are the closest family members results in non-adherence when the parents fall ill and need care and treatment.

We may have a mother who has not disclosed to her children; maybe she has done so to a close friend who lives far away. And at a certain moment she may be too sick and needs treatment but because she has not disclosed to any of her children, she finds it difficult to send them. So you find out that she has not been taking medication for a few weeks and cannot contact the support person maybe she is far away. We get a few cases. (Clinical officer, 28yrs)

The state of non-disclosure is influenced by several factors, including single mothers not wanting to overburden their young ones, and women's fear of isolation, victimization and violence from their partners.

Below, a female participant shares her experience and struggle to overcome her husband's objection to her and her sick child getting an HIV test and his eventual abandonment.

My blood was not tested there like the way they were doing it here. When we came here, he [her son] was sick all the time and it went on like that until he wasted completely. We were always being admitted all the time. I told my husband; "why don't we test and find out what it is?" it became a fight. I was forced to come back home and we were admitted until the child wasted. I told the doctor I would like to do some tests so that I would know what is ailing him and me too. This is because he was not getting well and even if I gave him milk he will vomit it. We came down and were tested, we were found positive. I told my partner who ran away until now. (Female, 46yrs)

Women who are tested during antenatal care find it especially difficult to communicate their positive results to their partners.

For the gender, women normally they have to be tested when they are pregnant. So when they go back and disclose “I have been tested and I am positive”, there is the fear of being abandoned or chased away or being beat. So for them you find disclosure being hard at times. (Nurse, 52yrs)

- ***Inability to take ART in presence of others***

The reported effect of lack of disclosure is the inability of the patient to take her medication in front of significant others or hiding their medication resulting in patients delaying or skipping their drug intake.

It will affect. Already when she is tested and started on treatment, how will she take the drugs and the men is there? It will mean she has to hide, maybe look for somewhere to keep the drugs or dismantle from the containers. (Nurse, 52yrs).

And if you find most of the clients who do not adhere to treatment, they are the clients who have not disclosed their status so it becomes very difficult for them to take their drugs on time because someone is there and they do not want them. (Nurse, 45yrs)

4.3.4 Stigma and discrimination in family

Stigma and discrimination by the family impaired adherence by causing mental abuse and social isolation.

- ***Mental abuse***

As a consequence of the discrimination, patients felt depressed and unhappy. A female patient still felt strongly emotional about an event that happened to her seven years ago:

But there was a problem, for my father if there is a funeral he will start telling the others about me and ask them for money stating that I'll be the next one to die. That really hurt me. Yes, at the beginning as most of the time I was confused... I had to return to the doctor for I was completely mixed up. I regretted telling my family so much! (Wiping tears from her eyes). (Female, 46yrs)

Health Care Workers have reported instances where men have refused their wives to go on ART. Some women due to their commitment would devise ways of ensuring their treatment continuity even risking violence and their marital relationship to do so.

There is this issue of a couple testing positive but the man refused the wife to take medication [ARVs]. She came to me and really wanted to be given advise and I told her to buy a tin where every time she bought flour she will put it inside the tin and hide her medicines at the bottom of the tin. It was so bad that at one time they travelled up-country [rural home] but her husband checked her bag and on finding the ARVs, he threw them in the pit latrine ... fearing violence she stole his phone, removed the sim card and sold it so that she could travel all the way back to Mombasa to get more medicine. (Nurse, 35yrs)

- **Social isolation**

Patients reported social isolation from the family. This situation improved once the family got better informed and this facilitated better adherence to treatment.

For me it made my children very unkind and did not want even to share a cup... when he [the son] came to understand how, he is the one who comes to collect the medicine for me. (Female 46yrs)

4.3.5 Stigma and discrimination in community

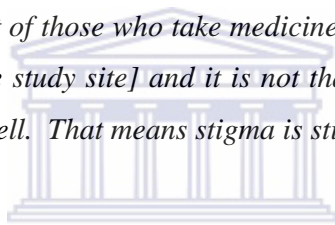
- *Patients seeking care in distant clinics*

Stigma and discrimination in the community was reported to be widespread and negatively influencing adherence with community members making unkind remarks about patients who are HIV positive.

Yes, the community talks about them. (Nurse, 35yrs)

To avoid the above, patients attend clinics that are far from their homes in order to avoid being seen by their neighbours and friends in the nearby health facility.

Even when you look most of those who take medicine here come from Kwale, Malindi, Lamu... [350km from the study site] and it is not that there are no clinics over there but we know them very well. That means stigma is still very present. (Male, 35yrs)



Consequently attending far-off clinics leads to extra transport costs which the patient at times cannot afford leading to delays in their coming for their refills and compromising adherence.

Another thing that contributes is transport or financial problems. Most of the patients are living as far as Lunga Lunga and the day they are supposed to come and collect the medicine, they do not even have a penny. So it has really affected compliance.

(Clinical Officer, 28yrs)

4.3.6 Religious Factors

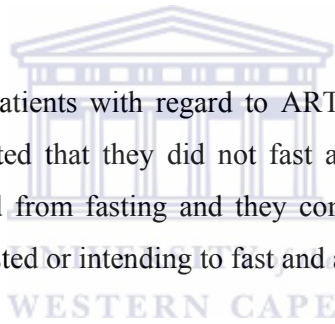
Kenyans have strong religious beliefs and cultural affiliations. Religion was both a facilitator as well as a barrier to adherence as patients mentioned drawing strength from their spiritual beliefs and activities to help them cope with life's daily challenges. Factors identified that were barriers to adherence were the fasting month of Ramadhan and the belief in faith healing.

- ***The Month of Ramadhan***

A source of conflict was noted during the Islamic fasting month of Ramadhan. During Ramadhan, Adult Muslims are required to refrain from taking any food, beverages or oral drugs from sunrise to sunset, an average of 15 hours in East Africa. Life's daily routine and habits change during this month with religious activities taking precedent over other activities. The first meal is taken after sunset at around 7:00pm and the last meal shortly before dawn at about 4am. Intake of drugs is therefore restricted and has to be adjusted to the activities of this month.

The commonly used current regimens provided by the government institutions require strict twice daily dosing with 12 hourly intervals, a situation that is incompatible with fasting. Taking drugs with the first meal in the evening at 7pm and the last meal before dawn at 4am would lead to alteration of the recommended dosing time as well alteration of the time span between the doses.

The response of the Muslims patients with regard to ART and drug ingestion was varied. Some patient participants reported that they did not fast as their religion exempts all sick persons, including HIV infected from fasting and they continued with their drug intake as usual. Others reported having fasted or intending to fast and altering the timing of medication.



I normally change the times for taking my medicines especially in the morning when I fast. Before 'Daku' [early morning meal at 4 am] I would take and the other I would take the normal evening time. (Female, 39yrs)

One patient participant however disclosed that her observing the fast for the last few years has affected her negatively so she was not going to do so the coming year.

It was reported that some patients discontinue their medicine during the fasting month.

Some people fast and then throw away their medicine... (Female, 38yrs)

A health care professional concurred with the above sharing her experience of patients defaulting from treatment during this month.

Okay, we have a few who think they have to fast. So during that month they will not tell you they are fasting but will come and collect their medicine and keep them maybe at home. After some time, when you monitor that client, the CD4 may have gone down because they have been fasting. When it drops you have to talk to the client and from the history they have to disclose. They have to tell us why the CD4 is decreasing yet they have been on medication, we get a few who are sincere and tell us. I have not been taking medication because of Ramadhan. (Clinical officer, 28yrs)

The HCW perceive that insisting on fasting despite being exempted is linked to the prevailing situation in the community and in the Muslim homes during this period. The entire family and community are involved in the fasting activities and for the patient not to involve himself may lead to self stigmatization as well as stigmatization from the community. This situation is likely to occur in instances where disclosure has not taken place.

When we talk to our clients some of them have been frank enough to tell us that it is not mandatory for those who are on medication. Now, because of the mood at home, there is the stigma part of it – people are not eating while you are eating. So you become... some people will look at you as if you are not, eehh. (Male, 36yrs)

- ***Faith healing***

Participants observed that some patients discontinue ART after attending prayers offering spiritual or faith healing and being convinced that they are no longer HIV positive.

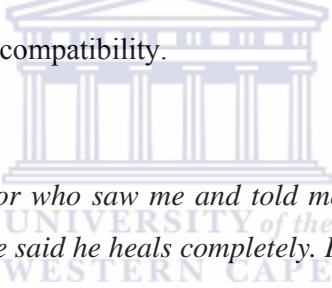
There is a colleague of ours whom we used to plan advocacy programs. We used to go round... there was one who went and was prayed for...he told us he was healed and stopped taking medicine. He did not finish 3 months... he was dead. (Male, 37yrs)

4.3.7 Traditional factors

Traditional influences such as use of alternative therapy and unplanned travel to attend funerals were reported as barriers to adherence.

- ***Alternative Therapy***

Though none of the patient participants reported defaulting from ART because of traditional medicine, they had several acquaintances that had done so. Patients who accepted to use herbal therapy were instructed to discontinue ART and were given strict orders not to mix herbs with ART due to alleged incompatibility.



There is one herbal doctor who saw me and told me to leave the medicines alone. I had a skin problem and he said he heals completely. I followed him up to his home and told me, 'stop taking these medicines and take these ones!' I was so confused and he had really convinced me and was almost stopping. When I told my sister she told me not to even try. (Female, 40yrs)

The positive consequences of disclosure and family support reported above has assisted with adherence and counteracting the negative influence of the traditional healers. A participant below narrates the almost fatal outcome following exclusive herbal therapy.

I buried my sister-in-law the other day... she stopped taking her medicines... turned to herbals and within two months everything inside her was destroyed. (Female, 39yrs)

Other patients report using herbal therapy as an adjuvant to ART and not compromising adherence.

There are times the family people who know about you will bring the traditional medicine and tell you that this one adds blood or that one cleans the blood. It is not like you are going to stop taking your medicine, it is like adding. (Male, 37yrs)

- ***Attending funerals***

Attending a funeral of a relative or close friend is obligatory under the customs and traditions of Kenyan and many other African cultures. It usually entails an unexpected four to seven days journey to their rural home, in addition to many customary rites which may take months to complete. This may result not only in lacking transport fare back to the clinic for a refill but also poor adherence as a consequence of being overwhelmed by crowds of people and activities especially in instances where disclosure has not taken place. All the patient participants acknowledged they were empowered with information and will not travel without ensuring they have enough medicine to last them the period they are to be away.

So if you come and want be to go for a funeral and may stay over for 2 to 3 days, I will say no. I will say, let us go to my place first, pick up my medicine and then we can go; I never miss. (Male, 39yrs)

Health care worker participants however reported that poor adherence as a result of travelling for a funeral was still widespread.

Some go for social events like burials and end up defaulting until the time when they come back here for medication and then they tell you they are from matanga [funeral]...not days, like this morning there was one who had gone home and went without medication for 4 months. (Nurse, 35yrs)

4.3.8 Poverty

With 50% of Kenyan living on less than one United States dollar a day, economic factors featured prominently in the discussions. Food security, transportation costs and employment issues are discussed below.

- ***Lack of food***

Lack of food was perceived as a barrier to adherence. The first line of ART regimen selected for use in Kenya does not have dietary regulations and patients are advised to take their medication regardless of food consumption. Patients reported following this advice though they complain of intolerance to the ART when hungry.

So even sometimes you do not get any food and are forced to take strong tea (tea without milk) so that you are able to take the medicine. You find that they disturb you because you have not eaten anything. (Female, 27yrs)

This observation was echoed by a nurse counsellor participant who narrated below:

Another thing that affects adherence is poverty as they have not been able to take even breakfast or supper and cannot take drugs on an empty stomach. (Nurse, 54yrs)

- ***Transportation cost***

Reports of transport cost affecting adherence were mixed. A majority of patients who live within the urban areas reported that since they get care at no cost to them at the clinic they could find means of getting transport fare to the clinic. However for the patients who come from far- flung districts, they at times experience lack of transport fare and are thus unable to refill their prescription on time. These patients do not wish to access care at the nearest health facility due to perceived stigma both of self and from the community as indicated earlier.

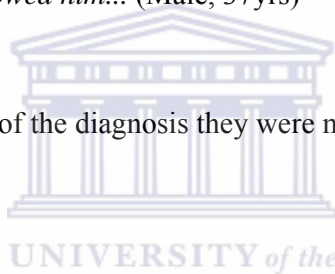
Another thing that contributes is transport or financial problems. Most of the patients live as far as Lunga Lunga [100km away] and they fail to come for their medication on the appointment date because they do not have any money. (Clinical officer, 29yrs)

4.3.9 Employment

The patients complained bitterly of the long hours spent at the hospital, negatively affecting their income generating activities and putting their jobs security was at stake. Below a patient narrates the consequences of the long waiting time he endured at the clinic.

I was forced to explain to him [His employer] at one time. There was a time I got late and the work I was supposed to do, got messed up...I had to take the card together with my medicine and showed him... (Male, 37yrs)

Once the employers were aware of the diagnosis they were more supportive but gave patients' limited time to attend the clinic.



If you have been given a day to go and get medicine and yet you want to go back the next day, and yet you spent the previous day there, they will not understand. (Male, 44yrs)

4.4 HEALTH SERVICES FACTORS

Health system factors mentioned that were affecting adherence positively were the counselling sessions provided and overall good quality of care offered at the CCC. Barriers to ART adherence that emerged from this theme were: Congestion and long waiting time at the clinic, negative staff attitude, the stand alone pharmacy and the overall substandard care provide.

4.4.1 Counselling

Most of the participants talked of the good counselling support they have had from the counsellors which in turn has enabled them adhere to medication and overcome impediment like side effects and alcohol abuse. The informative sessions of group counselling, and the contribution by trained lay counsellors who were people living with HIV was seen to facilitate adherence.

- ***Group therapy counselling sessions***

Patients reported the group counselling sessions where they shared their thoughts and experiences with other patients helped them come to term with issues such as alcohol abuse which affect adherence.

When I started, I used to have problems [with alcohol] as it happened for about 3 months; later is when I came to tow the line...while we were in a discussion here, a group therapy meeting. It is here when I came to hear that for the person who is on medication and also using alcohol, the body has to work to deal with the alcohol first and the medicine is supposed to be in your body. (Male, 37yrs)

- ***Informative counselling sessions***

Patients and health care workers noted that the adherence support counselling that was ongoing at every visit was a contributing factor to good adherence. The quality of counselling was reported as good in terms of time allocated as well as information given which even included the names of the drugs and their side effects.

They assist us because every time you come to collect medicine, they ask how you take your medicine, at what time whether you have forgotten... (Female, 30yrs)

Yes, once you get in there even when you are with your wife, they will explain to you well... (Male, 40yrs)

- **Trained Lay counsellors**

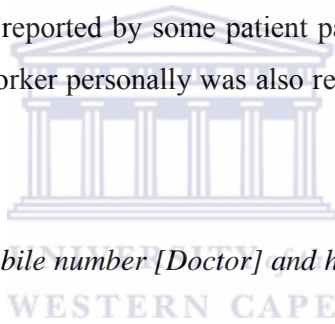
Participants reported that patients are better able to relate to lay counsellors who are also people living with HIV on improved adherence.

Yes, we have counsellors within... especially for those who are mostly in denial. We have counsellors who are HIV positive and on treatment, so we refer the clients to these counsellors for support and sometimes they feel better when it is so. (Female Nurse, 35yrs)

4.4.2 Quality of Care

- **Positive Staff Attitudes**

The attitudes of the HCW were reported by some patient participants to be positive towards the patient. Knowing a health worker personally was also reported as a motivator for patients to continue taking ART.



Personally I have his mobile number [Doctor] and he told me to call him in any case. (Male, 35yrs)

Doctors have been described, in their commitment to even go beyond the call of duty and provide financial assistance for hospital bills.

I am grateful to a certain doctor who helped me when I had the eye problem; he assisted me even with money for the operation. (Female, 30yrs)

4.4.3 Congestion at the clinic

All the patients spoke with great emotion on how the clinic was congested, noisy, and unwelcoming, with long waiting time and quarrels arising among patients. Factors identified

that contributed to congestion were the limited clinic space, an increased number of patients and poor patient flow resulting in long waiting time.

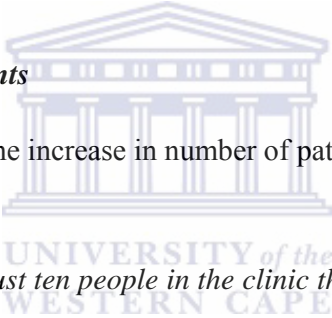
- ***Inadequate clinic space***

Participants were of the opinion that the clinic was too small and even suggested expanding the centre and opening up more sites. They noted that it is the same clinic space, set up six years ago at the launch of the HIV Comprehensive Care Clinic (CCC) that still serves the ever increasing number of clients accessing ART services.

Since the centre is still the same one and people are increasing, even getting to know a person who will assist them individually becomes difficult. (Male, 37yrs)

- ***Increased number of patients***

A male patient stated regarding the increase in number of patients seeking HIV services.



Before there used to be just ten people in the clinic the whole day, nowadays it gets so full until you disagree with people...a file cannot be found I do not know what...10 people the whole day. We would sit and talk until the time you leave you felt well. Nowadays there is a lot of noise! (Male, 37yrs)

Patient participants who have attended the clinic for more than five years observed that the staff are overwhelmed with the ever increasing number of patients and suggested more centres be opened up to cater for the increased patient load. These sentiments were echoed by a health care worker who observed that the clinic is weighed down with the number of patients it sees.

For me contrary to the truth the clinic is almost overwhelmed. (Male Nurse, 36yrs)

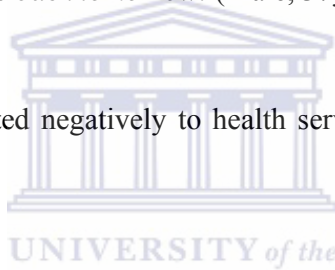
- ***Poor patient flow and long waiting time***

When a patient attends services at the HIV clinic, he/she is normally served by a minimum of four or a maximum of eight HCW each in a different room or location and it means a patient queuing many times over. These include the reception, triage nurse, nurse counsellor, clinician, pharmacy, laboratory, family planning services or nutrition support.

The laboratory also attends to patients who have come for other health services within the hospital. The above scenario, coupled with missing files and poor staff attitude, results in a patient spending many hours at the hospital. This long and drawn out procedures are a deterrent to accessing health care for ART as illustrated by this quote from a patient on ART.

The process, process after process, you can spend almost half a day here and if you are late, you have to come back tomorrow. (Male, 37yrs)

The long waiting time contributed negatively to health service utilization and consequently adherence.



You have spent the whole day here, did not get it and may decide not to come and get them the next day; you cannot spend two days in the hospital! (Male, 37yrs)

4.4.4 Poor Health Information system

- ***Poor filing***

A poor health information system that cannot cope with the increased patient load and inadequate space for filing patients records, leading to misplacement of files was reported to contribute to delays and increasing waiting time.

They are very slow because when you come no matter how early, you will still leave here late. Just getting your file takes time, at 9.00 yet you were here by 7.00 or the file gets lost somewhere because there are too many people. (Female, 36yrs)

The space that is where we feel we have a problem with spacing. Like in records where we keep our files, there are some which are lying on the floor. They have tried to expand the place, but because of some bureaucracy they cannot do that. (Male Nurse, 36yrs)

4.4.5 Stand-alone Pharmacy

The patients attended to at the Comprehensive HIV Care Clinic are served at a separate window at the main pharmacy. This has raised concerns by patient participants about lack of confidentiality.

- ***Lack of confidentiality***

Patient participants describe the pharmacy, which serves the CCC clients as being in an open place and infringing on their right to privacy and is perceived as a barrier to adherence. They expressed sentiments that other people were able to identify them as being HIV positive just by virtue of them being in a particular queue, exposing them to stigma and discrimination. A patient describes the scenario should his neighbour see him in the queue.

He does not know your status but when he sees the queue you have taken he will know what it is for, that it is for a certain illness. 'So my neighbour is like this!' He will go and spread it. (Male, 35yrs)

This situation is aggravated by the pharmacists who at times call out the name of the patient aloud and hence identifying them to nearby persons. This exposure may result in patients not returning for future refills.

When you get into the cubicle, they start calling us out aloud; it is okay for some of us who are not self-stigmatised but there is someone who will never come back. (Male, 37yrs)

4.4.6 Substandard Care

The patients lament the overall poor quality of health care provided at the CCC. They cited the harsh and unsympathetic staff who stigmatized their patients, discontinuation of home based care services and lack of monitoring of adherence as barriers to adherence.

- ***Harsh and Unsympathetic staff***

Harsh, rude and unsympathetic staff attitude emerged as a barrier to adherence. Patient participants complained of poor attitude by the HCW and describe how the staffs are harsh and waste time chatting and give preferential treatment to their friends while patients wait to be served. A patient narrated how harsh a doctor was towards her when she had poor adherence. She was therefore unable to confide to her the circumstances around her problem.

She was really harsh and therefore I was afraid of even explaining. (Female, 39yrs)

HCW are aware that the manner in which a patient is treated is important. This knowledge however may not yet be fully translated into good clinical practice.

The psychological well-being of that particular client, how he is being treated by other people out there and how he is treated by the service providers in here are things that we should first put into consideration. Not drugs alone can treat this person. (Nurse, 36yrs)

- ***Stigma by service providers***

Patient participant reported that some pharmacists were rude to patients and would utter remarks expressing stigma to patients especially when there is congestion at the pharmacy. A pharmacist was reported to have uttered the following words to a patient.

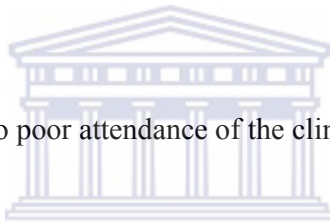
Am I the one who infected you? It is your silliness! (Female, 36yrs)

- ***Discontinuation of home based care and food aid***

The patients who have attended the clinic since its inception in 2003 recall with nostalgia the excellent quality of care that was provided at the launch of the clinic including home based care and provision of nutritional supplements.

But according to me, this service, as we continue to be many, the quality of service continues to go down. They used to visit us at home. They knew your problems at home, you're eating ways and even talk to your family. That has reduced...whenever we used to come every month, we would be given vitamin supplements...nowadays I do not see them. Sometimes USAID used to give food donations: oil, flour, to those who were not able to afford and I have noticed that has also been going down slowly. I do not know whether it is because the number of people has increased or what" (Male, 37yrs)

The above was reported to lead to poor attendance of the clinic.



It is like chasing people away, yes, that is why I was talking about provision of services that it has gone down and that makes people not adhere to medication. (Male, 36yrs)

- ***Poor monitoring of adherence***

During the early years of the clinic, patient's adherence level could be verified based on the remaining pill count that was conducted at the pharmacy. Unfortunately this practise is no longer being carried out due to an increased work load.

Earlier we used to come back with the container and upon counting he will know how you have been taking them. I am telling you the way people are throwing them away...the services of following us up here, as they used to come till home. (Male, 35yrs)

However, the HCWs perceive the health care system as being good and helpful to the patients as noted in the quote below:

Actually the patients are attended to well. (Clinical officer, 29yrs)

In the following chapter the major research findings in the study are compared with and discussed in relation to findings in previous studies.



CHAPTER 5

DISCUSSION

The discussion brings the findings together and draws on the literature to discuss the patterns that have emerged. Adherence to ART remains key to the success of ART programs. This study has added to the understanding of factors that influence adherence to ART in Kenya. Factors identified include the following: the influence of the individual, treatment, social, religious, cultural, economic factors and health care system factors.

Acceptance of diagnosis and commitment to treatment

The current study identified patient's acceptance of their diagnosis, together with the need and commitment to ART, as leading and crucial steps towards adherence to ART. This is concordant with findings of other published reports from Cote d' Ivoire, South Africa and the United states of America (Gilbert *et al.*, 2009; Godin *et al.*, 2005; Golub *et al.*, 2006). Eholie *et al.* (2007) identified that amongst the adults attending three HIV out-patient clinics in Abidjan, individual commitment was the strongest determinant for ART adherence.

Alcohol use

Our findings that excess alcohol intake being associated with forgetting to take medication corroborate with published reports from Ethiopia, USA and South Africa (Beyene *et al.*, 2009; Chander *et al.*, 2006; Nachega *et al.*, 2006; Mills *et al.*, 2006b). It was interesting to note that in the current study only the female patients and health care workers cited alcohol as a barrier to adherence, while male patients were unwilling to engage in an in-depth discussion on the topic. This may be attributed to the clinical setting in which this study was conducted. African culture being more accepting of men compared to women to consume alcohol whether in moderation or excessively may also have had an influence on men's reluctance to engage in the topic of alcohol.

Treatment success

This study found that improvement in health was a double edged sword when it intersected with adherence. Although good adherence to ART provided visible evidence of the benefits of

therapy in terms of improved well-being and regaining of normality to patients lives, the taking of the medication was also a constant reminder of their incurable infection. It is possible they avoid this constant reminder by missing on drugs.

Pill burden and side effects

The number, size of pills, and adverse drug reactions were not identified as barriers to adherence. This is similar to other studies especially from resource limited settings (Beyene *et al.*, 2009; Watt *et al.*, 2009; Weiser *et al.*, 2003) and is in contrast to results mainly from resource rich settings where pill burden and adverse drug effects were cited as major barriers to adherence (Fong *et al.*, 2003; Golub *et al.*, 2006; Ickovics & Meade, 2002).

Other possible reasons for this finding include advances in HIV therapeutics, with availability of fixed drugs combination (a combination of two or more drugs in one pill), simplification of dosing regimens and increase in the skills and competency of health care workers regarding the prompt diagnosis and correct management of adverse drug reaction. It was noted that the majority of the health care workers had worked at the Comprehensive HIV Care Clinic since its inception in 2003 and were highly skilled in ART provision.

While only a few patients in our study demonstrated late adverse effects of overt body image changes due to fat redistribution which did not affect adherence, more complaints are likely to arise in the future with increased survival of patients on ART across Africa and may impact on adherence in the long-term.

Disclosure and Social support

The positive influence of social support on ART adherence identified in this study has been well documented (Beyene *et al.*, 2009; Gardenier *et al.*, 2010; Luszczynska *et al.*, 2007; Nachega *et al.*, 2006; Remien *et al.*, 2003; Watt *et al.*, 2009). This vital support was forthcoming only after a patient's disclosure of his or her HIV status to close and loved ones. In this study disclosure was identified to be a critical positive step towards adherence as it was linked with acceptance of one's status and commitment to lifelong therapy. This is similar to results by Mills *et al.* (2006b), who in a systemic review of 84 studies examining barriers and facilitators to adherence, identified fear of disclosure as a consistent barrier from both developed and developing countries.

Modes of support demonstrated by partners included queuing for ones companion's prescription refills, reminders on drug intake and preparation of nutritious meals. This is in concordance to partner support reported from HIV clinic attendants in Johannesburg (Gilbert *et al.*, 2009). However, no female patient in our study reported receiving support from her male partner.

Stigma and discrimination

The enormity of stigma and discrimination reported in the community, family and even within hospital setting is cause for concern as it drove some patients to pursue HIV care and treatment at distant clinics, rather than risk being seen at nearby health facilities. This negatively affected adherence due to unavailability of resources to pay for their transport. Women reported fear of violence, abandonment and hardship from male partners making it difficult for them to disclose their HIV status and take their medications openly, thus impairing adherence. This is similar to findings by Murray *et al.* (2009) who reported fear of divorce, blame for bringing the virus home and violence as major barriers to acceptance and treatment adherence among urban Zambian women. The economic dependence of women on men has been cited as the likely cause of this discrimination. Newly diagnosed HIV positive pregnant women were identified as particularly vulnerable to stigma and discrimination; thus requiring special intervention. Despite the high levels of stigma and discrimination reported, this was overcome, by other positive factors such as motivation and acceptance of one's HIV status, and support from family and friends thus demonstrating the interrelated effects of many factors.

Religious practices

Findings from this study indicate poor adherence to medication by Muslim patients during the holy fasting month of Ramadhan. This is similar to reports from a clinical review indicating that up to 64% of patients arbitrarily change their drug intake timings and dosing without taking medical advice (Aadil *et al.*, 2004). Habib (2009) also reported that Nigerian patients altered their ART medication schedule to a median of 16.75 hours dosing interval (from the ideal of 12 hours interval). It is likely that fear of stigma and discrimination, the status of non disclosure of HIV infection in addition to a desire for spirituality drove Muslims to continue fasting during this month and become non adherent despite them being aware that they are exempted from fasting.

Alternate claims to healing and treatment

The reports by our patient participants on having used traditional medicine, suggests a high prevalence of use of traditional medicines amongst HIV infected persons in Kenya. The reports revealed in this study of spiritual healing and alleged seroconversion to HIV negative status as a barrier to ART have also been noted in Uganda (Wanyama *et al.*, 2007). The lure of being HIV-free appears irresistible even for patients having high treatment literacy as has been demonstrated in this study. Conflict between modern and traditional medicine was identified in this study where it was observed that traditional healers give instructions to patients to discontinue ART because they are “cured” of HIV, or the incompatibility of modern and traditional medicine. This conflict has been noted from many parts of sub-Saharan Africa and even from China (Eholie *et al.*, 2007; Fong *et al.*, 2003; Gilbert *et al.*, 2009; Kip, *et al.*, 2009., Watt *et al.*, 2009; Weiser *et al.*, 2003).

Food constraints

Despite ART being free at point of delivery, economic constraints other than the cost of the drugs have emerged as barriers to adherence. Lack of food which was identified as a barrier to adherence has been documented in other studies (Komu, 2008; Sankar *et al.*, 2006; Thobias, 2008). Patients reported fearing taking medication on an empty stomach and thus compromising adherence.

Transport cost

Transportation costs for clinic visits generally did not emerge as a factor influencing adherence in this study, possibly due to the urban location of the study site. It is also served by a good network of satellite health facilities and is easily accessible by public transportation. This finding is similar to studies from both rural and urban Zambia which did not report transport costs as a factor affecting adherence to ART (Carlucci *et al.*, 2008; Sanjobo *et al.*, 2008). Our results are in contrast to studies from sparsely populated areas such as Botswana, Namibia and rural Uganda where patients reportedly commute long distances, using unreliable transport to access care (Kip *et al.*, 2009; Komu, 2008; Hardon *et al.*, 2007; Thobias, 2008; Tuller, Bangsberg, Senkungu, Ware, Emenyonu & Weiser, 2009; Weiser *et al.*, 2003).

Employer's support

The study finding that shows that employers were not a barrier to adherence, but provided assistance to patients on ART is encouraging. This is likely to be a reflection of increased information regarding HIV/AIDS and ART that is abundantly available in the Kenyan media and may also be a consequence of work site programmes targeting organizations and high level managers which have been in place since 2000 in Mombasa (Family Health International, 2005). This is in contrast with studies from Botswana, Tanzania and Uganda which confirmed that patients often lose their jobs because of their HIV status (WHO, 2006).

The concerns of the employers that were demonstrated in this study on loss of employee productivity due to long waiting time in the clinics is a challenge to health care managers to improve efficiency in the clinic and ultimately improving adherence.

Health Systems constraints

The various health systems factors such as congestion in the clinics, long waiting time, staff shortages, negative staff attitude and a lack of privacy that negatively affect adherence, have also been noted in other parts of sub-Saharan Africa (Schneider *et al.*, 2006; WHO, 2006). A congested clinic makes it difficult to establish a trusting and confident patient-provider relationship, which has been identified to be a facilitator to ART adherence (Beyene *et al.*, 2009; Gilbert *et al.*, 2009; Remien *et al.*, 2003).

The comprehensive HIV care clinic at CPGH is a high volume site currently serving over 12,000 patients with over 5000 of them on ART. It has not undergone any infrastructural expansion since its launch in 2003, despite the exponential increase in the number of patients receiving ART. Countrywide, the number of patients receiving ART has increased by 37% from the year 2007 to 2008, placing Kenya as the country having the second largest number of patients on ART worldwide, second to South Africa (WHO, 2009). The strain of the HIV disease burden on the health care system reflected at the CCC is likely as a result of decades of economic crises; World Bank imposed structural adjustments programmes and declining public expenditure on infrastructure (Boulle & Ford, 2007; Van Rensburg-Bothuyzen, Engelbracht, Steyn, Jacobs, Schneider, & van Rensburg, 2008; McCoy *et al.*, 2005).

The reported factors of chronic staff shortage coupled with a negative staff attitude contributing to poor service delivery and poor adherence in our study have been documented in Botswana (Kip *et al.*, 2009). Migration of health care workers to resource rich countries and poor remuneration of the remaining staff are some of the reasons cited for the shortage (Schneider *et al.*, 2006). Recruitment of additional health care worker may improve patient-provider relations and thereby adherence. This however demands for secure funding, which is a challenge in resource limited settings. Kenya has yet to fulfil its commitment of the 2001 Abuja declaration to commit at least 15% of the total country budget for health financing. This commitment is actually on the decline, from 11.6% in 2000 to 7.8% in 2008, half of the desired target, an amount inadequate for the implementation of a successful health care system (WHO, 2010).

Health information

The poor health information system, identified in this study as a factor of delay in accessing care and increasing the congestion at the clinic, has also been documented in other studies (Kip *et al.*, 2009). In the current research setting the identified causes of the poor health information system were staff crises, shortage of filing space and an increased patient load, among other factors.

Dispensing of drugs

Even though the stand-alone queue at the CPGH pharmacy dispensing area was designed to improve efficiency with ART dispensing, it emerged in this study as a barrier due to lack of confidentiality. Stigma and discrimination against HIV infected patients by other hospital users also added to this situation. Similar findings were reported in Zambia by Sanjobo *et al.*, (2008), who noted that patients shun sitting on the bench meant for ART dispensing. In both these studies patients proposed that the ART be dispensed within the HIV clinics to reduce stigma, improve efficiency and encourage adherence (Sanjobo *et al.*, 2008). While this may be ideal, the staff crises being experienced compounded by lack of infrastructure and adequate finance, will make such a move challenging.

Of special note was that there were no reported stock-outs of ART drugs. This strength needs to be acknowledged and maintained as patient level adherence is dependent on an uninterrupted drug supply. This is in contrast to other reports from Botswana and Tanzania, which reported episodes of out of stock of ART, drugs (Mills *et al.*, 2006b; Kip *et al.*, 2009; WHO, 2006). The study site being one of the main distribution points for satellite sites in Coast Province, served with a good transport and communication system may have contributed to this success. In addition, as the ART programme has matured, there has been improved ART commodity management as a consequence of training and on the job experience.



CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

The results and discussion are summarised in the conclusion. A set of recommendations for improvement of adherence and future research are then presented.

6.1 CONCLUSIONS

This exploratory qualitative study on patients and health care workers at a comprehensive HIV care clinic in a general hospital in Kenya, demonstrates that influences of adherence to ART are complex and interrelated. Disclosure of one's HIV status and social support were identified as key facilitators for adherence of ART. Social support was however not always forthcoming from the immediate family especially during the early period following diagnosis. Stigma and discrimination was a major challenge to adherence. Domestic violence and male dominance in gender relationships were identified as barriers for women in their access to care which in turn influenced adherence negatively. The reported extent of stigma and discrimination that was present in the health facility from other (non-HIV) patients but also from health care workers was surprising.

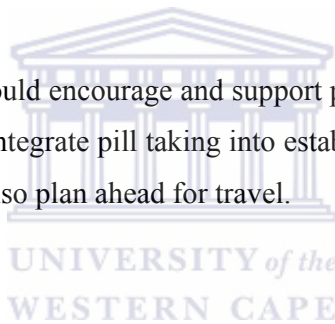
The health care system came under a lot of criticism from the patients, in not being able to respond adequately to the increased number of persons seeking HIV care. Congestion in the clinic, poor health information system and poor patient flow all added to long waiting time at the clinic which discouraged clinic attendance and in turn adherence. In contrast to patient's reports, health care workers described the health care system as good and working for the wellbeing of the patient.

Food insecurity and alcohol abuse were identified as barriers to adherence of ART. Surprisingly employers were found to be supportive of their employees accessing HIV care, but were not happy about the long hours the patients spend at the HIV clinic that compromise their economic productivity. The onus rests on health care providers to improve efficiency in the clinics and ultimately adherence to ART. Religious practises of faith healing, alternative cures for HIV infection and fasting were identified as barriers to adherence.

6.2 RECOMMENDATIONS FOR IMPROVEMENT OF ADHERENCE

Patient related

- Pre treatment risk assessment done at the onset of care for each patient should include detailed social history, level of acceptance of the disease, alcohol consumption, use of traditional medicine as well as religious beliefs and practises.
- At initiation of ART, each patient needs counselling sessions that should include steps to take during unscheduled travel and the consequences of non adherence. Patients should also be encouraged to attend the clinic with a treatment supporter.
- Adherence should be assessed at every visit and any underlying cause of non adherence identified and addressed.
- Patients abusing alcohol need to be linked with local organisations supporting responsible alcohol use.
- Health care providers should encourage and support patients to: use electronic reminders such as cell phones, integrate pill taking into established daily schedule such as listening to the news, and also plan ahead for travel.



Treatment related

- Fixed drugs combinations or co-formulated therapy should be offered as far as possible to reduce pill burden and simplify dosing schedules.
- Systems to monitor adherence by correlating remaining pill count to appointment schedules should be re-introduced.
- Muslim patients who are likely to observe the fast should where possible be offered once daily regimens.
- Future research is needed to explore the effect of late adverse drug reaction on adherence.

Social factors

- The health care worker should encourage and support patient's disclosure of their HIV status to their close and loved ones and to develop a network of friends or family members who can support the patient in taking their medication.
- Involvement of traditional healers in HIV care and treatment to maximize adherence. This view has however not been universally accepted by medical practitioners and who continue to view each other with suspicion. Until such an alliance becomes a feasible reality, continued counselling and community health education appears the best way of addressing the issue.

Economic Factors

- Introduction of food supplementation programmes through partnership support.
- Dispensing medication for three months to reduce the number of hospital visits and loss of earnings.

Health systems factors

- Peer review should be implemented for and by staff in order to improve staff moral and motivation.
- There should be employment of additional health information officers, increased file storage space and the introduction of an electronic medical record system so as to improve the health information system.
- Dispensing of ART should be done within the CCC.
- There should be an increase in the operating hours of the clinic to include weekends and public holidays.
- Health services should be decentralised with a shift towards community-based care and task-shifting away from physicians to trained nurses and from nurses to lay healthcare workers.

At the community level

- There should be linkages of patients on ART with support groups of PLHIV.

- There should be support provided for the establishment of organisations of women living with HIV. These should be linked with micro- finance institutions.
- There should be community outreaches using drama, music and skits to educate the community on the importance of adherence to ART and the need to support PLHIV.
- Community outreaches using drama and music targeting men in their workplaces and in areas they frequent such as sports events.
- The identification of and linkages with organizations in the community that work at supporting persons with hazardous alcohol use towards behaviour modification should be encouraged.
- Further studies are needed at the community level to identify the effect of traditional medicine, alcohol abuse, religious activities, and the interaction between genders, to adherence to ART.



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6.3 LIMITATIONS OF THE STUDY

This study had strengths and limitations that need acknowledgment. The fact that respondents were drawn from patients and health care providers can be seen as strength because views from the two different interest groups ensured that any information gap or bias from one group would be compensated by inputs from the other. The study was conducted by a social scientist, trained and experienced in qualitative interview techniques.

The study's limitations included the fact that it was conducted in a single site, a regional referral hospital, using a small sample size and focussing on only four FGD'S. The findings may therefore be too specific to apply to other settings.

Methodologies of data collection were limited to only one in this study; that of focus group discussion. It is possible that the exclusion of six patients who refused to participate in the

study for various reasons such as lack of time, living far away from the clinic, lack of fare to return for the discussion and pressure of work, may have introduced bias in the study.

As an insider in ART provision at the study site, I may have brought into the research my own experience and interpretations and therefore introduced bias. With this in mind, I made a purposeful effort to minimize the level of bias by not being present during the focus group discussions and relied on feedback from the moderator especially on the dynamics of group participation and non verbal communication. Errors may have been introduced during translation of the recorded discussion from Kiswahili to English language. This possibility was minimized by having a moderator cum transcriber who was fluent in both languages. Finally, it is likely that conducting the study in a hospital setting and using a social scientist as the moderator may have inhibited some patient respondents from expressing views which are contradictory to known health science norms and recommendations.



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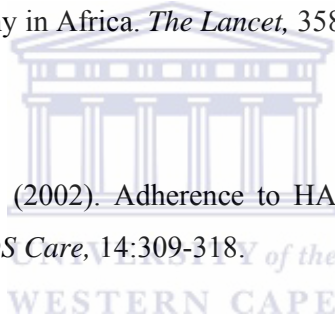
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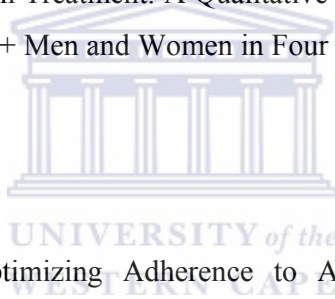
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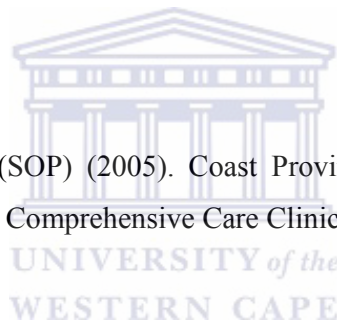
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APPENDIX1: Consent form for of Patients on ART to participate in FGD. (English)



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School of Public Health

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Tel: 021- 959 2809, Fax: 021- 959 2872

Consent from patients

STUDY: FACTORS AFFECTING ADHERENCE AMONGST ADULTS ON ANTIRETROVIRAL THERAPY AT CPGH, MOMBASA, KENYA.

I hereby agree to participate in research which discusses my experience and opinion regarding medication adherence as a patients taking ART at the Coast provincial General Hospital, Mombasa. I understand that I am participating freely without being forced to do so. I also understand that I can stop participating at any point, should I not want to continue and this will not in any way affect the services I receive in this institution.

I understand that this is study is done for the researchers' partial fulfilment of the Master's degree programme. Findings from this study could inform interventions to improve adherence to ART and its purpose is not to benefit me personally in the immediate or short term.

I understand that my participation will remain confidential and pledge not to repeat or pass any information acquired during the interview.

Signature of participantDate.....

Signature of Witness..... Date.....

APPENDIX -2- Patients consent form in Kiswahili



CHUO KIKUU cha WESTERN CAPE

Taasisi ya Afya ya Jamii

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Tel: 021- 959 2809, Fax: 021- 959 2872

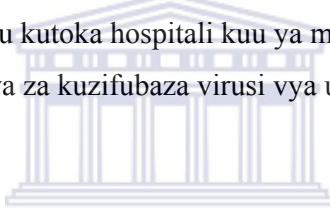


Fomu ya kuridhika kwa wagonjwa

**Sibabu za ufuatilizaji wa dawa za kuvifubaza virusi vya ukimwi ,
Mombasa, Kenya**

Mimi.....

Nakubali kujumuika na wenzangu kutoka hospitali kuu ya mkoa wa pwani, Mombasa, na kuzungumza juu ya utumiaji dawa za kuzifubaza virusi vya ukimwi.



Nafanya hivi bila ushawishi au tisho lolote. Naelewa yakwamba naeza kutoka kwenye utafiti huu wakati wowote ninapotaka. Naeleawa pia, huduma ninazozipata katika hospitali hii zitaendelea vile vile hata kama nikijitoe kwenye utafiti huu.

Nafahamu ya kwamba utafiti huu unatekelezwa na mtafiti mkuu kwa azma ya kupata shahada ya juu kutoka chuo kikuu.

Naelewa yakuwa, matokeo ya utafiti hayatanisaidia mimi binafsi sasa au karibuni bali yatatoa uongozo wa kusaidia wagonjwa wafuatilie vyema dawa za kuvifubaza virusi vya ukimwi.

Naelewa ya kwamba habari ya zoezi hili la utafiti hazitaelezwa kwa mtu yeyote asiyehusika, bali yatapeanwa kwa watafiti husika na daktari wangu.

Sahihi ya mshirikaTarehe.....

Sahihi ya shahidiTarehe.....

Appendix 3- Health Care providers consent form



UNIVERSITY OF THE WESTERN CAPE

School of Public Health

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Tel: 021- 959 2809, Fax: 021- 959 2872



STUDY: Factors affecting adherence amongst adults on Antiretroviral therapy at CPGH, Mombasa, Kenya.

I hereby agree to participate in the above research which discusses my experience and opinion as a health care provider regarding medication adherence amongst patients taking ART at the Coast provincial General Hospital, Mombasa. I understand that I am participating freely without being forced to do so and that the discussion will be audio taped for clarity and in order for the researcher not to miss any contribution. I also understand that I can stop participating at any point, should I not want to continue and this will not in any way affect my employment or services I receive in this hospital.

I understand that this study is done for the researchers partial fulfilment of the Master's degree programme. Findings from this study could inform interventions to improve adherence to ART and its purpose is not to benefit me personally in the immediate or short term. I understand that my participation will remain confidential.

Signature of participantDate.....

Signature of WitnessDate.....

Appendix 4- Participant information sheet.



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Tel: 021- 959 2809, Fax: 021- 959 2872

Request for your participation in a research

Thank you for your time and willingness to listen to me. I am Dr. Anisa Baghazal a student at the School of Public Health (SOPH), University of Western Cape (UWC). I would like to request for your participation in a research I am conducting. The research is for a Mini-Thesis – which is part of the requirement for a Masters degree in Public Health (MPH).

This is an explanation of the research project and your potential involvement.

The title of the research: Factors affecting adherence amongst adults on antiretroviral therapy at CPGH, Mombasa, Kenya.

Purpose of the study

This research is trying to understand the challenges the patients on ART are facing with regard to adherence of ART. It is hoped; with your participation a better understanding of the facilitators to successful adherence of ART within an African setting will be obtained and will guide the ART providers in developing interventions to better support patients on ART ultimately leading to improved outcome of patients on ART.

Description of the study

The study will consist of Focus Group Discussions with patients who are on ART and health care workers providing care at the CCC, CPGH. The discussions will be audio taped so as not to miss any contribution. The questions and discussion will evolve round your experience with ART. This study has been approved by the ethical committees of the University of Western Cape, University of Nairobi/KEMRI and Coast Provincial General Hospital.

Confidentiality

Your name will not be used but a standard code. Any information you volunteer will be kept confidential at all times. Should you agree to participate I shall keep all records of your participation including a signed consent form which I need from you, locked away in a secure location. Once the study is complete and had been analyzed and presented I will destroy all records.

Voluntary participation and withdrawal

Your participation in this study is entirely voluntary. Even if you choose to participate you may withdraw or stop at any time. You may also refuse to answer any particular question/s that is asked in the study. The services you and your family receive in this institution will not be affected in any way should you wish to withdraw or not participate in the study.

Benefits, costs and harm

There are no direct benefits, nor harm from this study. The information we will get from this study will guide us to support patients on ART with anticipated better ART success. There are no costs in participating from this study other than the time you will spend participating in the discussion. There will not be any other follow up once you have completed the discussion.

Informed consent

Your signed consent form is required before I proceed to interview you. I have included the consent sheet in this information sheet so that you can review it and decide whether you want to participate in this study or not.

Should you have any other questions or concerns please don't hesitate to contact me at the following addresses.

Dr Anisa Baghazal.

Room No. 11. Comprehensive HIV Care clinic (CCC) at Coast Provincial General Hospital.

Office Telephone No. 2314201 Extension 3424. Cell phone No. +254 723 549 747.

E Mail address drbaghazal@yahoo.com 2707383@uwc.ac.za

I am accountable to my supervisors

Dr. Brian Van Wyk

School of Public Health

University of Western Cape

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Appendix 5- Patients information sheet in Kiswahili



CHUO KIKUU cha WESTERN CAPE



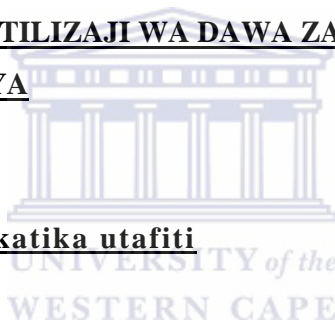
Taasisi ya Afya ya Jamii

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UTAFITI: SIBABU ZA UFUATILIZAJI WA DAWA ZA KUVIFUBAZA VIRUSI VYA UKIMVI, MOMBASA, KENYA

Ombi la kushiriki kwako katika utafiti



Asante sana kwa kunisikiza. Jina langu ni Dk. Anisa Baghazal, mwanafunzi katika taasisi ya afya ya jamii ilioko chuo kikuu cha Western Cape (UWC), Afrika Kusini. Ningependa kuomba ushiriki wako katika utafitio wangu. ninaoutekelezwa kwa azma ya kutimiza shahada ya juu katika masoma ya afya ya jamii. (Masters in Public Health)

Haya ni maelezo kuhusu utafiti na vipi wewe unaweza kushiriki

Kichwa cha Utafiti

Sibabu za ufuatilizaji wa dawa za kuvifubaza virusi vya ukimvi , Mombasa, Kenya

Sibabu ya utafiti.

Utafiti huu unajiribu kufahamu sababu za ufuatilizaji wa dawa za kuzifubaza virusi vya ukimwi (Antiretroviral Therapy, ART). Tunafahamu kwamba wagonjwa wanaotumia dawa hizi wanapata shida fulani kutekeleza maagizo ya wauguzi, na utafiti huu unataka kufichua hizi pingamizi pamoja na usaidizi ambao unarahisisha ufuatilizaji mzuri wa dawa za ART.

Utafiti huu hususan, unataka kufichua sababu hizi katika bara Afrika, na tuna imani kwamba pamoja na ushirikiano wako tutafaulu. Matokeo ya utafiti yanatarajiwa kutupa uongozo katika juhudi letu la kuboresha ufuatilizaji wa hizi dawa. Hii hatimae inatarajiwa kuleta matokeo bora ya dawa za kuzifubaza virusi vya ukimwi, (ART).

Maelezo ya utafiti.

Kutakuwa na makundi mawili ya wagonjwa, baina ya miaka 25 hadi 35, wanaotumia dawa za ART, (moja la wake na moja la waume). Kundi la tatu litakuwa ni la wauguzi wanaotoa huduma katika kliniki ya CCC. Kutakuwa na mazungumzo katika haya makundi, hasa maoni na uzoefu wako juu ya ufuatilizaji wa dawa za ART. Mazungumzo haya yatachukua muda wa saa moja yatarekodiwa katika chombo cha kurekodi sauti ili tusikose maoni yoyote.

Utafiti huu umeidhinishwa na jopo angalizi la utafiti kutoka chuo kikuu cha Western Cape, pamoja na chuo kikuu cha Nairobi na mkuu wa hospitali kuu ya mkoa wa pwani.

Usiri

Jina lako halitatumika wala kurekodiwa pahali popote, bali tutatumia jina la bandia. Ukikubali kushiriki, maoni yako yote yatahifadhiwa mahali pa faragha na hayato tolewa kwa watu wa nje. Ni kundi la watafiti wanaohusikana na utafiti huu tuu ambao wataweza kuona maoni yako. Ukikubali kushiriki nitakuomba uweke sahihi katika karatasi ya kibali, na hiyo pia nitaihifadhi mahali pa siri. Utafiti utakapo kamilika, kumbu kumbu zote zitafishwa.

Kukubali na kukataa kwako

Kushiriki kwako ni kwa hiari yako. Hata kama umeamua kushiriki unaweza kuamua kutoshiriki au kutojibu swala lolote wakati wowote, na huduma unazozipata wewe na familia yako, katika kituo hiki zitaendelea kama kawaida.

Faida, hasara au athari

Hakuna faida , hasara au athari kwako, kama utaamua kushiriki katika utafiti huu. Lakini, matokeo ya utafiti huu utatupa wauguzi muelekeo wa kuwasaidia wagonjwa wanaotumia dawa za ART.

Hakuna malipo ya kushiriki baada ya wakati utakao tumia wakati wa mazungumzo, na wala hatutokuota tena.

Ruhusa yako

Ni lizima utupe idhini yako ya kushiriki kwa kutia sahihi katika karatasi ya kukubali ambayo utapewa leo.

Kama una swali au wasi wasi wowote,tafadhali julisha wahusika ambao anwani zao ni-

Dk. Anisa Baghazal.

Chumba No. 11. Comprehensive Care clinic (CCC) katika hospitali kuu ya mkoa wa pwani.

Nambari ya simu ya ofisi. +254 2 314201 X 3424

Simu ya mkono +254 723 549 747.

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Appendix 6 INTERVIEW GUIDE FOR ART HEALTH CARE PROVIDERS

SECTION A: ICE BREAKER

(The aim of this section was to establish briefly how familiar they were with the CCC at CPGH.)

INTERVIEWER: I would like to begin our discussion by asking you to recall the history of this CCC. Your honest answers will help us with our study and guide the investigator to provide recommendations on how to improve service delivery at CCCs.

1. Can you tell us how long ago this CCC was established at CPGH? Do you recall the total estimated number of patients this CCC was designed to serve? *(Probe to establish whether the expected maximum number of patients has been reached or exceeded)*

SECTION B: CORE DISCUSSION

2. What is the current total number of patients visiting the CCC? In your opinion, does this CCC have capacity to serve all enrolled HIV infected persons? *(Probe to enquire why yes or why not?)*
3. What are the most common problems experienced by HIV infected persons attending this CCC? What about those on ART? *(Probe until they mention at least 4-5 problems and steer the discussion toward problems of medical adherence)*
4. How do you see the general level of adherence to medication among patients at this CCC? Why do you think that is so good or poor? *(Probe to establish % adherence for majority of patients and what proportion of patients have satisfactory adherence i.e. >95%. Also enquire about the average duration for satisfactory adherence e.g. 3 months, 6 months, 12 months, etc.)*
5. What is this CCC doing to promote medical adherence for patients on ART?

6. Can you describe any HEALTH CARE factors that you think may influence patients' adherence either positively or negatively. (*Probe each of the following one by one by enquiring how*)

STAFF: available workforce, experience, attitude, motivation

INFRASTRUCTURE: privacy

TIME: work load

OTHERS:

7. Have you observed any patient-related factors that you think could influence the ability of patients to adhere or not adhere to medication? (*Probe on the following factors one by one and ask respondents to cite examples of cases where available without disclosing patient details*)

Demographic: AGE; GENDER; EDUCATION LEVEL; MARITAL STATUS

Health status: clinical symptoms or WHO CLINICAL STAGES (*Probe: Do you see that patients who initiate ART at a latter e.g. stage 4 are better at adherence than those initiated in earlier stages?*)

Occupation: Factors at WORK? TRAVEL?

Family: Factors at HOME? DISCLOSURE TO PARTNERS? EXTENDED FAMILIES?

CULTURE: (*Probe for any common traditional beliefs and practices*),

SOCIAL EVENTS, BURIALS, WEDDINGS,

Religious: any religious factors? (*Explore fasting, religious crusades, faith healing*).

8. Identify other external factors that may influence medical adherence, i.e. not related to the patient or the health care system? (*If confused, give example of post-election violence*)
9. Finally, what recommendations do you suggest for improving medical adherence? (*Based on discussion, focus on critical patient factors, health system factors & external factors*)

Appendix 7 INTERVIEW GUIDE FOR PATIENTS ON ART

SECTION A: ICE BREAKER

1. Tell me about yourself, including how long you have known you are HIV positive and on ART?
2. How did you feel about it at first?
3. How did you feel about it now?

SECTION B: CORE DISCUSSION

TREATMENT FACTORS

1. Tell me about your experience with your medication?
2. What has been the effect of you taking your pills daily?
3. Probe positive and negative effect of treatment.
4. What makes it easy to take the medication?
5. What makes it difficult to take the medication?
6. Probe no of pills, adverse drug reaction.

INDIVIDUAL FACTORS

1. Tell are there any factors that affect taking medication? Probe Influence of Education, Individual commitment, Alcohol and miraa use?

SOCIAL/FAMILY

1. Tell me how is our family treating you?
2. Does your family know that you are on ART?
3. Are they affecting how you take your medication?
4. Probe how? Easy? Hard?
5. What about the community? Probe neighbours, friends. How are they treating you?
6. Are they affecting how you take your medication?
7. Probe how? Easy? Hard?

RELIGIOUS FACTORS

1. Tell me about your religious orientation.
2. Has religion affected how you take your medication?

3. In what way?
4. Have any of you heard of your friends attending prayer meetings religious crusades?
5. Had that influenced their medication adherence? In what way?
6. What about the Muslims in this discussion. Has the month of Ramadhan influenced your adherence in any way?

ECONOMY

1. Tell me about your work and work place.
2. Has your work place influenced your taking medication?
3. In what way positively? Negatively?
4. Has your employer/ work colleagues influenced your taking medication?
5. How do you come to the clinic? Any problems at accessing the clinic? Transport availability, Cost?

HEALTH SERVICE

1. Tell me about your experience during your hospital visits?
2. How are the staff and process, atmosphere?
3. Do those experiences influence your adherence?
4. How? Probe positively and negatively. Staff factors. Commodities?
5. Have you ever missed ART in the hospital?

RECOMMENDATIONS FOR IMPROVING ADHERENCE

- 9 Finally, what recommendations do you suggest for improving medical adherence?
(Based on discussion, focus on critical patient factors, health system factors & external factors)



KENYATTA NATIONAL HOSPITAL

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14th May 2009

Ref: KNH/UON-ERC/ A/217

Dr. Anisa Abdalla Baghazal
P O Box 90006
Mombasa 80100
KENYA

Dear Dr. Abdalla

Research proposal: "Determinants of Medication Adherence amongst Adults on Antiretroviral Therapy in Mombasa, Kenya" (P135/5/2009)

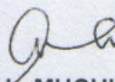
This is to inform you that the Kenyatta National Hospital Ethics and Research Committee has reviewed and **approved** your above cited research proposal for the period 14th May 2009 –13th May 2010.

You will be required to request for a renewal of the approval if you intend to continue with the study beyond the deadline given. Clearance for export of biological specimen must also be obtained from KNH-ERC for each batch.

On behalf of the Committee, I wish you fruitful research and look forward to receiving a summary of the research findings upon completion of the study.

This information will form part of database that will be consulted in future when processing related research study so as to minimize chances of study duplication.

Yours sincerely


DR. L. MUCHIRI
AG. SECRETARY, KNH/UON-ERC

c.c. The Chairperson, KNH/UON-ERC
The Deputy Director CS, KNH
Supervisors: Dr. Brian van Wyk
Dr. C. N. Muyodi
Dr. S.A. Abdalla