# TITLE: INTEGRATED MOBILE PHONE INTERVENTIONS FOR ADHERENCE TO ANTIRETROVIRAL TREATMENT IN CLIENTS WITH HIV INFECTION IN ACCRA, GHANA

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**DECLARATION**

I, GLADYS DZANSI declare that the dissertation entitled: "**. Integrated Mobile Phone Interventions for Adherence to Antiretroviral Treatment in Clients with HIV Infection in Accra, Ghana**" is my own work and has not been submitted for any other degree or examination in any other University other than the University of the Western Cape. I have given full acknowledgement to the resources referred to in my study.

**DEDICATION**

This thesis is dedicated to the memory of my parents Miss Catherine Ziangro and David Gregory Kodjo Djansi who inspired me to make strong case in my believe that “We can achieve our dreams if only we believe”

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Let God be praised for I am forever grateful for His saving grace, indeed he directed my steps. For if it has not been for the Lord who was on my side...*Psalm 124.*

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## ABSTRACT

Mobile phone interventions such as text messaging have been used to improve treatment adherence globally and in sub-Saharan Africa. Nevertheless, integrated mobile phone intervention for adherence support in Ghana, has not been greatly extensively explored. An explanatory integrated mixed method research approach was employed within the context of a pragmatic paradigm to conduct a study in three phases.

In phase one; a randomised control trial was done to determine the effect of mobile phone intervention on adherence in a two groups (Intervention and Control). Respondents (n = 362) age 18-60 years, HIV seropositive, with access to mobile phone were recruited and followed-up for six months.

The Control group received standard care while the Intervention group received standard care, alarm prompting, weekly text messages and monthly voice calls. The implementation of interventions was based on King's transactional model of goal attainment while the logic model was used for intervention evaluation.

Primary (overall adherence: Self-report, visual analogue, pill identification, pill count) and secondary (CD4 count and Body Mass Index) outcomes were measured at baseline, month three and month six. In phase two, individual interviews were conducted with six clients and two health professionals; three focus group discussions were held with participants from the Intervention group at month six.

Additionally three documents (guideline of antiretroviral therapy) were reviewed. Phase three involved synthesis of data, engagement with stakeholders for feedback on study outcome and recommendations. Ethical approval was obtained and the right of participants protected throughout the study. The mean age was 44.4 (*SD* = 9.82) with more females (n = 228, 63%) while 306 (84%) had basic education.

Respondents were highly adherent at baseline (n =255, 70%) month three (n = 176, 80%) and month six (n = 180, 67%). Evaluation of intervention revealed Overall adherence outcome for the three timelines in the Intervention (*M* = 99.2, *SE* = .059, *CI* = 99.1, 99.4) and Control (*M* = 99, *SE* = .066, *CI* = 98.9, 99.2) groups was statistically significant *F* (1, 2547) = 4.24, *p* = .04. The observed change occurred in both groups; therefore not attributable to the treatment. Intervention was rated as helpful and qualitative outcomes show a readiness for integration of mobile phone in care.

Preference was expressed for alarms and voice calls with scepticism about the use of text messages. Adherence was facilitated by adherence counselling, improvement in patient's wellbeing, self-consciousness and fear of death while

sleep and work schedule were among the barriers. Resource availability, technology and literacy gaps pose major barriers to the use of mobile phones in adherence support. A task-shifting algorithm and brochure was developed and proposed as a guide in the integration of mobile phones for improving adherence; pending resolution of issues relating to policy framework and resource mobilisation.

**Key words**: Mobile phone intervention, adherence, optimal adherence, sub-optimal adherence, poor adherence, non-adherence, antiretroviral therapy

**ABBREVIATIONS**

3TC - Lamivudine

AIRTP - Fogarty International AIDS Training and Research program

ART - Antiretroviral therapy

ARV - Antiretroviral drugs

AZT - Zidovudine

BARS - Brief Adherence Rating Scale

BMI - Body Mass Index

CD4 - Cluster of differentiation 4

CI - Confidence Interval

DGT - Dolutegravir

DMC - Data Management Committee

EFV - Efavirenz

FTC - Emtricitabine

GAC - Ghana AIDS Commission

GHS- Ghana Health Service

GSS- Ghana Statistical Service



HAART - Highly Active Antiretroviral Therapy

HCT - HIV Counselling and Testing

HBM - Health Belief Model

ICT - Information Communication and Technology

IMPI - Integrated mobile phone intervention

IMPIMA - Integrated Mobile Phone Intervention for Monitoring Adherence

M - Mean

MASRI - Medication Adherence Self-Report Inventory

MEMS - medication event monitoring system

MMAS - Morisky Medication Adherence Scale

MPR - Medication possession rate

NACP - National AIDS Control Programme

NGO - Non-governmental organisation

NNRTIs - Non-nucleoside reverse transcriptase inhibitors

NRTIs - Nucleoside or nucleotide reverse transcriptase inhibitors

NVP - Nevirapine

PDC - Proportion of days covered

PI - Protease inhibitors

PIT - Pill Identification Test

PLWHIV - Persons Living with HIV/AIDS

PMTCT - Prevention of mother-to-child transmission

PPU - Pill pick-up

RCT - Randomised control trial

SCT - Social Cognitive Theory

SD - Standard Deviation

SDG- Sustainable Development Goals

SMS - Short Message Service

SPSS - Statistical Package for the Social Sciences

SR - Self report

TDF - Tenofovir disoproxil fumarate

TPB - Theory of Planned Behaviour

TRA - Theory of Reasoned Action

TSC - Trial Steering Committee

UNAIDS - The Joint United Nations Programme on HIV/ AIDS

VAS - visual analogue scale

VAS - Visual Analogue Scale

WHO - World Health Organization

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# CHAPTER 1: INTRODUCTION AND BACKGROUND OF STUDY

## 1.1 INTRODUCTION

The introduction of Antiretroviral Therapy (ART) in the management of persons living with HIV represented a major boost to efforts aimed at combating the HIV epidemic (Broder, 2010; UNAIDS, 2016a). Consistent with all treatment regimens, adherence to the ART remains crucial in the fight against HIV. Clients on ART are expected to take medication strictly 95% of the time if the desired effect of suppressing the virus is to be achieved (Ankrah, Lartey, Agyepong, Leufkens, & Mantel-Teeuwisse, 2015; Kalichman et al., 2015; Kobin & Sheth, 2011).

Providing adherence support via information technology is an emerging trend that has the potential to provide greater efficiency in the delivery of health services to clients on ART, if used appropriately (Granger & Bosworth, 2011). The use of text messaging to improve adherence has been reported as an effective intervention in studies since 2009 (Bärnighausen et al., 2011; Horvath, Azman, Kennedy, & Rutherford, 2012; Lester et al., 2009), though this has not been examined in terms of usability and acceptance in all socio-cultural contexts.

The mobile or cell phone is one of the hand-held technology devices that are being explored globally to support health care. Access to mobile phones in developing countries is improving tremendously. The mobile phone subscriber base for Sub Saharan Africa is estimated at 367 million people as at 2014, with an increasing penetration rate which is expected to reach 49% by 2020 (GSMA-Intelligence, 2015). Smart phone ownership is also projected to increase from 3%

in 2010 to 52% by 2020 (GSMA-Intelligence, 2015). Other reports suggest that about two thirds of the general population in Africa own and use mobile phones (Poushter & Oates, 2015). The anticipated increase in access to mobile phones provides the opportunity for the beneficial integration of mobile phone interventions in health care - referred to as Mobile health or M-health. M-health has been permeating various aspects of healthcare and developed countries are now using mobile health care for purposes such as adherence monitoring, clinic visit reminders, motivational therapies and surveillance and research (PHilbriCk, 2013; Postolache, Girão, & Postolache, 2013). M-health has been used in interventions relating to clients care and health staff development. More specifically, M-health has supported projects in HIV, malaria, tuberculosis and maternal health (Aranda-Jan, Mohutsiwa-Dibe, & Loukanova, 2014). Health professionals use M-health for improving supply chain management, disease surveillance, collecting health data and providing health education to clients (Aranda-Jan et al., 2014). Mobile phones will continue to be with us for the foreseeable future and more sophisticated applications, for them, are being introduced continuously.

In Africa M-health care is emerging with prospects of bridging some communication gaps and creating access to healthcare information and services (Horvath et al., 2012; Kaplan, 2006; Pop-Eleches et al., 2011). Evidence suggests that mobile phones have been used to improve adherence to different treatments in different populations (Bosworth et al., 2005; Gurol-Urganci, de Jongh, Vodopivec-Jamsek, Atun, & Car, 2013; Horvath et al., 2012; Thirumurthy & Lester, 2012).

WHO has recommended that mobile phone text messaging be used to support adherence based on moderate evidence about its effectiveness (WHO, 2013). Nevertheless, there is limited information about HIV clients receiving antiretroviral treatment in Ghana using mobile phone to support adherence.

The focus of this chapter is to introduce the study and provide some background on the study by exploring the burden of HIV, and examining issues of antiretroviral treatment adherence and the use of mobile phones in adherence support. The background, problem statement aims, objectives, research questions, significance of the study and the conceptual framework will be presented.

## 1.2 BACKGROUND

The detection of Human Immunodeficiency Virus (HIV) in the 1980's, increased the global burden of illness. HIV is a retrovirus that attacks the cells of the immune system disrupting their ability to defend and protect the body from infection (De Clercq, 2010; WHO, 2015b). Over time the infected person becomes more susceptible to infections due to the disruption of their immune system. HIV then progresses to Acquired Immune Deficiency Syndrome (AIDS) which is characterised by lowered immunity, exposure to opportunistic infections and psychosocial problems (WHO, 2015b). Sexual transmission remains the major method by which the virus is spread, with other modes of transmission including the transfusion of contaminated blood, sharing of contaminated needles and mother-to-child transmission during pregnancy, childbirth and breastfeeding (WHO, 2015b). However, the activities of the virus can be disrupted with antiretroviral drugs (ARV) when taken as prescribed.

## 1.3 PREVALENCE OF HIV/AIDS INFECTIONS

The burden of HIV continues to increase, although new HIV infections decreased from 3.1 million in 2002 to 2.7million in 2010, the number of people living with HIV (PLWH) increased from 29.5 million to 34 million (WHO, UNICEF, & UNAIDS, 2011). These figures suggest a decrease in new infections but nevertheless the burden of care continues to increase. Notably, access to antiretroviral therapy increased from 3 million in 2002 to 6.65 million in 2010 (WHO et al., 2011). More recent data indicates an estimated 18.2 million people were receiving ARV as at June 2016 (UNAIDS, 2016a). The increase in the access to treatment has implications for monitoring adherence and retention in treatment because these are key considerations for optimising treatment outcome (Holtzman, Brady, & Yehia, 2015). Improving access to ART should be analogous with interventions that promotes individual adherence to treatment.

### 1.3.1 Prevention and new HIV/AIDS Infections



Data on the HIV epidemic from the Joint United Nations Programme on HIV/ AIDS (2014) shows a steady decline in the rate of new infections. The estimated global rate of new infections declined from 3.1 million in 2000 to 2 million in 2014 (UNAIDS, 2015). New infections in children declined by 58% from 520 000 in 2000 to 220 000 in 2014 (UNAIDS, 2015). The global trend depicts a reduction in the burden of new HIV infections; however the rates of infection among high risk populations continue to pose a major threat especially in areas where sexual discrimination persists (Beyrer et al., 2012; Figueroa et al., 2013; WHO & UNAIDS, 2015).

There have been differences in the reporting of estimated new infections across regions, with most regions reporting declines in new cases. However, increases were reported in two regions; Eastern Europe & Central Asia and the Middle East & North Africa (UNAIDS, 2015). Despite Sub Saharan Africa being the worst affected with 66% of the overall global estimate of new infections, Sub Saharan Africa has nevertheless, experienced a 41% decline in new HIV infections since 2000 relative to the 2014 report on new HIV infections. Decline in new HIV infections by 50% occurred in the Caribbean, 31% in Asia and the Pacific, and 17% in Latin America. The United State of America recorded more than 50% of the 85,000 new cases that were reported in Western and Central Europe and North America. There was a 30% increase in new HIV infection in Eastern and Central Europe. Similarly, a 26% increase in new HIV infections was reported in the Middle East and North Africa (UNAIDS, 2015).

The WHO's vision is to ensure zero new infections, with the aim of preventing sexual transmission in all populations including men who have sex with men, commercial sex workers and drugs users (WHO & UNAIDS, 2015). A premium is also being placed on eliminating mother-to-child transmission, the scaling up of voluntary testing and counselling services and the screening of mothers during antenatal services (Bertozzi et al. 2006; Delva et al. 2012; WHO & UNAIDS, 2015). In the field of prevention, behavioural change interventions have positively contributed to the gains made in reducing the rate of new infections, though the utilisation of behavioural change and related models as a response strategy for addressing HIV/AIDS remain diverse (Kippax, 2012; Melkote, Moore, & Velu, 2014). While the argument for a cultural context approach has been suggested as

a more responsive strategy in the prevention of HIV/AIDS (Bojko, Dvoriak, & Altice, 2013; Kippax, Stephenson, Parker, & Aggleton, 2013)

In addition to prevention, specifically targeting populations at high risk for screening and treatment has been identified as a key strategy to reduce the burden of HIV/AIDS globally (Cohen et al., 2011). Reducing new infections is directly linked to curbing the burden of HIV/AIDS related illnesses and deaths. In this context, the use of ART, in identifiable risk groups, which further seeks to reduce the burden of new HIV infection in all populations is central (Cohen et al., 2011). The arguments for early initiation of treatment in all HIV infected people to improve health outcomes in spite of the cost implication of such decisions have been promoted (Zwahlen et al., 2009).

### 1.3.2 Burden of HIV/AIDS Mortality and Morbidity

With the decrease of HIV/AIDS related deaths, the burden of people living with HIV/AIDS has increased. The Joint United Nations Programme on HIV/ AIDS (UNAIDS) 2015 fact sheet indicated HIV/AIDS related deaths were high in the early stages of the epidemic. In 2003 to 2006 an estimated 2 million people died from HIV/AIDS related causes annually but AIDS deaths have steadily declined by 42% to 1.2 million deaths in 2014 (UNAIDS, 2015).

Globally AIDS mortality outcomes have improved across all regions (UNAIDS, 2015) and the focus on minimising the impact has continued to drive many of the intervention strategies globally, with the understanding that the reduction in the death rate will shift the burden as more people will be living with the illness and will require treatment (UNAIDS, 2015). In this context, the number of people living with HIV/AIDS continued to increase worldwide following the scaling up of

voluntary counselling and testing, prevention of mother-to-child transmission (PMTCT) and antiretroviral therapy over the years.

These initiatives, while reducing death, have led to more survivors and HIV is now considered a chronic illness (Deeks, Lewin, & Havlir, 2013; Siegel & Lekas, 2002 with PLWHIV increasing from 28.6 million in 2000 to 36.9 million as at March 2015 (UNAIDS, 2015). Access to treatment also increased from 6.1 million people in 2009 to 15 million globally as at March 2015. The burden of ensuring access to ART is more intense in sub-Saharan Africa with five (5) of every seven (7) people receiving antiretroviral drugs being from sub- Saharan Africa. A total of 10.7 million people from this region were receiving treatment in 2015 compared with 100,000 in 2002 (UNAIDS, 2015).

A second burden associated with HIV/AIDS is the prevalence of co-morbidities (Lorenc et al. 2014; Wilson et al. 2012). As new infections continue to occur and HIV related deaths continue to reduce more and more people will be receiving ART, and co-morbidities will be unavoidable. The difficulty of ensuring adherence to treatment through the provision support will also increase. HIV/AIDS has created social and economic burdens since the first case was reported approximately 34 years ago. Co-morbidities such as hepatitis, mental health disorders and cardiovascular disease were observed following a point prevalence-audit in the Brent Primary Care Trust with a minimum co-morbidity of one being present in every person living with HIV/AIDS (Lorenc et al. 2014). Rodriguez-Penney et al. (2013) reported that the burden was worse in older people living with HIV/AIDS.

One of the biggest co-morbidities in HIV/AIDS is tuberculosis co-infection. Evidence suggests that there is the possibility of TB resurfacing in persons infected with HIV, due to immunodeficiency and related cellular activities, which had previously been treated for TB (Pawlowski, Jansson, Skold, Rottenberg, & Kallenius, 2012). The emergence of HIV/AIDS and TB co-infection was a major setback in the response strategy until TB screening and treatment was initiated in HIV infected persons and vice-versa (Bruchfeld, Correia-Neves, & Källenius, 2015; Sharma, Mohan, & Kadhiravan, 2005).

### 1.3.3 Socio-economic Burden of HIV/AIDS Infection

In addition to co-morbidities, HIV/AIDS infections are accompanied by socio-economic difficulties. Issues of stigma, discrimination, employment, income, housing, food security, and poverty continue to be a major challenge (Amuri, Mitchell, Cockcroft, & Andersson, 2011; Falagas, Zarkadoulia, Pliatsika, & Panos, 2008; Sadoh & Oviawe, 2007). Previously, access to treatment was a major barrier, however, the scaling up of access to treatment has made a difference (UNAIDS, 2015; WHO & UNAIDS, 2015). The direct and indirect costs of treatment and nutritional issues continue to engage the attention of many researchers (Adedigba et al., 2009; Amuri et al., 2011; Apanga, Punguyire, & Adjei, 2012).



However, the socio-economic factors associated with the HIV/AIDS epidemic created a burden on families and opportunities for managing the epidemic with social support generally contributed to reducing the burden of HIV/AIDS on the infected individuals and their families (Wohl et al., 2011).

## 1.4 ANTIRETROVIRAL TREATMENT AND ADHERENCE

The introduction of Highly Active Antiretroviral Therapy (HAART) commonly referred to as antiretroviral therapy (ART) marked a major milestone in addressing the burden of HIV/AIDS.

ART consists of different drug combinations that act by suppressing the replication of the virus, thereby improving CD4 count levels (Mocroft et al., 2003; Walsh, Pozniak, Nelson, Mandalia, & Gazzard, 2002). It is administered to HIV positive clients, including pregnant women with a CD4 count of less than 350 cells /ml and / or symptomatic with HIV infection in WHO clinical stage three (3). Pregnant women may be put on ARV prophylaxis from the week 14 of gestation if the CD4 count is greater than 350. Antiretroviral Therapy is restricted in clients who have low motivation, a lack of interest, or who fail to complete two adherence counselling sessions or who have severe hepatic problem or a terminal disease (NACP, 2010). Currently the eligibility criteria for initiating ART have been further reviewed and access to treatment expanded.



### 1.4.1 Adherence support measures and mobile phone interventions

Adherence is the behavioural changes required to diet, activity and lifestyle that are required for an individual to strictly follow the prescribed medication regimen. Adherence requires self-regulation and keeping of appointments with practitioner(Cohen, 2009; O'Donohue & Levensky 2006).

In the early days of the HIV epidemic when ART was introduced, clients were expected to take several pills numerous times in a day. Consequently, the number

of pills, timing, side effects and change in regimen accounted for non-adherence in some clients (de  Bonolo et al., 2005; McNabb, Nicolau, Stoner, & Ross, 2003; Weiser et al., 2003). The quantity of pills, the dosage, and the side effects have been minimised with the introduction of single dose therapies and other measures (Hanna et al., 2014; Nachega et al., 2014).

Interventions such as treatment supporters, directly observed therapy, diary cards, food rations and text messaging via mobile phone have been used to improve treatment in sub-Saharan Africa. However,  (Bärnighausen et al. (2011) reviewed evidence of the various interventions aimed at  increasing adherence and noted that, although these measures were effective, context specific randomised control trials were needed to determine their implementation in sub-Saharan Africa.

The expansion of the telecommunication sector in Sub-Saharan Africa provides the opportunity to explore how mobile phone technology could be integrated into health care particularly in improving adherence. Text messages are the most commonly used mobile phone application in treatment adherence. Weekly text messaging was observed to improved adherence levels and the quality of life in HIV infected clients in a randomised control trial done in Nairobi, Kenya (Lester et al., 2010; Lester et al., 2009). A meta-analysis of the two studies concluded that weekly text messaging increased adherence and improved outcomes, and the number of HIV infected clients lost to follow-ups could also be reduced by setting reminders on mobile phones and sending text messages to clients. Additionally, clients' mobile phone alarms could be set at medication times as a form of reminder that ensures the prompt taking of pills ( Horvath et al. (2012).

### 1.4.2 Contextualising Antiretroviral Therapy, Adherence and Mobile Phone Interventions in Ghana

Although the prevalence rate of HIV in Ghana declined from a peak of 3.1% in 2003 to 1.5% in 2010, the population of HIV infected clients continues to increase (NACP, 2010b). The National AIDS/STI Control Programme (NACP) invested in the provision of highly active ART for prevention and management of opportunistic infection and continuous supportive counselling. The NACP 2010 Annual Report indicated that ART sites were increased from two (2) in 2003 to one hundred and thirty-eight (138) in 2009. However, People living with HIV/AIDS (PLWHIV) lost to follow-ups continue to increase while published data on adherence levels in this population in Ghana is limited. The possibility of using text messaging on mobile phones as a method of intervention has emerged.

The penetration of mobile phones in Ghana increased from 34 million in November, 2015 to 35 million in March 2016 (Laary, 2016). The ownership of phones is estimated at 85% (GSS, GHS, & ICF International, 2015) and there is strong advocacy for expanding the telecommunication sector and further reducing the cost of services (GSMA-Intelligence, 2015). Anecdotal evidence suggests that there is a mobile phone in every household in Ghana. Individual family members who do not have access to their own phone, make use of phones of other family members (Burrell, 2010). Records from the Korle Bu Teaching Hospital showed that about 95% of clients with HIV have supplied mobile phone number (Fevers-Unit-KBTH-Biostatistician, 2013). Mobile phones also have been used in other settings to promote medication adherence (Bärnighausen et al., 2011; Belzer et al., 2015; A. Chib, van Velthoven, & Car, 2015; Georgette et al., 2016). Exploring

the opportunities for using mobile phone in supporting medication adherence in HIV infected clients is worthwhile.

## 1.5 PROBLEM STATEMENT

Personal adherence to ART requires that clients complete all cycles of medication and strictly follow timing, dosage, lifestyle modifications and medication replenishments consistently (O'Donohue & Levensky 2006). Reports from ART services in Ghana suggest that there is a suboptimal adherence in this population. In 2009, a report revealed an estimated 85% of adults adhering to treatment (NACP, 2010b). In a more recent study, 90% of clients reported for scheduled follow-up visits, however, adherence levels were estimated to range between 41-76.7%, depending on the type of medication clients were receiving (Obirikorang, Selleh, Abledu, & Fofie, 2013b).

In the context of the current HIV/AIDS epidemic and the advent of ART, a focus on adherence and the influence of institutional and personal factors (Mannheimer & Hirsch-Moverman, 2015) contributing to adherence has been examined in various populations, but have been least explored among the current population in Ghana. Country specific reports among some Ghanaian clients on treatment adherence noted inhibiting factors such as perceived and actual side-effects of medication, forgetfulness, number and size of the pills, food restrictions and failure to replenishment medication affected adherence outcomes (NACP, 2014a). Other factors for suboptimal adherence included being away from home, running out of medication and not having food (Obirikorang et al., 2013b).

Text messaging in low resource countries has become one of the most widely-used adherence support interventions (Lester et al., 2010; Pop-Eleches et al.,

2011), with some success reported in the use of text messaging and voice calls (Abbott & Coenen, 2008; Cole-Lewis & Kershaw, 2010; Cook, McCabe, Emiliozzi, & Pointer, 2009; Fraser et al., 2005; Horvath et al., 2012). Currently adherence interventions used in Ghana include adherence counselling and the use of treatment supporters. However, there are no published studies on mobile phone or text messaging support of adherence. Some non-governmental organisations have piloted the use of text messaging as an adherence support measure but the outcomes have not been published.

There is a paucity of literature on adherence intervention for clients infected with HIV in Ghana and very little on mobile interventions to facilitate adherence. International evaluations of mobile interventions are limited and have a narrow focus. Only a few studies employed a mixed method design, rigorous evaluations using randomised controlled trials and multilevel adherence assessments to determine adherence and the influence of other variables such as integrated mobile phone interventions. In addition, few studies have used theoretical frameworks or nursing specific models to support adherence.



There is a need to examine factors influencing adherence to inform interventions for improving adherence with strategies that relate to the specific needs of the client for adherence support. In addition, there is a need to examine and evaluate integrated mobile phone interventions using a theoretical framework such as the goal attainment framework, proposed by King, to assist in identifying adherence needs, planning strategies and maintaining feedback. To this end, the following study was proposed.

## 1.6 THE STUDY

### 1.6.1 Aim of the Study

The aim of the study was to evaluate the integration of mobile technology in routine nursing practice to improve and support adherence to ARTs in PLWHIV in Accra, Ghana.

The findings of the study were intended to facilitate the planning, implementation and integration of a mobile phone based adherence monitoring strategy as part of existing adherence support measures.

### 1.6.2 Research Objectives and Questions

There were four research objectives, and the related research questions were presented after each objective.

**Research objective one**



To assess adherence to treatment among HIV infected clients in Accra, Ghana before during and after an integrated mobile phone technology intervention to support adherence.

**Research Questions**

a. *What is the level of treatment adherence in HIV infected clients at baseline assessment?*
b. *What is the level of adherence in HIV infected clients at month three and months six?*

**Research objective two**

To identify the demographic, clinical variables and support measures that may predict ART adherence in *HIV infected clients*.

**Research Questions**

a. *What demographic characteristics of HIV infected clients predict adherence to ART?*
b. *Which clinical variables of HIV infected clients predict adherence to ART?*
c. *What adherence support measures predict adherence to ART in HIV infected clients?*

**Research objective three**

To evaluate the effectiveness of using mobile phone interventions to promote ART adherence among HIV infected clients.

**Research Questions**

a. *What are the mobile phone usage practices among HIV infected clients?*
b. *What are the differences between the intervention group and the control group of HIV infected clients following the usage of integrated mobile phone interventions?*
c. *How did phone alarm, text messaging and voice calls influence adherence behaviour in HIV infected clients on ART?*

**Research objective four**

To evaluate the experiences of HIV infected clients and the perspectives of significant others in integrating mobile phone interventions in ART adherence support.

a. *What experiences of HIV infected clients are associated with HIV diagnosis and treatment?*

b. *What are the experiences of HIV infected clients in relation to treatment adherence?*
c. *What are the experiences of HIV infected clients in using integrated mobile phone interventions?*
d. *What are the perspectives of HIV infected clients and professionals in integrating mobile phone interventions in adherence support?*
e. *What are the existing health service policies and guidelines on integrating mobile technology in adherence?*

**Research objective five**

To make recommendations for integrating mobile phone interventions in health service adherence monitoring strategies

**Research Questions**

a. *What are the outcomes and implications of using an integrated mobile phone ART adherence support strategy?*
b. *What measures could be implemented in order to integrate mobile phone interventions in adherence support in health service adherence to ART support strategies*

### 1.6.3 Hypothesis

a. No significant clinical, demographic and adherence score differences will be observed between the intervention and control groups at baseline
b. Significant differences will be observed in adherence scores between the intervention and control groups across timelines (Time 1, 2 and 3)

c. Significant differences will be observed in each study arm across timelines (Time 1, 2, and three).

d. Selected demographic variables, clinical variables and adherence support measure will predict adherence to treatment.

## 1.7 OPERATIONAL DEFINITIONS OF TERMS

The following terms have been operationalised for this study (Table 1: Definition of Terms)

***Table 1: Definition of Terms***

| Term | Definition |
|---|---|
| Antiretroviral therapy | This is the combination of at least three retrovirus suppressing drugs that reduce the replication of these viruses and stop HIV disease progression (http://www.who.int/hiv/topics/treatment/en/, accessed/9/1/2013) |
| Adherence | "The extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (Haynes,1979; and Rand, 1993 in WHO, 2003)<br>*Operational definition:* Scoring overall 95% or more on self-report, Pill identification test, Visual analogue scale and pill count |
| Experts | *Operational definition:* stakeholders involved in policy planning, implementation and evaluation on ART |
| Goal attainment | *Operational definition:* A state of client satisfaction with mutually agreed upon actions and interactions. |
| Health Professionals | *Operational definition:* A person certified to provide health care services to clients |
| HIV infected clients | *Operational definition:* Individuals who have been clinically diagnosed and confirmed to have HIV irrespective of the stage of the infection |

| Term | Definition |
|---|---|
| Inputs | *Operational definition:* resources and measures included in the planning and implementation of the process of integrated mobile phone interventions for adherence to ART project |
| Integrated Mobile phone intervention | *Operational definition:* the use of alarm, text message and voice call to monitor clients on medication, give feedback and maintain interaction between client and caregivers |
| Mobile phone | A hand held electronic device that is able to generate and receive signals that allows for setting alarm, sending text messages and placing and receiving voice calls |
| M-health | 'The delivery of healthcare services via mobile communication devices'(Solanas et al., 2014) |
| M-health interventions | *Operational definition:* The delivery of health care service and related health information through the use of mobile phone applications |
| Non-adherence | Non-adherence is defined by Merriam Webster dictionary as "a lack of adherence"<br><br>*Operational definition:* Failure to take medications as prescribed and missing medication replenishment appointments |
| Optimal adherence | *Operational definition:* Taking prescribed medication at the right time and dose consistently for more than 95% of the time and following recommended dietary/lifestyle changes |
| Outcomes | *Operational definition:* The expected and actual effects of implementing measures included in the integrated mobile phone interventions for adherence to ART project |
| Outputs | *Operational definition:* The measurement indicators used to determine the impact of integrated mobile phone interventions for adherence to ART |
| Process evaluation | *Operational definition*: The systematic assessment of inputs, activities, outcomes, and output in the integrated mobile phone interventions for adherence to ART project |
| Poor adherence | *Operational definition:* Taking medication for less than 75% of the time, taking wrong dose and failing to follow recommended diet lifestyle changes |

| Term | Definition |
|---|---|
| SMART phone | Hand held electronic device with the ability to initiate and receive radio signals, store, process and transmit data similar to the functions of computer operating systems (Free et al., 2013) |
| Suboptimal adherence | *Operational definition:* Taking prescribe medications at right dose and time for less than 95% and more than 75% of the time as measured with the multi-method adherence tool |

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## 1.8 CONCEPTUAL FRAMEWORK FOR STUDY

Two frameworks were used for the study, namely the Goal Attainment Theory and the Logic Model.

### 1.8.1 Goal Attainment Theory (Imogene King)

Goal attainment theory was proposed by King as a micro level theory of her systems theory. King's goal attainment theory focused on the patient-nurse relationship that is aimed at setting mutual goals and exploring strategies for the attainment of the set goals (King, 1981 in Fitzpatrick & Wallace, 2006). King noted that perceptual accuracy, role congruence and communication in nurse-client



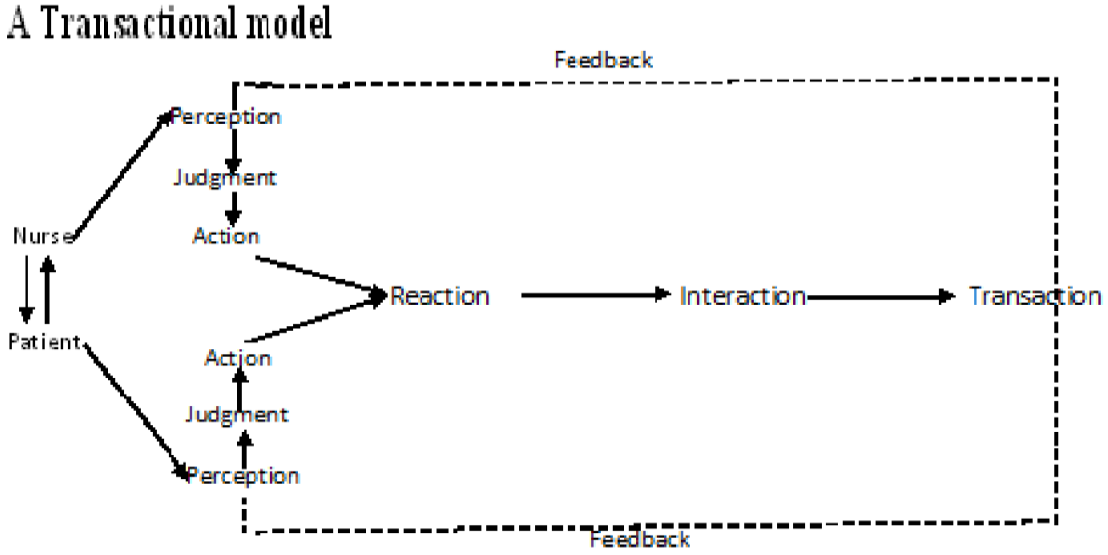



*Figure 1 : King's Goal Attainment Theory*

interaction lead to a transaction, goal attainment, growth and development. The outcome of goal attainment is patient satisfaction and effective nursing care (King, 1981, Fitzpatrick & Wallace, 2006). Transaction process which is core to the interaction involves actions based on perception and judgment, reaction and interaction with a feedback mechanism that keeps an interaction fluid as shown in the transaction model in figure 1.

The nurses' role in the relationship is to explore perception, communicate and interact to identify needs, set mutual goals, assess and agree on the means of achieving goals, implementing strategies and evaluating outcomes (King, 1981). The interaction occurs through communication that could be verbal or non-verbal, direct or indirect, and includes the use of telephones. King supports the use of technology that enhances goal attainment (Basavanthapa, 2007). King (1986) hypothesised in her theoretical framework that, among other things, functional abilities will be greater in clients who participate in goal setting than those who do not; there is a positive relationship between functional abilities and goal attainment and goal attainment increases clients' learning and coping skills (King, 1986 cited in Fitzpatrick & Wallace, 2006).



### 1.8.2 Logic Model

In addition to the goal attainment framework, the logic model was used as a programme evaluation framework. Grounded in the programme theory perspective, the logic model takes into account the input, process, output and outcome of the intervention programme (Funnell & Rogers, 2011). The logic model is a systematic and graphic representation of ideas relating to how a given intervention is expected to be implemented to ensure effectiveness (Knowlton &

Phillips, 2012; Rohwer et al., 2016). McLaughlin and Jordan (2004) claim that there are contextual variables that ought to be considered in the evaluation of process. The antecedent contextual issues relate to demographic characteristics, the physical environment and economic factors. The mediating antecedents occur during the programme and include policy changes, staffing, and concurrent programmes (McLaughlin & Jordan, 2004). There are different approaches to mapping up a logic model one of these approaches which was used in this study is depicted in Figure 2.

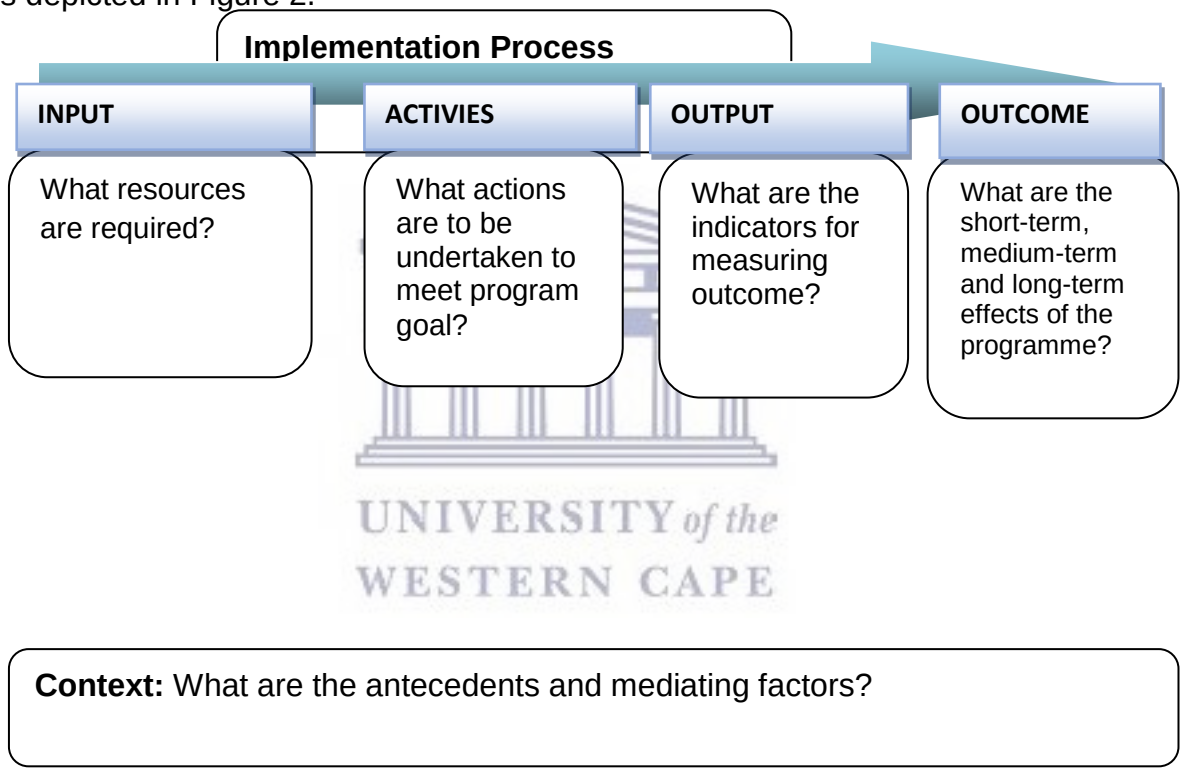





**Figure 2: Showing the logic model.** *Adopted and modified from (McLaughlin & Jordan, 2004)*

## 1.9 SIGNIFICANCE OF THE STUDY

This study aimed to document adherence to ART, identify predictors of adherence and add to the existing knowledge of the use of mobile phone interventions in ART treatment adherence. The acceptance of mobile phone technologies among HIV infected clients and gaps in its application to health service adherence

support strategies were also explored using a nursing goal attainment conceptual framework.

This study explored the integration of the various mobile phone applications namely; alarm, text messages and voice calls in improving adherence. It was anticipated that the results would provide insight into the readiness and acceptance of the use of mobile phone technology in existing adherence interventions in HIV/AIDS care in Ghana. The findings could also serve as a baseline for future studies. It is hoped that the study may contribute to existing policies and guidelines on the care of HIV infected clients, that it may influence future reforms in curriculums for training health professionals working in HIV/AIDS care and that the algorithm and brochure developed could be used to educate clients on the use of mobile phones as an adherence support strategy.

## 1.10 ORGANISATION OF THESIS



This thesis consists of nine chapters. Chapter one contains the introduction, the background of the study and the conceptual framework. The research problem, objectives, questions and hypotheses were also covered in the chapter. Additionally, the significance of the study and a definition of terms were provided.

Chapter two captures a narrative literature on existing evidence relating to HIV/AIDS treatment and experiences, conceptualisation of adherence, theories of adherence, factors influencing adherence, assessment and adherence interventions with an emphasis on mHealth interventions.

Chapter three covers a description of the research methodology; the design, paradigm setting and the approach for each phase of the study.

In chapter four the intervention used in the study is evaluated using the logic model. Quantitative results are presented in chapter five and the qualitative findings are in reported in chapter six.

Chapter seven focuses on an integrated discussion of the quantitative and qualitative findings.

In Chapter eight there is a report on the final phase of the study which involved a synthesis of the study findings.

Chapter nine is the final chapter of this thesis and consist of the conclusions and recommendations made within the context of the study outcomes.

## 1.11 SUMMARY OF THE CHAPTER

This chapter discussed the context for the study and sets out the introduction and background to the principal issues of integrating mobile phone interventions in adherence monitoring strategies. It also highlighted the identified problem, conceptual frameworks and the significance of the study. This chapter sought to set the stage for the remainder of the enquiry, with the research objectives, related research questions and the operational definitions having been spelt out.

# CHAPTER 2: LITERATURE REVIEW

## 2.1 INTRODUCTION

Literature review is a process involving critical appraisal of evidence relating to the problem being studied to facilitate the appreciation of the problem, the methods employed and the variations in the context of evidence (Polit & Beck, 2013). The approach to review may be traditional or systematic (Jesson, Matheson, & Lacey, 2011). The traditional review is narrative inclined, has no specified method of review, analysis techniques are not defined and there are variations in the style. Systematic reviews on the other hand are well structured, the method is rigorous, and synthesis and meta-analysis of evidence is expected (Jesson et al., 2011). The traditional or narrative approach or what (Polit and Beck (2013) referred to as the *traditional narrative review* was adopted in this study with the aim of exploring the literature from different perspectives and situating it within the research problem.



In this review existing literature, on the prevalence of HIV/AIDS, treatment experiences, and adherence to determine how adherence was conceptualised from different perspectives, was explored. Additionally, the review examined the theoretical underpinning of adherence behaviour, factors influencing adherence interventions, measures of assessing adherence and mobile phone use in health with an emphasis on mobile phone use in adherence interventions.

## 2.2 LITERATURE SOURCES

In contextualising this study literature on HIV and adherence was examined using various search strategies, databases and search terms.

The following key words/phrases as search terms included: *HIV/AIDS; Adherence, compliance, concordance; Antiretroviral therapy; Burden of HIV/AIDS; HIV/AIDS treatment; Adherence monitoring in HIV/AIDS care; Factors influencing adherence to antiretroviral therapy; Determinants of adherence; Mobile phone use health care; Effects of text messaging on adherence to ART; Antiretroviral therapy adherence strategies;* and *Tools for measuring adherence.*

A basic search was done using Google to determine unclassified literature sources. Major bibliographic databases such as Google Scholar, EBSCO Host, Pubmed, Emerald and Science Direct were then searched based on more advanced approaches. HTML articles were also hyperlinked for direct access to secondary sources in HTML articles. All titles and abstracts of journal articles found were read for their relevance to the topic, thereafter relevant articles were retrieved. A hand search was used in the articles that provided relevant information for further sources, such as books, journals, legislation or policy statements and institutional reports. Experts who were consulted recommended further journal articles which in turn paved the way to finding other articles.



## 2.3 HIV/AIDS PREVALENCE

### 2.3.1 Global prevalence of HIV and the response strategy

The prevalence of HIV has declined in terms of new cases and mortality while the number of HIV infected clients continue to increase (UNAIDS, 2016a). The number of new HIV cases recorded globally in 2015 was 2.1 million compared with 2.7 million in 2010. Mortality resulting from HIV declined by 45% from 2 million in 2005 to 1.1 million in 2015 (UNAIDS, 2016a). The major cause of HIV related deaths was tuberculosis (UNAIDS, 2016a). The decline in new HIV cases

is attributable to the response strategies adopted namely: prevention of mother-to-child transmission and behavioural change interventions (WHO, 2013). In spite of the value of prevention, WHO (2016b) reported that only 60% of the general population are aware of their HIV status.

Across all regions AIDS mortality outcomes improved (UNAIDS, 2015). However, the Middle East, North Africa, Eastern Europe, Central Asia, Asia and the Pacific recorded increases in deaths. The report indicated that “between 2000 and 2014 the number of AIDS-related deaths in the regions more than trebled” in the Middle East and North Africa (UNAIDS, 2015). The response strategies used in these regions were critiqued for a lack of cultural context, vulnerability, geographical relations and immigration issues. The argument suggests that the response strategies used have accounted for the increase mortality observed in these regions (Alkaiyat, 2014; Roudi-Fahimi, 2007).



The number of people living with HIV since it was first discovered is estimated at 78 million with 35 million deaths representing 44.8% mortality rate (UNAIDS, 2016a). Nevertheless, an increase in access to treatment has led to improvements in clients’ health (Jeffrey V Lazarus et al., 2016) while increasing the burden of care relating to treatment and support. In 2015, an estimated 36.7 million people were living with HIV with at least 18.2 million people receiving ART by June 2016.

UNAIDS introduced a fast-track strategy to curbing the HIV menace with the target of reaching all individual at every stage of life (UNAIDS, 2016a). This life cycle approach to managing HIV is also consistent with the Sustainable Development Goals (SDG). SDG three focuses on ensuring good health and well-

being, SGD five on promoting gender equality; SDG ten focuses on reducing inequalities; SDG 16 promoting peace, justice and equity and SDG 17 strengthening partnership in goal implementation (UNAIDS, 2016b). UNAIDS and WHO have a target of zero new infections, zero discrimination and zero deaths by 2030 as part of the strategy to end the HIV epidemic (UNAIDS, 2016b; WHO, 2016a). The targets seem ambitious but are attainable; (Lazarus et al. (2016) argues that strategies in combating HIV should include the conscious screening and management of co-morbidities and promoting the quality of life with a health system sensitive to the growing need of the client.

Sub Saharan Africa still leads in terms of the total HIV burden and is home to two thirds of reported cases (UNAIDS, 2016a). Factors such as poverty, literacy, religion, cultural practices including circumcision, access to treatment for sexually transmitted infection and contraceptive use have been found to be associated with the prevalence of HIV in this region (Mondal & Shitan, 2013). The of HIV epidemic in the sub region although similar, there may be contextual diversities that could influence prevalence rate in Ghana.



### 2.3.2 Prevalence of HIV in Ghana and response strategy

According to the Ghana AIDS Commission (GAC) report, the HIV phenomenon in Ghana is classified as a generalised epidemic (GAC, 2014). The prevalence rate in the general population decreased from 1.5% in 2010 to 1.47% in 2014 (GAC, 2014; NACP, 2014b). The prevalence rate estimated with the annual sentinel survey in pregnant women also declined from 1.9 % in 2013 to 1.6% in 2015; the adult prevalence rate was also 1.6% as at 2015 (GAC, 2014; GSS et al., 2015). The estimated total number of people living with HIV increased from 250, 232 in

2014 to 270,000 in 2015. New HIV infections decreased from 15,216 in 2010 to an estimated 11.356 in 2014. HIV related death also decreased from 14,753 in 2010 to 9,248 in 2014. A total of 83,712 (33.4%) of HIV infected clients were receiving ART out of 250,232 people living with HIV in 2014 (GAC, 2014).

HIV prevalence rates in Ghana were reported to differ with regards to religion, ethnicity, gender, age, employment status and relationship status (GSS et al., 2015). Other factors affecting prevalence rates include marginalisation of key populations (female sex workers, men who have sex with men, and drug users), low condom use, multiple sexual partners, stigma and discrimination (GAC, 2014).

The response strategy in addressing the HIV epidemic in Ghana includes prevention, treatment and monitoring strategies (GAC, 2014; NACP, 2014b). Prevention strategies include; HIV counselling and testing, prevention of mother-to-child transmission, condom promotion, blood safety practices, prevention of exposure in health institutions and behavioural change interventions including advocacy (NACP, 2014b). With regards to treatment, clients are enrolled in ART and opportunistic infections treated (NACP, 2014b). Treatment guidelines for ART have been developed and measures of monitoring adherence have been included in these guideline (NACP, 2014a).



### 2.4 HIV/AIDS TREATMENT AND EXPERIENCES WITH HIV DIAGNOSIS

The progression from HIV to AIDS is dependent on the immune response of the host cell and other related cellular activities. Suppression of viral activity through an effective immune response delays progression to AIDS (Levy, 1993). Initial clinical studies sought to identify the character of the virus, how its replicates and how the process could be interrupted or slowed. Drugs that were developed

therefore targeted breaking cellular replication at various stages (De Clercq, 2009; Levy, 1993).

However, the effects of these drugs and the number of pills to be taken resulted in poor adherence to treatment. Adherence is important because the breaking of treatment leads to the development of drug resistant strains of viruses (Bennett, Bertagnolio, Sutherland, & Gilks, 2008). The components of antiretroviral drugs are therefore formulated to target specific characteristics of HIV.

### 2.4.1 Antiretroviral Drugs and Regimens

In 1987 Zidovudine (AZT) became the first antiretroviral drug to be approved for managing HIV/AIDS. Further studies revealed that combining different classes of drugs, that interrupted the life cycle of the virus, was a more effective way of augmenting the immune response and preventing opportunistic infections (Broder, 2010; De Clercq, 2010). The five classes of ARV are: 'Nucleoside or nucleotide reverse transcriptase inhibitors (NRTIs), Non-nucleoside reverse transcriptase inhibitors (NNRTIs), Protease inhibitors (PIs). Entry or fusion inhibitors and Integrase inhibitors are combined into different drugs to inhibit or alter enzyme activity at different stages of the life cycle of the virus (De Clercq, 2009).



The WHO reviewed treatment guidelines on ART to address the exclusion in treatment based on new evidence. All individuals living with HIV were to be placed on ART without recourse to CD4 cell count levels. ART was to be initiated in adults at clinical stage three or four of the disease and a CD4 count of less than or equal to 350 cells/$mm^3$ (WHO, 2015c). Hitherto, antiretroviral therapy was given to HIV positive persons with a CD4 count of less than 350 cells /ml and / or persons

who displayed symptoms of HIV infection in WHO clinical stage three of the disease (WHO, 2013).

First line treatment recommended by WHO (2015c) is the combination of the following drugs: Tenofovir Disoproxil Fumarate (TDF), Lamivudine (3TC), Emtricitabine (FTC.), Efavirenz (EFV), Zidovudine (AZT), Dolutegravir (DGT) and Nevirapine(NVP).

*First line treatment combination*(WHO, 2015c)

- TDF + 3TC (or FTC) + EFV

*Alternative first-line regimens are*:

- AZT + 3TC + EFV (or NVP)
- TDF + 3TC (or FTC) + DTG
- TDF + 3TC (or FTC) + EFV
- TDF + 3TC (or FTC) + NVP



A public health approach is recommended in the case of second and third-line ART. Preferred second-line regimens and alternatives should be utilised with regards to the need for the optimisation of resources, availability of fixed-dose combinations, tolerability and the risk of resistance mutation (WHO, 2015c). Second and third line treatment involves the combination of NRTIs with Darunavir with low dose Ritonavir (DRV/r), Atazanavir with low dose Ritonavir (ATV/r), Lopinavir with low dose Ritonavir (LPV/r) and Raltegravir (RAL).

*Second line treatment*:

- 2 NRTIs + ATV/r or LPV/r
- 2 NRTIs + DRV/r

*Third line treatment*

- DRV/r1+ DTG (or RAL) ± 1–2 NRTIs
- DRV/r + 2 NRTIs ± NNRTI

Additionally, viral load monitoring is to be used for determining response to treatment. It is recommended that the routine viral load testing be done six months after the initiation of treatment and then repeated at 12 months. The use of dried blood specimen from venous or capillary blood is recommended. Continuous viral load monitoring is to be carried out every 12 months once a patient is stable. CD4 count should only be used in areas where viral load is not available and when treatment failure is suspected (WHO, 2015a, 2015c).

ART is restricted if the client has hepatic problems, motivation and interest is low or they fail to complete two adherence counselling sessions (NACP, 2010). Clients who are not ready to take medication cannot be coerced to do so. Adherence assessment is a key component in the management of HIV/AIDS but not without the arguments about how to measure adherence (Bangsberg, Moss, & Deeks, 2004; Bisson et al., 2008; Chalker et al., 2010; Mannheimer & Hirsch-Moverman, 2015). The importance of adherence led to a plethora of intervention developments, reviews and testing of evidence on the efficacy of some of these interventions. ARVs, in spite of being a major landmark in the fight against HIV, are associated with physical and psychological experiences that pose hindrances to achieving the target to end the menace by 2030 (UNAIDS, 2016a).

### 2.4.2 Experiences associated with HIV/AIDS treatment

The physical experience of clients associated with ART vary from minor side effects to adverse experiences of the drugs that can affect all the body systems

(Hawkins, 2010). The nature of the adverse experiences are relevant to the type of medication taken (Hawkins, 2010) as shown in Table 2 (Cardenas, 2013).

***Table 2: Common Adverse Events reported with ART(Hawkins, 2010)***

| Class | Drug | Adverse effects |
|---|---|---|
| NRTI's | Zidovudine | Anemia, nausea, rash, myopathy, dyslipidemia |
| | Stavudine didanosine | Nausea, comma, lipoatrophy, comma, dyslipidemia, pancreatitis, lactic acidosis, hepatic steatosis, heart disease, DSPN |
| | Abacavir | HSR, hepatotoxicity, heart disease |
| | Tenofovir | Renal insufficiency, bone loss |
| NNRTI's | Efavirenz | CNS adverse effects, rash, hepatotoxicity, lipoatrophy, teratogenicity, hypertriglyceridemia |
| | Nevirapine | Rash, HSR, hepatotoxicity |
| | Etravirine | Rash, hepatotoxicity |
| PI's | All PIs | Nausea, diarrhea, rash, dyslipidemia, insulin resistance, hepatotoxicity |
| | Atazanavir | Jaundice, scleral icterus, nephrolithiasis |
| | Indinavir | Jaundice, scleral icterus, nephrolithiasis |
| | Lopinavir fosamprenavir | Heart disease |
| Entry inhibitors | Enfuvirtide | Injection site reactions, pneumonia, HSR |
| | Maraviroc | Cough, fever, respiratory tract infections, rash, hypotension (postural) hepatotoxicity, HSR |
| Integrase inhibitors | Raltegravir | Headache, insomnia, dizziness, fatigue |

*Hypersensitivity reactions (HSR), Central nervous system (CNS) Distal sensory peripheral neuropathy (DSPN)*

The WHO treatment guidelines indicate that the first six months following the initiation of ART are crucial due to the undesired experiences associated with taking the treatment (WHO, 2013). These experiences may get worse if there are opportunistic infections. In some clients, immune reconstitution inflammatory syndrome (IRIS) may develop where underlying diseases can trigger severe

symptoms (WHO, 2013). The side effects of ARV are worse in advanced HIV diseases where immunodeficiency is severe and other co-infections and co-morbidities may be present, there may also be low haemoglobin levels and severe weight loss (WHO, 2013).

The most commonly reported adverse side effects are gastrointestinal symptoms such as nausea, vomiting and diarrhoea (Ankrah et al., 2015; Hawkins, 2010; Johnson et al., 2005). In some cases, the adverse effects of ARV are under reported due to its association with the disease rather than the treatment itself. The experience of these symptoms threatens adherence and therefore needs to be monitored and managed (Langebeek et al., 2014).

Apart from the physical symptoms, some of the medications affects the central nervous system (Hawkins, 2010) and clients may therefore experience nightmares, difficulty in sleeping, mood swings (Kyajja, Muliira, & Ayebare, 2010) anxiety and depression (Johnson et al., 2005; Johnson & Neilands, 2007). In instances where medications were switched because of adverse side effects, a follow up evaluation indicated that mental health improved (Maiese, Johnson, Bancroft, Goolsby Hunter, & Wu, 2016).

Johnson, Dilworth, Taylor, and Neilands (2011) reported the outcome of an intervention study that demonstrated that when clients are given self-management skills to deal with side effects they are more likely to seek information and support to cope with the side effects.

Information provided on the side effects of medication during adherence counselling enables client to report symptoms and seek support (Agu, Oparah, &

Ochei, 2012) however, some patient cope with side effects by taking pill breaks when they feel sick (Amico et al., 2007).

### 2.4.3 Experiences of clients diagnosed with HIV

The emergence of ART improved the quality of life of clients infected with HIV but there are mixed accounts about their lived experiences and these have a direct impact on the adherence and continuation of treatment.

The experience of being diagnosed with HIV and adjusting to post-diagnosis circumstances has been explored extensively (Andersen, Kagee, O'Cleirigh, Safren, & Joska, 2015; Brener, Callander, Slavin, & de Wit, 2013; Cain et al., 2013; Dako-Gyeke, Dako-Gyeke, & Asampong, 2015; Liamputtong, Haritavorn, & Kiatying-Angsulee, 2012; Wekesa & Coast, 2013). The issues explored include; the physical experience of symptoms such as fatigue (Cook et al., 2016), psychological issues such as depression (Andersen et al., 2015) and social issues like stigma and discrimination (Dako-Gyeke et al., 2015; Liamputtong et al., 2012).



#### 2.4.3.1 *Physical concerns of HIV infected clients*

HIV causes immunosuppression; therefore infected persons suffer opportunistic infections, including pneumocystis, toxoplasma encephalitis, microsporidiosis and tuberculosis. (Kaplan et al., 2009). Common immunosuppressive symptoms such as oral thrush, nausea, diarrhoea, weight loss, fatigue and coughing are often reported. Some of these symptoms have implications for treatment outcomes (Evans, Maskew, & Sanne, 2012).

Evans et al. (2012) investigated the effects of oropharyngeal candidiasis and body mass index (BMI) on ART outcomes and reported that individuals with low BMI

were more likely to have oral thrush and poor treatment outcomes. However, following recommendations for the early initiation of ART irrespective of CD4 count levels, clients are now less likely to experience these symptoms (WHO, 2015a).

Fatigue is one of the most commonly reported symptoms among clients living with HIV affecting about 20% to 60% of clients (Barroso & Voss, 2013; Cook et al., 2016). Fatigue suggest the presence of conditions such as anaemia and hypogonadism (Barroso & Voss, 2013). Other reports associate fatigue with side effects of the treatment and associated sleep problems (Barroso & Voss, 2013). Cook et al. (2016) in a predictive evaluation of fatigue and other psychosocial variables concluded daily stress and stigma predicts fatigue. The prevalence of fatigue among HIV clients limits the performance of daily activities and affects other aspects of clients' lives.

#### 2.4.3.2 *Psychosocial experiences associated with HIV/AIDS diagnosis*



In a qualitative study, done in Nairobi, that explored the experiences of people living with HIV after diagnosis (Kenya, Wekesa and Coast (2013) reported there were negative reactions such as shock, distress and denial following the confirmation of a HIV positive status. The narrative also showed that individuals who discovered that they were HIV positive status, while undergoing other health care treatment, impacted negatively on their response to their HIV status confirmation. Other studies reported similar emotional reactions including anger and disbelief (Cain et al., 2013).

Some HIV infected individuals respond to their positive HIV diagnosis more positively by accepting responsibility and making a decision to move on with life (Liamputtong et al., 2012; Wekesa & Coast, 2013). Other clients demonstrated ambivalence in accepting their HIV status and treatment and this affects decisions about treatment and adherence (Russell & Seeley, 2010; Wekesa & Coast, 2013).

Depression is one of the commonly reported psychological symptoms prevalent during diagnosis of HIV and adjustment to living positively with HIV. Andersen et al. (2015) in a qualitative study sought to understand the experience of depression among clients living with HIV/AIDS. Four core categories of symptoms of depression (affective, somatic, cognitive and behavioural) were explored. The findings revealed participants experienced affective symptoms that included sadness, loneliness, anger and irritability. Somatic symptoms were sleep problems, slowed mobility, lethargy and poor appetite. Participants noted they experienced intrusive thoughts, poor concentration and suicidal ideas as part of the cognitive symptoms while behavioural symptoms were withdrawal, crying and a lack of interest in talking.



The limitation of their study, because only 14 participants were recruited, was acknowledged by (Andersen et al. (2015) however, it was not clear whether data saturation was achieved. More so, the study focused on clients with depression and HIV/AIDS. Depression is one of the more poorly assessed HIV co-morbidities, but has been found to be one of the factors associated with non-adherence (Do, Dunne, Kato, Pham, & Nguyen, 2013).

Social experiences of clients diagnosed with HIV/AIDS in the literature predominantly relate to stigma and discrimination (Brener et al., 2013; Dako-

Gyeke et al., 2015; Liamputtong et al., 2012; Wekesa & Coast, 2013) and the relevance of social support (Amuri et al., 2011; Mannheimer & Hirsch-Moverman, 2015; van Loggerenberg et al., 2015). In their study (Wekesa and Coast (2013) reported that some participants battled with disclosing their HIV status in the initial stages of diagnosis but this changed over time. However, some of the participants were coerced into disclosing their status while others accepted their status and assumed responsibility as HIV positive role models and got involved in teaching others about HIV. A reluctance to disclose ones status was often associated with the fear of stigma and discrimination coupled with the moral judgement placed on the patient by society. The perception of HIV as a disease of the promiscuous in some societies accounts for the prevalence of stigma in such societies (Brener et al., 2013; Cain et al., 2013; Wekesa & Coast, 2013). The decision of accepting treatment, strictly adhering to a treatment regimen or rejecting therapy is also associated with the psychosocial orientation of the individual (Calvetti, Giovelli, Gauer, & Moraes, 2014).



The physical and psychological experience associated with HIV treatment and diagnosis impacts on the adherence decisions of clients diagnosed with HIV (Rao et al., 2012). Experts recommend the management of these symptom to promote adherence and retention in care (Enriquez & McKinsey, 2011). However, without a clear understanding of adherence as a concept and a theory underpinning it, moderating adherence behaviour, contextualising adherence interventions will remain a challenge.

## 2.5 CONCEPTUALIZING ADHERENCE

The concept of adherence is defined as: "*the action of continuing to obey a rule, law,… agreement or support for or belief in an idea, plan or opinion etc.*" ("Adherence" In MacMillan online dictionary, 2015).

Adherence implies taking a decision and action to follow or accept conditions without compromise. It similarly suggests a pattern of behaviour that is presumptive and restrictive, but dependent on choice (Bissonnette, 2008; Chisholm-Burns & Spivey, 2008; Ho, Bryson, & Rumsfeld, 2009; O'Donohue & Levensky 2006). However, the meaning of concepts may differ depending on the context and in which it is applied. Clarifying concepts and defining the attributes exposes the variations in perspectives and guides decisions related to preferences (Walker & Avant, 2005).

Adherence has been used along with surrogate terminologies that have either been critiqued for negative undertones or remained uncommon due to a lack of popular acceptance (Cohen, 2009). Compliance, concordance, and persistence have all been used to connote adherence. Compliance is arguably believed to reflect a notion of client dependence and subjugation (Cohen, 2009; Horne et al., 2005), but the only difference in the meaning of adherence and compliance is the introduction of the aspect that allows clients to participate in the decision to adhere (Horne et al., 2005). Bissell, May, and Noyce (2004) noted that concordance reflects a concept of agreement and accounts for clients' interest in the treatment process. However, the problem associated with choosing and applying concordance is the divergence in the connotation of the concept. Concordance has different meanings when used in the field of theology, library and information science, music and genetics. However, the meaning and

application of adherence is more consistent. A generally accepted definition of adherence is:

> "*The extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider"*(WHO, 2003).

However, (Vrijens et al. (2012) argued that the WHO definition of adherence is limited in scope because issues related to the measurement of behaviour were not addressed. They proposed a three element taxonomy of adherence, which consists of i) adherence to medications, ii) management of adherence and iii) adherence related sciences. Adherence to medication according to (Vrijens et al. (2012), is defined as "*the processes by which clients take their medication as prescribed"*. Three stages were outlined in the process of medication: initiation, implementation and discontinuation. Initiation occurs when the first dose of medication is taken. Implementation is the dosage regimen and strict adherence to the prescription. The discontinuation stage is the period between taking the last dose, omitting a dose or stopping. A concept of persistence was also described as the period between initiation and stopping treatment although this concept was not fitted into the process of adherence to medication (Vrijens et al., 2012). Management of adherence, the second element of the taxonomy, was defined as *"the process of monitoring and supporting clients' adherence to medications by health care systems, providers, clients, and their social networks"*(Vrijens et al., 2012). The third component of adherence, which was called *Adherence-related sciences* describes the interdisciplinary fields of professionals and their quest to understand and quantify adherence to medication (Vrijens et al., 2012).

Adherence to medication is a behavioural pattern imputing choice that is initiated by the presence of illness and the desire for wellness with a health professional as the mediator and facilitator of the process. Nevertheless, once decision making and behavioural change is anticipated non-adherence is a predictable consequence (O'Donohue & Levensky 2006).

Poor adherence, suboptimal adherence and non-adherence are concepts that have dominated the literature on medication adherence. These concepts have all been used to imply the failure to follow a prescription or the pattern of behavioural change that is expected (Chisholm-Burns & Spivey, 2008; Christensen, 2004; Haynes et al., 2005; Ho et al., 2009; O'Donohue & Levensky 2006; Patterson, Swindells, & Mohr, 2001; Ross-Degnan et al., 2010). In their book "*Promoting Treatment Adherence: A Practical Handbook for Health Care Providers"* (O'Donohue and Levensky (2006) indicated that non-adherence included; missing follow-up appointments, reporting late, and not taking medication according to prescription. Additionally, they noted that failure to start treatment, implement adjustment in lifestyle and deliberate discontinuation of treatment constituted non-adherence (O'Donohue & Levensky 2006).



The context of adherence quantification is relative to the type of disease and the type of medication. Acute illnesses have endpoints and therefore treatment is discontinued once disease is eliminated as in tuberculosis infections, for example (Rennie & Bates, 2015). However, in chronic illnesses there is no endpoint to treatment and any discontinuation is considered a violation of treatment. Any adjustment to schedule, dose and lifestyle that deviates from agreed standards is considered inappropriate (O'Donohue & Levensky 2006; WHO, 2003).

Adherence as behaviour could be explained and predicted when the theories of adherence behaviour are understood.

## 2.6 THEORETICAL FOUNDATIONS OF ADHERENCE BEHAVIOUR

Theories are the structured abstraction of ideas, events and issues aimed at offering perspectives and predictions of phenomenon (Parker & Smith, 2010). Adherence behaviour is explained and predicted using different theories (O'Donohue & Levensky 2006). Adherence is contextualised in five main domains according to (Leventhal and Cameron,1987) cited in WHO (2003) namely: the biomedical, behavioural, communication, cognitive and self-regulatory perspectives.

### 2.6.1 Biomedical Theories of Adherence

Biomedical theories are perceived as paternalistically oriented because the health care provider assumes the dominant role in adherence planning, implementation and evaluation (Munro, Lewin, Swart, & Volmink, 2007; WHO, 2003). Adherence behaviour is therefore measured using patient characteristics such as socio-demographic variables (age, gender, education, economic status) and clinical outcomes (body mass index, virology, blood pressure, blood glucose levels, white cell count) in determining conformity with the treatment regimen.

The design and measurements, used in a study conducted by (Paterson et al. (2000) to determine adherence to protease inhibitors (PIs) virologic, immunologic and clinical outcomes in HIV clients, reflects the biomedical perspective, although this was not indicated. The clients in the study were monitored via an electronic device and their viral load and CD4 count compared with the electronically monitored adherence outcomes (Paterson et al., 2000; Patterson et al., 2001).

Despite their objectivity and the use of a technologically advanced monitoring system, the biomedical theories often neglect the client psychosocial factors influencing adherence patterns (Brawley & Culos-Reed, 2000; O'Donohue & Levensky 2006; WHO, 2003). The biomedical perspective is further critiqued for the subtle way in which clients are held responsible for non-adherence to therapy instead of assuming collective responsibility (Bissell et al., 2004).

### 2.6.2 Behavioural Adherence Theories

Behavioural adherence theories are situated within the context of operant conditioning experiments which associate learning with environmental conditions (Skinner, 2004). Adherence behaviour is therefore expected to be observable and predictable in relation to previous circumstances and consequences (Munro et al., 2007; WHO, 2003). Adherence behaviour is influenced by the use of measures that serve as a reward or punishment (Munro et al., 2007). It is presumed that positive and negative reinforcements that follow a particular adherence behaviour will affect adherence outcomes (Munro et al., 2007; O'Donohue & Levensky 2006; WHO, 2003).



Although not explicitly stated, behavioural perspectives seem to have informed the use of mobile phone interventions such as reminders, text messaging and/or voice calls to reinforce adherence behaviour. Lester et al. (2009) and Pop-Eleches et al. (2011) reported adherence to antiretroviral treatment improved following the use of text messaging as a reinforcement of adherence behaviour. However, the effect size in some of the studies and reviews was considered small. There are issues about the cost effectiveness of such interventions since most of

these studies lack a cost analysis of the intervention (Free et al., 2013; Goldie et al., 2003; Gurol-Urganci et al., 2013; Horvath et al., 2012).

In spite of the contribution of the behaviour theories in adherence interventions it is limited by the emphasis on the action and outcome of the adherence behaviour. The personal state, interest and experiences of the individual are sublimated for the reward (Munro et al., 2007)

### 2.6.3 Communication Perspective

Communication occurs at all levels of client interaction and communication theories argue that adherence behaviour improves when communication is effective (Munro et al., 2007; WHO, 2003). Adherence behaviour is influenced by the quantity and quality of information available to the individual. Therefore, non-adherence is considered to be associated with inadequate information about treatment or poor communication skills demonstrated by the caregiver (Sanjobo, Frich, & Fretheim, 2008). Interventions to promote adherence are often designed to provide clients with information regarding treatment, while others concentrate on building the skills of the health practitioners to communicate effectively (Munro et al., 2007). Evidence suggests some improvement in outcomes, in some studies, that sought to enhance the interaction skills of caregivers, but these were not specific to adherence to treatment (Dwamena et al., 2012; Griffin et al., 2004).

Finocchario-Kessler et al. (2012) reported improvement in adherence outcomes in a randomised control trial that used pictorial images for adherence counselling; an intervention that draws on the communication perspective with the focus of enhancing the clarity of information given to a patient.

Despite the positive outcomes recorded in some of the interventions that implicitly or explicitly integrated the communication perspective; inadequacies exist in the implementation of this theory. Confounding variables that interfere with the process of communication and its influence on the pattern of behaviour have not been isolated. Personal characteristics, motivation and environmental factors which could affect the communication process ought to be considered by integrating this perspective with other theories (Munro et al., 2007; WHO, 2003).

### 2.6.4 Cognitive Adherence Theories

Cognitive theories postulate that individuals make decisions and choices about behaviour relative to their belief, attitude and their expectation of the outcome in a given situation (Bandura, 2004; Fishbein & Ajzen, 2011; Fisher, Amico, Fisher, & Harman, 2008). Several micro level theories and models have emerged from the cognitive perspective. Munro et al. (2007) described five of these theories, namely: health belief model; social cognitive theory; theory of reasoned action; theory of planned behaviour and protection motivation theory.



The Health Belief Model (HBM) maintains that decisions about health behaviour are determined by the benefits that accrue and the limitations posed in the outcome of an action. However, expectations and threats could be influenced by socio-demographic variables while a cue to action is associated with media, personal influence and reminders (Munro et al., 2007; WHO, 2003). Therefore, in the case of adherence to treatment the severity of the illness and the benefit of the treatment would influence the adherence pattern or behaviour. However, a major limitation of this model is the difficulty in comparing the relationship that exists between the constructs in the model (Munro et al., 2007; WHO, 2003).

Social Cognitive Theory (SCT) assumes that behavioural change is influenced by the interaction between individual characteristics, action and the environment. Constructs within the SCT that influence behaviour are; knowledge of health risk, benefit of change, self-efficacy, outcome expectancies and facilitators/barriers (Brown, Littlewood, & Vanable, 2013; Munro et al., 2007). Self-determination is a major driver in achieving desired results. More so, support from the environment facilitates positive behavioural outcomes (Bandura, 2004; Munro et al., 2007).

Self-efficacy is the most applied construct in studies that established an association between self-efficacy and adherence to ART (Brown et al., 2013). Some studies that evaluated the outcome expectancy of SCT construct have reported negative effects of medication and related factors for non-adherence (Murphy, 2002; Rudy, et al, 2010). Personal decisions to adhere to treatment according to Bandura are a reflection of the individual's experiences and the consequences of potential or actual outcomes. Brown et al, (2013) indicated that suboptimal adherence is associated with low self-efficacy, perceived norms and behaviour that limit attainment of adherence goals. However, there is a paucity of literature regarding the association between the construct of self-efficacy and outcome expectancies proposed in the SCT (Brown et al., 2013).



The Theory of Reasoned Action (TRA) depicted in figure 3, postulates that individual actions and decisions are consciously and intentionally determined. Behavioural intentions are influenced by personal attitude and subjective norms. Individual attitudes towards an action (for example) adhering to ART would be determined by the belief about adhering to the treatment and the possible benefit of the treatment. The subjective norms reflect what other individuals consider as

right as such the motivation to adhere in informed by the desire to satisfy the subjective norms (Munro et al., 2007; Stroebe, 2011). TRA is critiqued because of a lack of evidence in support of behaviour intention and the inability to explain the differences occurring in behaviour which were involuntary actions (Munro et al., 2007). The limitations of the TRA, in involuntary actions, led to the expansion of the theory to include perceived behavioural control called The Theory of Planned Behaviour (TPB).

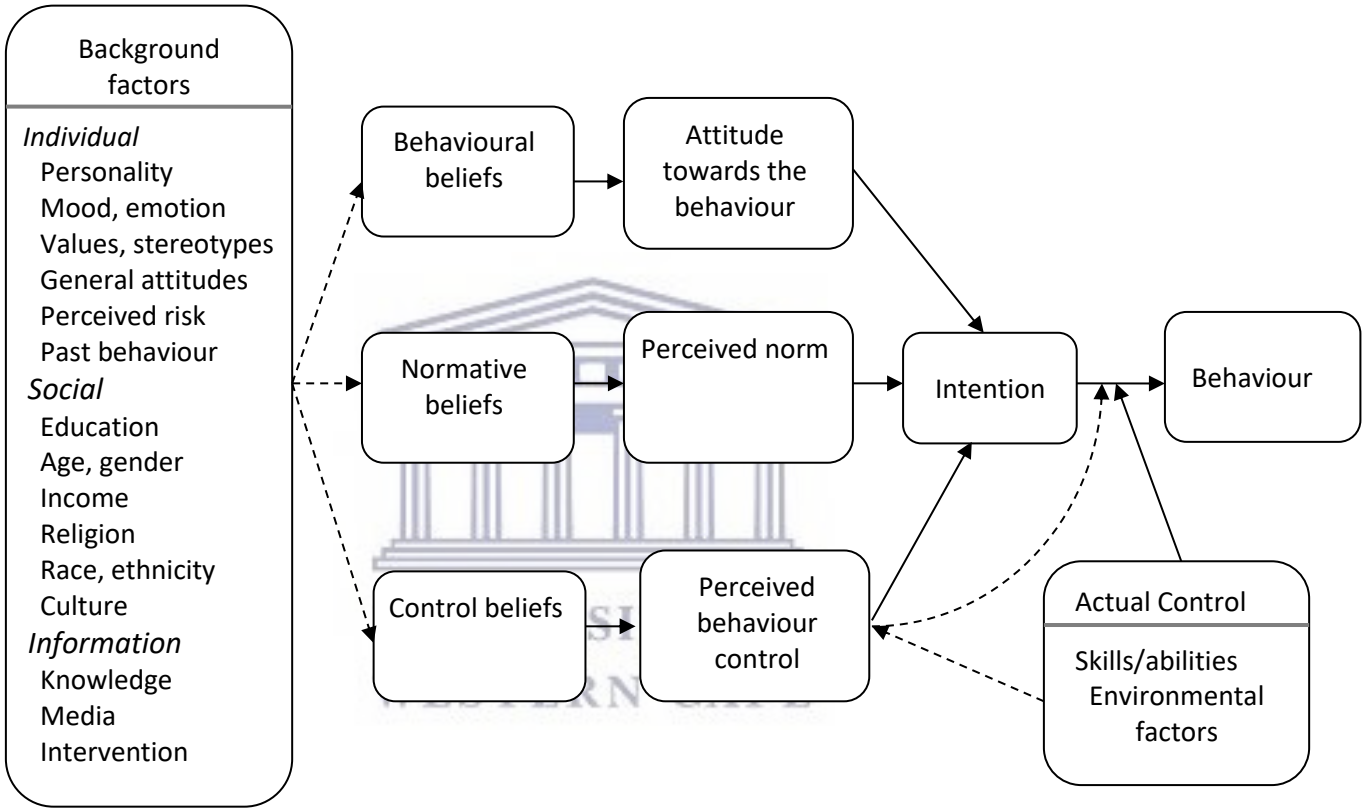



**Figure 3: Reasoned Action Model (Fishbein & Ajzen, 2011)**

TPB emphasises the enthusiasm or difficulty with which desired action for behaviour change is pursued relative to personal belief and action, such as the ability to remember pill times and doses. The TRA and TPB are both critiqued for a lack of consideration of factors such as emotions and religion, which are not indicated as a construct within the model, and the influence these factors have on the construct of intention explicated in both theories (Munro et al., 2007; Sutton, 2001).

In a recent modification of the theory to a model, the constructs were expanded to include other variables. Background factors mentioned were those relating to the individual (personality, mood, values, perceived risk and past behaviour); Social factors (education, age, gender, income, religion, race and culture) and information (knowledge, media, intervention) which interplay with beliefs (Fishbein & Ajzen, 2011). The three types of belief posited in the model are the behavioural, normative and control beliefs with background factors constituting the antecedents of the behaviour (Fishbein & Ajzen, 2011). The beliefs further influence intention of the behaviour with recourse to attitude, perceived norms and controls. There is also the aspect of the actual action which is reflected in the skills, abilities and environmental factors. Nelsen et al. (2013) reported that intention to adhere predicted self-reported adherence in clients taking ART.

The Protection Motivation Theory (PMT) assumes that individual motivation for protection from threat would influence behaviour change. Severity of perceived threat, vulnerability and intrinsic reward comprises variables in the threat appraisal which leads desire for protection. Response efficacy and response cost were named as the coping appraisal that drives protection motivation. The PMT

theory postulates that there is a linear relationship between perceived severe threat and motivation for protection. This implies that when the individual perceives that a threat is severe there is an intrinsic motivation to respond positively to avoid the cost associated with not avoiding the perceived threat (Munro et al., 2007; Stroebe, 2011). Floyd, Prentice-Dunn, and Rogers (2000) reported the PMT had a moderate effect following a meta-analysis but was useful for adherence intervention, subject to the consideration that other variables influence motivation. Appreciation of these theoretical perspectives is as relevant as knowledge of the disease, treatment and related issues, as it provides a broader context for discourse on adherence behaviour.

## 2.7 FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY

Inference from the theoretical perspectives on adherence revealed that a multiplicity of factors facilitates or inhibit adherence. These factors could be social, clinical, economical, cognitive or unclassified. Departing from theoretical reasoning for adherence; Mannheimer and Hirsch-Moverman (2015) categorised four main factors: patient related, treatment related, daily schedules and interpersonal relationship that facilitate or inhibit adherence to ART. Health service related factors have also been reported to influence adherence in other studies (Portelli, Tenni, Kounnavong, & Chanthivilay, 2015; Sanjobo et al., 2008; Wakibi, Ng'ang'a, & Mbugua, 2011).

### 2.7.1 Patient related factors influencing adherence

Adherence to treatment by clients on ART is facilitated by the premium placed on the treatment by the patient, beneficial outcomes, self-efficacy, acceptance of diagnosis and status disclosure (Langebeek et al., 2014; Mannheimer & Hirsch-

Moverman, 2015; Ruanjahn, Roberts, & Monterosso, 2010; Starks et al., 2008). Starks et al. (2008) reported that the will to live facilitated adherence among participants interviewed in their study conducted in Beijing.

A secondary data analysis of 1 496 samples from 11 trials was done by (Saberi et al. (2015) which sought to determine the association between self-reported adherence and plasma levels. The findings revealed that forgetting to take pills affected adherence to ART.

Forgetting to take pills was also reported in some qualitative studies that assessed adherence behaviour in clients receiving ART (Portelli et al., 2015; Sanjobo et al., 2008). Other patient related factors contributing to non-adherence to ART include feeling depressed, stigma (Mannheimer & Hirsch-Moverman, 2015; Portelli et al., 2015; Van Tam, Pharris, Thorson, Alfven, & Larsson, 2011) lack of self-worth, age, low health literacy levels, preference for alternative treatment, denial of HIV status, limited financial resources and cognitive impairment (Mannheimer & Hirsch-Moverman, 2015).



Portelli et al. (2015) interviewed 43 participants from Lao, People's Democratic Republic to obtain in-depth information on barriers and facilitators of adherence. The findings pointed out that self-stigmas were reported by participants and were reflected in their narratives. They indicated that the inability to regularly take medication was common. This was affected by the fear of disclosing their status and the risk of losing support if their HIV status was disclosed. Similar findings relating to stigmas revealed that clients hid to take medication or disguised pills to avoid suspicion (Mannheimer & Hirsch-Moverman, 2015; Van Tam et al., 2011). Conversely, acceptance of status and openness is a relationship-related factor

observed to improve adherence. Nevertheless, treatment-related factors also influence adherence (Mannheimer & Hirsch-Moverman, 2015).

### 2.7.2 Treatment-related factors influencing adherence

The initial stages of introducing ART were characterised by treatment related non-adherence due to pill burden, the side effects and the complexity of the drugs regimens (Mannheimer & Hirsch-Moverman, 2015; Ruanjahn et al., 2010; Sanjobo et al., 2008). In recent times, regimens have become simpler with single daily doses in some instances or twice daily doses. The side effects of treatment have drastically improved thereby minimising the barriers to adherence. Wasti, Simkhada, Randall, Freeman, and van Teijlingen (2012) explored factors influencing adherence to ART in a study conducted in Nepal. They employed mixed method design, recruited 330 respondents and 34 participants. The findings supported the influence of treatment-related factors such as the side effect of drugs, duration of treatment, lack of knowledge about the treatment and insufficient pills accounting for nonadherence. Treatment fatigue and undesired changes in body image also affects adherence to treatment, but there are factors that improve adherence to treatment (Mannheimer & Hirsch-Moverman, 2015).



Adherence to treatment is facilitated by a simple drug regimen, low pill burden, clients' certainty about the effectiveness of the drug, which is reflected in an observed improvement in the quality of life, and adequate knowledge about the benefits of treatment (Mannheimer & Hirsch-Moverman, 2015; Portelli et al., 2015; Sanjobo et al., 2008). The cognisance of clients about the importance of adherence also facilitates adherence to ART. However, workings schedules could be a barrier that affects adherence (Portelli et al., 2015; Ruanjahn et al., 2010)

### 2.7.3 Daily schedules

Taking ART is lifelong treatment for clients with HIV as long as the eligibility criteria are attained (van Loggerenberg et al., 2015). However, fitting treatment into daily schedules remains a major challenge (Mannheimer & Hirsch-Moverman, 2015). Several studies have reported non-adherence associated with work schedules, sleeping through doses and being away from home without medication (Portelli et al., 2015; Ruanjahn et al., 2010; Saberi et al., 2015; Wakibi et al., 2011).

Wakibi et al. (2011) conducted a cross sectional study in Nairobi, Kenya among 403 respondents and mentioned that busy schedules accounted for non-adherence in addition to difficulties with the dosage schedule. Patient who consider ART to be a bother have difficulty incorporating it into their daily routines while others may fail to replenish medication within the scheduled timeframes thus contributing to non-adherence (Mannheimer & Hirsch-Moverman, 2015).



Some clients take their medication with food, this implies that clients who do not have food or are not ready to eat risk missing their medication (Sanjobo et al., 2008). Some clients who have no support structures to help them remember their daily drug regimens can get overwhelmed by their schedule and are therefore likely to miss a dosage. Interpersonal relations have been reported to influence adherence both positively and negatively (Mannheimer & Hirsch-Moverman, 2015; Ruanjahn et al., 2010; Sanjobo et al., 2008).

### 2.7.4 Interpersonal factors influencing adherence to ART

Building trusting relationship, disclosing ones status without the fear of stigma, the ability to obtain support, the desire to live for a loved one including children,

and sharing treatment decisions have all been noted as key facilitators of adherence (Mannheimer & Hirsch-Moverman, 2015). Social support is a major theme that runs through several studies (Portelli et al., 2015; Ruanjahn et al., 2010; Saberi et al., 2015; Sanjobo et al., 2008; Starks et al., 2008; van Loggerenberg et al., 2015; Van Tam et al., 2011).

Support for people infected with HIV emanates from different sources such as the family, non-governmental organisations (NGO's) and peers living with HIV (Portelli et al., 2015). Instrumental support involves giving money for transport and food; motivational support includes constant reminders and encouragement; religious support through prayer and other modes of expression of faith are some measure of support for facilitating adherence (Sanjobo et al., 2008). Providing education on HIV/AIDS in order to decrease related stigmas was also reported as a promoter of adherence behaviour (Saberi et al., 2015).

The use of electronic reminders such as alarm clocks and monitors can address problems such as forgetting to take medication due to busy schedules and hence facilitate adherence (Portelli et al., 2015; Starks et al., 2008). Conversely, a lack of trust, social isolation, low social support and weak social networks were identified as contributors to non-adherence among clients on ART (Mannheimer & Hirsch-Moverman, 2015).



### 2.7.5 Health Service factors influencing adherence

Health service related factors influencing adherence to ART have been mentioned in several studies. These factors are usually related to service structure, services provided and health professional characteristics (Amankwah, 2015; Portelli et al., 2015; Ruanjahn et al., 2010; Sanjobo et al., 2008; Wasti et

al., 2012). WHO (2013) mentioned that health system factors affecting adherence to treatment included service cost, shortage of drugs and lack of monitoring. Studies have explored service providers and clients' perspectives with similar concerns (Portelli et al., 2015; Ruanjahn et al., 2010; Sanjobo et al., 2008; van Loggerenberg et al., 2015; Van Tam et al., 2011; Wakibi et al., 2011).

Patient perspectives on health system factors influencing adherence pointed out that delays in service delivery, perceptions of poor service and a lack of privacy affect adherence (Amankwah, 2015). These outcomes were reported following a study that explored the barriers and facilitators of adherence among patient with HIV/AIDS in Ghana using a mixed method approach. The study involved 120 clients selected without any rigorous estimation of sample size. Additionally, interviews and focus group discussions were done with 16 participants. Barriers such as long waiting times at the clinic, distance from home to the clinic, inadequate counselling, poor staff competence and a lack of follow-ups also negatively impacted on adherence to ART (Sanjobo et al., 2008).



In spite of the barriers, there are positive factors which have reportedly promoted adherence to treatment. Notably, counselling initiated prior to putting the patient on treatment facilitates adherence (van Loggerenberg et al., 2015; WHO, 2013). Adherence counselling is a prerequisite for enrolment in ART. The counselling assesses patient readiness, education on medication regimen and sexual life. Additionally, the importance of adherence to medication, including medication replenishment are emphasised noting the implication for non-adherence (NACP, 2014a; WHO, 2013, 2015a).

Measures like nutritional support, knowledge of professionals and free ART services have reportedly improved treatment adherence among clients on ART (Amankwah, 2015; Sanjobo et al., 2008). The theme of 'good clinic and good carers' emerged from a qualitative study (van Loggerenberg et al., 2015) in which participants reported factors influencing adherence. Participants noted that empathy, sensitivity of the staff, receiving phone calls from the staff, home delivery of pills, assistance with transport whenever needed and the approachability of staff facilitated their adherence behaviour. Examining the barriers and facilitators of adherence interventions developed over the years some had immediate impact while others raise issues of sustainability (Bärnighausen et al., 2011; S. Mannheimer et al., 2006; WHO, 2013). Some of these interventions have included reviewing the treatment regimen regularly based on evidence related to virology.

## 2.8 ASSESSING ADHERENCE TO ANTIRETROVIRAL THERAPY



Adherence monitoring is an important strategy in the care of clients with HIVAIDS. The purpose of monitoring adherence is to determine the effectiveness of treatment and minimise adherence related drug resistance (WHO, 2013). Optimum ART adherence is achieved at 95% adherence level (Paterson et al., 2000). Meanwhile Ortego et al. (2012) in a meta-analysis compared the adherence levels between men and women and reported a 90% adherence in about 62% of clients receiving treatment. Adherence levels among clients in parts of Ghana were also reported to range from 73.6% to 91% depending on six months to one week recall duration; the one month period recorded the highest adherence level (Obirikorang et al., 2013b).

Adherence may be assessed during routine clinic visits, scheduled evaluation programmes and research studies (Chalker et al., 2008; WHO, 2013). Objective, subjective, direct, indirect assessment, or a combination of these measures are used to determine medication adherence behaviour in clients (Bärnighausen et al., 2011). The most common direct measure of adherence is the therapeutic measurement of serum drug levels, which is often validated with viral loads. This is considered the most objective adherence measurement. Directly observed therapy is another way of monitoring adherence but some authors have argued that it is more of an intervention than a measurement. The indirect measures for determining adherence include; self-reporting, pill counts, audits of pharmacy records, provider estimates, pill identification tests, medication event monitoring systems (Bärnighausen et al., 2011; Steel, Nwokike, & Joshi, 2007).

***Table 3: Summary of measures for determining ART Adherence***

| **Adherence measure** | **Description** | **Advantages/Disadvantages** | **Psychometric validation** |
|---|---|---|---|
| Self-reporting | It involves the use of a tool to assess the judgement of the patient regarding their own level of adherence to treatment on a scale | Merits: it is easy to use, cheaper and requires no special technical skills. It does not overburden the client and takes less time to complete.<br><br>Demerits: it is subjective and thus liable to overestimation | Internal consistency is: α = 0.55 for MMAS-4<br><br>α = 0.71 for MMAS-8. |
| Pill count | It involves counting pills and computing percentage adherence by relying on the number of pills | Merits: it is objective, reliable as it enables tracking of prescriptions. It provides flexibility by allowing for either face-to-face or telephone assessment.<br><br>Demerits: it is unable to monitor dumping and sharing | |

| | | | |
|---|---|---|---|
| | dispensed and the pills returned | of pills, it is tedious, time consuming and require more resources | |

None of these measures summarised in table 3 are conclusive in themselves; however, a combination of these measures optimises outcomes. Steel et al, (2007) developed a multi-method measure for ART adherence in resource-constrained settings.

### 2.8.1 Self-Reporting and Visual Analogue scale

The literature suggests that self-reporting has been used to measure adherence to treatment in different populations (Culig & Leppée, 2014; Simoni et al., 2006; Stirratt et al., 2015). Self-reporting has become the most acceptable and easy to use adherence assessment tool (Stirratt et al., 2015). The tool consists of items structured to elicit behavioural responses of adherence based on the individual's personal judgement. Critiques argue that self-reporting tends to overestimate adherence and its validity and precision is questionable (Stirratt et al., 2015).



Despite the limitations of self-reporting it remains the most widely used adherence tool in research and clinical practice. This measure pre-empts adherence pattern assessment before clinical features of non-adherence are manifested (Garfield, Clifford, Eliasson, Barber, & Willson, 2011). Costs involved are relatively low and no specialised skill is required to administer self-reporting questionnaires when compared with other measures such as biological markers. Additionally, administration of self-reporting is not stressful to the client and the time involved is minimal ( Simoni et al., 2006; Stirratt et al., 2015).

However, there are variations in the ways questions are stated, the recall period (Lu et al., 2008), response items, administration of the tool and their scoring (

Simoni et al., 2006; Stirratt et al., 2015). The pattern of questions was reported to affect correlation of the self-reporting measure with the medication event monitoring system (MEMS) by Lu et al. (2008). They assessed optimal recall periods and response tasks in 156 HIV clients. The result showed overestimation of adherence was lower in one-month recall periods compared with three to seven-day periods when validated with the MEMS. Additionally, responses that focused on frequency estimation and percentage adherence overestimated adherence when compared with the rating of missed doses (Lu et al., 2008).

Self-reporting questionnaires which have been used and demonstrated moderate to high correlation with MEMS include Brief Adherence Rating Scale (BARS), Morisky (4 item) and Medication Adherence Self-Report Inventory (MASRI) (Shi et al., 2010).


The Brief Adherence Rating Scale (BARS) is usually used to assess the adherence of clients taking anti-psychotic medication. There are four items with three questions and an overall visual analogue rating scale which assesses the amount of medication taken, in percentage, by the patient over a one month period (Pot-Kolder, Veling, Geraets, & van der Gaag, 2016).

Morisky Medication Adherence Scale (MMAS) has two versions; MMAS-4 and MMAS-8. MMAS-4 consists of four items with a scoring scheme of “Yes” = 0 and “No” = 1. The MMAS-8 has eight items with a scoring scheme of “Yes” = 0 and “No” = 1 for the first seven items and a 5-point Likert response for the last item. The items are summed to give a range of scores; low adherence, moderate adherence and high adherence. The tool has been validated for measuring adherence in clients with hypertension (Morisky, Ang, Krousel-Wood, & Ward,

2008). Internal consistency of the self-reporting tool indicates a Cronbach alpha of 0.55 for MMAS-4 and 0.71 for MMAS-8 and the average item-test correlations for MMAS-4 is 0.65 and MMAS-8 0.57. MMAS has been used in a wide range of studies on adherence although originally used in hypertension clients (Andy et al., 2015; Garfield et al., 2011; Morisky et al., 2008; Murri et al., 2004; Shi et al., 2010; Steel et al., 2007).

The visual analogue scale (VAS) is a type of self-reporting that allows client to rate their adherence behaviour numerically or in percentages with reference to doses taken in the previous days or months (K Rivet Amico et al., 2006; Giordano, Guzman, Clark, Charlebois, & Bangsberg, 2004). An unmarked ruler is another instrument that can be used by asking a client to show an estimated adherence point on the ruler (Steel et al., 2007). The single item nature of the VAS makes it easy to administer. Studies have confirmed the validity of the tool compared with MEMS and self-reporting (Amico et al., 2006; Kalichman et al., 2009). However, VAS is critiqued for its reliance on a clients relative judgement (Kalichman et al., 2009).



### 2.8.2 Pill Count and Pharmacy Records

The pill count is an adherence assessment measure that involves counting pills and computing percentage adherence based on the number of pills dispensed and the number of pills returned (Lehmann et al., 2014). It can be done during a routine visit or randomly (WHO, 2013). The pills would be counted face-to-face during a clinic visit or over the telephone. Williams, Amico, Bova, and Womack (2013) argued that a pill count should be used with other measures following a study in which adherence was assessed through counting pills over the telephone without prior notice. Steel et al. (2007) in a study did not only count the

pills, but included a pill identification test that required respondents to indicate the pill name, dosage and additional instructions.

Pill counts have been widely used for monitoring adherence, although this measure is objective it is unable to monitor dumping and sharing of pills and therefore adherence may be overestimated (Agot et al., 2015; Kebaabetswe et al., 2015). Agot et al. (2015) assessed factors accounting for misreporting of adherence and noted that differences occurred in adherence when pill counts were compared with drug concentration levels. Additionally, the process is tedious, time consuming and more resources are required for unannounced pill counts in the home (WHO, 2013).

Pharmacy replenishment data indirectly estimates adherence behaviour in clients with HIV/AIDS by monitoring the medication pick up dates and schedules of subsequent appointments for consistency (McMahon et al., 2011; WHO, 2013). This is based on the assumption that consistently adhering to medication replenishment appointments translates to taking the medication (WHO, 2013). However, this may often not be the case considering that several factors influence medication adherence (Saberi et al., 2015; WHO, 2013).



However, some studies have reported that medication replenishment outcomes could be relatively reliable (Bisson et al., 2008). In more sophisticated settings, pharmacy replenishment records are processed using databases that are linked to prescription claims. Adherence is estimated by conducting retrospective analysis of the date a prescription was issued and the expected completion date (Lehmann et al., 2014). Estimates of adherence using pharmacy data are calculated using the medication possession rate (MPR), Pill pick-up (PPU)

(Williams et al., 2013) or proportion of days covered (PDC) approach (Lehmann et al., 2014). MPR estimates are determined by the date of supply divided by time interval until the next medication pick-up. PDC measures the days covered by the prescription divided by the period of measurement.

The use of pharmacy replenishment data in monitoring adherence is subject to having complete and accurate records. The data must include the dosage of the medication and relevant instructions (Williams et al., 2013). However, pharmacy data lacks information about the personal pill taking behaviour of clients and therefore adherence could be misreported (Lehmann et al., 2014).

### 2.8.3 Electronic monitoring of adherence

The electronic monitoring of adherence involves using devices with a microprocessor function to monitor clients on medication (Lehmann et al., 2014; Williams et al., 2013). The Medication Events Monitoring System (MEMS) and Med-eMonitor are some of the common devices. Once the pill cap or pill box is opened, information on the date and time of activity is generated, processed and transferred directly to a computer or uploaded later to a computer. Devices such as the SIMpill have been modelled to automatically deliver text messages to clients to remind them to take their medication if they have not taken their pills timeously. (Lehmann et al., 2014).

Pop-Eleches et al. (2011) conducted a randomised controlled trial using text messaging to improve adherence to ART in a limited resource setting. MEMS were used to monitor adherence in the four groups and adherence was observed to improve. The use of MEMS was not compared with other indicators to determine misreporting. However, it is also worth noting that electronic monitoring

has been used in some studies to validate self-reporting, pill counts, pill identification tests and visual analogue scales (Steel et al., 2007) for correlation. In some instances the electronic measures were more accurate in estimating adherence despite the limitation of accounting for pocket dosing and pill dumping events (Agot et al., 2015).

## 2.9 ADHERENCE INTERVENTIONS

Adherence intervention strategies became necessary following reports of non-adherence to treatment resulting in drug resistance. Different evaluation of adherence predictors showed that personal characteristics, medication related events, institutional and other related factors contributed to non-adherence (Mannheimer & Hirsch-Moverman, 2015; Saberi et al., 2015; Wakibi et al., 2011; Wasti et al., 2012). In light of this, interventions were designed with diverse perspectives that related to adherence facilitating factors (Mannheimer & Hirsch-Moverman, 2015). Existing studies and reviews revealed variations in the effectiveness of adherence interventions (Bärnighausen et al., 2011; Chaiyachati et al., 2014; Chung et al., 2011; Moore et al., 2011; Pradier et al., 2015; Wagner, Lovely, & Schneider, 2013) although some of these studies suggested text messaging was an effective intervention strategies (Belzer et al., 2015; Georgette et al., 2016; Lester et al., 2009; Smillie et al., 2014).

Bärnighausen et al. (2011) in a systematic review examined the effectiveness of adherence interventions in sub-Saharan Africa relative to the theoretical orientation of the interventions. Adherence interventions were examined within the behavioural, cognitive, affective, biological, structural or a combination of these theories. An intervention's effectiveness was dependent on the type of intervention and the environment in which the intervention was implemented.

Interventions such as the use of treatment monitors, diaries, nutritional support and text messages were relatively effective. Nevertheless, bias was considered as a major limitation as most of the interventions used observational studies. However, interventions that measured text message usage, based on a randomised control trial, showed a lower risk of bias. Bärnighausen et al. (2011) recommended the use of randomised control trials in future studies.

Mannheimer and Hirsch-Moverman (2015) in a more recent discussion of adherence to ART classified adherence interventions according to more specific criteria. These include: client readiness interventions, regimen focused strategies, education and counselling, social support, pill boxes, conditional economic incentives, directly observed therapy and the use of mobile phone technology. These interventions have arguably improved adherence outcomes in different populations.



### 2.9.1 Client readiness interventions

Patient readiness interventions are often directed towards empowering an individual by providing them with knowledge related to a disease, its prognosis and treatment thereof. Treatment plans are developed in collaboration with the client and measures of identifying and managing undesired effects of treatment are also determined (Mannheimer & Hirsch-Moverman, 2015). Client readiness interventions prepare clients to receive information about treatment and make decisions to accept treatment and be retained in therapy (Wagner et al., 2016). Adherence interventions need to be deliberate and structured to enable the appropriate evaluation of outcomes.

In a randomised controlled trial to determine efficacy of medication managers, (Mannheimer et al. (2006) concluded that patient structured adherence support measures were an effective intervention for promoting adherence. The trial was a 2x2 factorial design that utilised cluster randomisation to allocate four groups and two interventions (medication manager and electronic reminder) over a thirty month period. The results demonstrated treatment efficacy following the evaluation of adherence outcome and CD4 count levels. Mannheimer et al. (2006) admitted the use of a multifaceted approach and repetitive nature of the intervention contributed to positive the outcome. The design was rigorous and the theoretical context explicitly indicated an information, communication and motivational approach, contrary to the observation by (Bärnighausen et al. (2011) that the theoretical underpinning of interventions are often not indicated.

Patient readiness also facilitates adherence behaviour and in the long-term improves the health of clients on medication (Mannheimer & Hirsch-Moverman, 2015; Wagner et al., 2013). An adherence readiness programme (ARP) was piloted by ( Wagner et al. (2013) to determine if it could be utilised in a larger study. The programme involved monitoring respondents in pre-trial stage, early treatment stage and treatment tailored adherence training. Respondent were trained on the relevance of medication and its side effects, motivation, support and self-efficacy among other areas. Adherence was electronically assessed and viral loads monitored. Adherence improved at week eight of the assessment and declined by week 24. The researchers concluded that the adherence readiness intervention was beneficial in spite of the small sample size and weaknesses in the maintenance of the intervention. The relevance of adherence readiness is reflected in its inclusion as one of the pre-requisite assessments in initiating ART

in the treatment guidelines (WHO, 2013). Readiness assessments are often done during adherence counselling sessions and integrated into most ART counselling sessions.

### 2.9.2 Education and Counselling interventions

Adherence counselling sessions provide the opportunity to inform clients about the long-term nature of ART and the importance of sticking to the treatment (Mannheimer & Hirsch-Moverman, 2015; Wagner et al., 2013). Chaiyachati et al. (2014) mentioned that the most widely used adherence intervention is cognitive-behavioural therapy (CPT). Education and counselling interventions have a cognitive-behavioural theoretical underpinning in which the focus is to educate clients on the medication, its side effects, the disease condition and the importance of taking medication strictly according to the regimen, with the assumption that literacy would improve adherence behaviour (Bärnighausen et al., 2011; Chung et al., 2011; Pradier et al., 2015; Wagner et al., 2013).



Adherence counselling involves a one-on-one interaction with clients to facilitate an understanding of their treatment. Adherence counselling is one of the effective interventions recommended and integrated in all ART services. A minimum of two counselling sessions are recommended for each client (WHO, 2013). Studies show that adherence counselling is one of the most effective adherence interventions (Bärnighausen et al., 2011; Chaiyachati et al., 2014; Mannheimer & Hirsch-Moverman, 2015).

Chaiyachati et al. (2014) conducted a systematic review and reported that 28 interventions, which were education based, recorded 79% of outcome effectiveness. However, they noted the outcome may vary in different settings

and therefore recommended a rigorous and continuous evaluation of adherence intervention.

Evidence from a randomised controlled trial in Nairobi Kenya revealed adherence counselling effectively improved adherence to treatment (Chung et al., 2011). In this study respondents were new clients who were starting ART. Using a factorial design, they were assigned to two interventions and four groups. A standardised counselling session which lasted for a minimum of 30 minutes was given. Pharmacy replenishment records and virology status were used to evaluate outcomes. The results revealed that the intervention was effective. However, it was observed that post treatment adherence contributed to the positive outcome. Chung et al. (2011) pointed out limitations posed by the studies' outcomes, due to non-compliance with intention-to-treat analysis, but noted adherence counselling is an effective measure for reducing treatment failure in patient receiving ART.



Adherence counselling sessions however, have an eligibility criterion which requires a treatment monitor to be present during the counselling session. This requirement in a way suggestively integrates a level of social support even at the counselling stage as indicated in the treatment guidelines (NACP, 2014a; WHO, 2013, 2015a).

### 2.9.3 Social support as adherence intervention

Recognising the extensive evidence on the influence of social support on adherence, some of the interventions on treatment adherence employed the use of existing social support systems within the family, community (Duwell et al., 2013) and peer groups ( Horvath et al., 2013). Simoni, Frick, and Huang (2006)

applied a cognitive affective model of adherence evaluation and reported association between social support and adherence to ART but noted that negative affect and spirituality influenced the relationship.

Treatment supporters continue to play a major role in promoting adherence with a number of studies reporting improved adherence following the use of treatment supporters/partners (Chaiyachati et al., 2014; Duwell et al., 2013; Dwamena et al., 2012).

### 2.9.4 Other adherence interventions

Other interventions recommended include food supplementation, conditional incentives, directly observed therapy and the use of text messaging (Bärnighausen et al., 2011; Chaiyachati et al., 2014; Horvath et al., 2012; Lester et al., 2010; Mannheimer & Hirsch-Moverman, 2015; Nachega et al., 2014; WHO, 2013).



Directly observing clients taking their medication is another effective mechanism for ensuring medication is taken regularly. However, using this strategy increases the cost of care and requires additional personnel. This type of intervention may be helpful in the short term when initiating ART (Mannheimer & Hirsch-Moverman, 2015) and for hospitalised clients.

The use of text messaging and reminders is part of the emergence of telehealth care or, more specifically M-health, in which mobile phone applications are used to support health care (Thirumurthy & Lester, 2012). Text messaging has been widely used in adherence interventions with evidence of ‘no effect to moderate and large effects’.

## 2.10 MOBILE PHONE USE IN HEALTH CARE

Mobile phones, sometimes referred to as cell phones, is a communication device which works through a radio frequency system to transmit information via provider services (SMS) or text messages (WHO, 2011). Depending on its sophistication the phone could have other applications such as a camera for pictures and video. Smart phones have functions that are like the operating system of computers and are able to perform functions such as data storage, data processing, and transmission of information including graphics, voice, and videos. Smart phones have wireless features and work if signals are available and accessible. Smart phones also use Bluetooth to transmit data within a limited range of about 5–10 meters (Free et al., 2013) .

The use of mobile technology to deliver healthcare is referred to as M-health which is an integral component of Telehealth. Telehealth is focused on the application of Information, Communication and Technology (ICT) in health. Another context of the application of technology to healthcare is in the discipline of nursing (Telenursing). Although the field of technology application in health is widely studied and applied in developed countries, the process is still emerging in developing countries particularly around the use of mobile phone applications to support healthcare.

Abbott and Coenen (2008) argued that nurses should use telephones creatively to improve the care of clients in view of the globally expanding access to mobile phones. However, it is important to explore the literature to determine the mobile applications that have been used, their effectiveness, acceptance and applicability across populations.

### 2.10.1 Application of mobile phone in healthcare

Mobile phones have been used in healthcare to support an array of services and outcomes. They have been used to communicate diagnostic tests results; monitor clients with chronic diseases, promote treatment adherence, schedule clinic appointments, foster interaction between clients and service providers, remotely monitor clients during emergencies and manage patient records (Adler, 2007; Krishna, Boren, & Balas, 2009).

Mobile phone applications such as SMS and multiple media messaging have been used to facilitate interaction between clients as well as providing educational and motivational information, to promote behaviour change, in different populations including clients infected with HIV/AIDS. However, SMS applications dominate the literature with varied reports relating to its effectiveness in achieving the desired outcomes (Amico, 2015; Balas et al., 1997; Bielli et al., 2004; Brunner, 1993; Cole-Lewis & Kershaw, 2010; Consulting, 2009; DeMaio, Schwartz, Cooley, & Tice, 2001). Mobile phones have also been widely used for medication monitoring and psychosocial counselling (Abbott & Coenen, 2008; Cook et al., 2009; Fraser et al., 2005).



Mobiles phones are widely accessible and affordable for health delivery in most developing countries (Abbott & Coenen, 2008; Kaplan, 2006). Studies and reviews on text messaging demonstrated that messages, irrespective of length, delivered on weekly basis are an effective strategy for promoting adherence in HIV infected clients (Horvath, et al, 2012; Shet, et al, 2010; Lewis-Cole & Kershaw, 2010). Lester et al (2009) conducted a randomised control trial in Kenya. The treatment group received short and long text messages and were compared to another group that received standard care. The outcome showed

significant improvement in CD4 count and the quality of life for those who received the text messages.

Evidence suggest that text messaging is an important adherence support tool that improved adherence in different populations (Belzer et al., 2015; Arul Chib, Michelle Helena van Velthoven, & Josip Car, 2015; Georgette et al., 2016; Mechael et al., 2010; Pop-Eleches et al., 2011; Rodrigues et al., 2015; Smillie et al., 2014). Text messaging was found to be useful and acceptable among young people on ART (Belzer et al., 2015). Most mobile phone interventions tend to use text messaging which are unidirectional (Georgette et al., 2016; Pop-Eleches et al., 2011) or bidirectional ( Lester et al., 2010; Rodrigues et al., 2015). The bidirectional messaging seems more effective because of the feedback mechanism integrated into the intervention as demonstrated in the WeTel study in Kenya ( Lester et al., 2010;  Lester et al., 2009). A randomised control trial was conducted using three study sites with 1:1 group allocation. Weekly messages were sent to clients in the intervention group while the control group received standard care. The outcome of the intervention revealed significant improvement in adherence and virology outcomes but concerns about the social desirability were expressed.



The use of mobile phones in adherence support is considered effective, although it has been found, in other randomised control trials, that the interventions could yield outcomes that are not significant (Shet et al., 2014). Weekly automated messages and pictorial message were used to support adherence in southern India by (Shet et al. (2014) and the evidence from the trial did not show that the intervention was effective. However, it was argued that the lack of interaction and feedback in the intervention design could have accounted for this outcome. It is

worth noting that the cultural context of intervention effectiveness cannot be discounted, considering reported differences in outcomes of other intervention studies (Rodrigues et al., 2015; Shet et al., 2014).

### 2.10.2 Acceptability and feasibility of mobile phone use in adherence support

The integration of mobile phones in adherence interventions is subject to the acceptability and feasibility of the programme (Belzer et al., 2015; Arul Chib et al., 2015). The competency of clients in using mobile phones would also contribute to the acceptance of mobile phones (Rotheram-Borus et al., 2011). Factors such as individual characteristics, system viability, service delivery, interactivity and relevance of device were reported to influence usage of technological devices including mobile phones (Hassenzahl & Tractinsky, 2006). Some studies have indicated individual factors such as age , literacy, usability and access (Patrick, Griswold, Raab, & Intille, 2008) influenced usage. While young people tend to use mobile phones frequently, and sometimes develop addictions, older people were observed to have a lower tendency to use mobile phones, particularly sophisticated phones (Kurniawan, Mahmud, & Nugroho, 2006). Kim et al. (2015) also reported that clients who were employed were more likely to use mobile phones following a cross sectional study which assessed feasibility and acceptability of using Short Message Service (SMS) to clients on ART in Uganda. Results revealed the readiness of respondents who owned mobile phones to use their phones for health communication. Nevertheless, (Kim et al. 2015) noted their study was limited to rural settings and the type of ownership (shared or personal) of the device was not examined.

Studies and reviews suggest that text messaging is an acceptable and feasible strategy for improving adherence (Bärnighausen et al., 2011; Belzer et al., 2015; A. Chib et al., 2015; Georgette et al., 2016; Smillie et al., 2014). Although there is a paucity of literature on cost analysis of using M-health, some reports indicates that the interventions are relatively cost effective compared with the cost of non-adherence to treatment (Belzer et al., 2015; Georgette et al., 2016; Smillie et al., 2014).

Exploring clients' perspectives on M-health used in adherence support is relevant to any up scaling of interventions (Rodrigues et al., 2015). The qualitative outcome provides in depth information that explains experiences contextually. In a qualitative study by (Rodrigues et al. (2015) usage and usefulness of mobile phones to support treatment adherence is observed to be varied among clients. Some clients prefer voice calls to text messages and complain of an inability to use the text messaging settings on the phone. Additionally, participants had concerns about the unintended disclosure of their status which may follow the receipt of automated voice messages. When frequent phone calls are made or received, participants believed suspicions could be raised about the reasons for the calls and consequently their HIV status could be questioned. Therefore, careful concealment of phones and other privacy measures were employed.



Finitsis, Pellowski, and Johnson (2014) mentioned that interventions would be more effective and acceptable provided the frequency of messages are regulated and reduced. Messaging ensured a two-way communication between clients and service providers, and the message content was unique to each individual's preference and delivered to coincide with their medication schedule.

### 2.10.3 Considerations in integrating mobile phones in ART adherence support

In adopting mobile phone health care, consideration ought to be given to the ethical, legal and resource implications of such interventions particularly in developing economies ( Chib et al., 2015; Caron L Jack & Maurice Mars, 2014). Aranda-Jan et al. (2014) noted that for M-health interventions to be effective the design must be appropriate, technology and resources should be context derived and there should be collaboration with stakeholders. It is relevant to question the feasibility and acceptance of such intervention from the personal and institutional point of view (Aranda-Jan et al., 2014; Jack & Maurice Mars, 2014).

**Personal considerations**

HIV is a highly stigmatised disease, therefore interventions targeted at HIV positive people should seek to ensure fairness, protect privacy and ensure confidentiality (Labrique, Kirk, Westergaard, & Merritt, 2013). In some populations phone ownership is shared and information meant exclusively for a patient is threatened under such circumstances (Jack & Mars, 2014). There are issues of access, types of phones, technology acceptance, fear of change, literacy and cost of airtime that may affect implementation of M-health interventions in Sub Saharan Africa (Aranda-Jan et al., 2014; Belzer et al., 2015; Chib et al., 2015; Jack & Mars, 2014; Labrique et al., 2013; Mechael et al., 2010). Aranda-Jan et al. (2014) suggested the bridging of these gaps by developing a local content approach to project design which should include training, supply of airtime and partnerships between clients, health institutions, stakeholders including telecom operators and the government.

**Health service or organisation considerations**

Notwithstanding the suggestion of low cost in M-health interventions (Mechael et al. (2010) argued that existing interventions are not integrative and are slowing down the scaling up of M-health in low-middle income countries. An effective M-health intervention ought to be centred around policymakers, the business community, private-public health partnership, information technology (IT) stakeholders and sustainability plans (Mechael et al., 2010).

There is the need to overhaul the health system by transforming data capturing systems integrating this into electronic databases which allows for real time service delivery and monitoring (Aranda-Jan et al., 2014). The training of service providers is a key deliverable in the success of M-health interventions. Health service staff should be able to capture, transfer, utilise and monitor digital information without increasing their workload (Aranda-Jan et al., 2014; Rotheram-Borus et al., 2011).



Task-shifting models have worked effectively for HIV treatment and care. Nurses were trained to manage clients with HIV to fill human resource gaps in deprived areas (Shumbusho et al., 2009) but with reference to mobile phone support little is known. Task-shifting and mobile phone is a useful strategy for monitoring and improving access to ART (Selke et al., 2010). The approach was employed to deliver treatment in a two arm randomised control trial and results revealed that using persons' living with HIV/AIDS (PWLA) to support their peers was a useful intervention. The PLWA's were trained and assigned responsibility of using personal digital assistance (PDA) to monitor clients and, prompted by an alert mechanism, to visit clients and to assess and deliver their medication. The

respondents monitored by the peer service providers had similar outcomes when compared with the control group that received treatment from the clinic (Selke et al., 2010).

Partnerships with stakeholders are another issue that if managed correctly will facilitate integration on M-health interventions. Health institutions must collaborate with telecommunication owners, related agencies and governments to expand in-country technology capacity that would enhance coverage, access and affordability (Aranda-Jan et al., 2014; GSMA-Intelligence, 2015). It is important not to be ignorant to the real issue of resource constraints that is one of the major barriers to M-health integration in sub-Saharan Africa where major telecom expansion scale ups are required (GSMA-Intelligence, 2015). The work of Aranda-Jan, Mohutsiwa-Dibe, and Loukanova "*What works, what does not work and why*" in exploring the implementation of M-health is worthwhile, but the suggestion of scale ups requires further investigation in view of the admission that there is lack of clarity in the short to long term effectiveness of M-health interventions in Africa.



## 2.11 LIMITATIONS OF LITERATUREREVIEW

### 2.11.1 Limitations of literature review approach

The major limitation of the literature review approach is the choice of a narrative review over a systematic review. There are strong recommendations for using a systematic review when conducting intervention studies. This allows for the synthesis of existing studies in relation to the problem, approach, design, intervention, outcome and implications.

The narrative approach has widened the scope of the review but the quality of articles included was not rigorously subjected to any eligibility criteria. The articles were included be they quantitative, qualitative or mixed methods approaches, but the narration and build-up of arguments based on themes and issues implicitly led to a weak critical review of the studies included.

### 2.11.2 Limitations of published literature

The various adherence theories approached adherence behaviour mainly from a biological and/or psychosocial point of view. Adherence was evaluated based on clinical indices and physiological responses. Others used rewards and motivation to facilitate adherence all within the context of minimising barriers.

The barriers identified were related to the individual (decisions and roles); their environment; (health facility, family and significant others) drug related (benefit of treatment, side effect and dose) and resources (transport and food). More specifically the following gaps were observed in the literature:



- No nursing models were found to have been specifically applied to adherence behaviour, intervention or evaluation
- There was a paucity of literature regarding the assessment of adherence among clients living with HIV/AIDS in Ghana.
- No studies were found on the integrating of alarm, text messages and voice calls in adherence as an approach.
- Although interventions relating to mobile phone usage were reported; no specific policies and guidelines for the use of mobile phones in adherence support were found.

The use of text messages to support ART adherence ought to be contextualised within the ethnographical orientation of the end users, if the desired outcomes are to be achieved. Stigma, and other structural barriers that influence adherence in general, (Kagee et al., 2011) arguably pose similar threats to integrating mobile phone interventions in adherence support. Evidence reviewed indicated that most of the literature on mobile phone usage focused on the outcomes of using the phone rather than skills required and benefits of using one.

### 2.11.3 Synthesis of the theoretical context of the study

Three main models informed the implementation, evaluation and synthesis of the processes and outcome of this study.The goal attainment model as described earlier enhances an interactive transactional process between the nurse and the patient. The nurse implements decisions collaboratively with the patient. There is constant feedback that allows for continuous engagement within the continuum of care. The process of setting goals and implementing the decisions takes into account the beliefs, behaviour intentions, and actual behaviour. The feedback mechanism within the transaction facilitates evaluation of the process and the behaviour. The context and design of this study assumed that there is an interaction between the goal attainment model, the theory of reasoned action and the logic model.



The logic model facilitates evaluation of the inputs, activities, output and outcome to validate intervention appropriateness. The goal attainment model is patient focused while the logic model is programme oriented. The integrative application of the two models produces a synergistic outcome that ensures that the intervention follows an inclusive process. The patient have opportunity to

participate in decisions about the intervention while the entire process could be monitored logically.

The theory of reasoned action suggest that background factors such as personality, mood, education, knowledge may influence beliefs. Behaviour is supposedly an interplay of attitudes, perceived norms and behaviour intentions. The individual skills, abilities and environment determine the control that will be exhibited in their behaviour. The choice of the goal attainment model reflects an understanding the interplay of these factors.

## 2.12 SUMMARY OF LITERATURE

The review covered HIV/AIDS treatment and experience, the conceptualisation of adherence, a review of adherence theories, a discussion of factors influencing adherence to ART, an assessment of adherence and adherence interventions with an emphasis on mobile phone interventions.



The literature highlighted the need to explore the use of mobile phones in research populations. It also assessed the actual adherence in these populations and the importance of a rigorous evaluation when implementing integrated mobile phone interventions to support ART adherence.

Additional literature will be discussed in the exploration and discussion of findings.

The next chapter presents the description of the methodology used in this study.

# CHAPTER 3: METHODOLOGY

## 3.1 INTRODUCTION

This chapter describes the research approach, study design and research processes used to evaluate the integration of mobile phone technology in routine nursing practices to improve and support adherence to ARTs in PLWHIV in Accra, Ghana.

The research approach and paradigm is initially described in relation to theoretical postulates and application. A detailed description of the setting is provided followed by the three main phases of the study, namely; a randomised controlled trial, descriptive qualitative evaluation and document review. In each of these phases, the research design, population and sampling, method of data collection, data analysis and validity/rigor will be described with respect to each study.



## 3.2 RESEARCH STUDY PHASES

### 3.2.1 Phase 1: Randomised controlled trial

Phase 1 had two components, the development and implementation of the intervention and the evaluation of the intervention.

#### 3.2.1.1 *Development and implementation of an integrated mobile phone interventions to support ART adherence*

Based on the review of the literature, the researcher selected integrated mobile phone interventions to support ART adherence due to the likelihood that this was able to influence adherence behaviour in HIV infected clients. The programme dubbed "*Integrated mobile phone interventions for monitoring adherence* (IMPIMA)" included:

- *Primary Behavioural Reinforces:* alarm usage, motivational text messages and voice calls

Respondents in the intervention group participated in setting adherence goals and were assisted to programme their mobile phone alarms to sound when it was time for them to take their medication and when they had to make follow-up appointments. Additionally, weekly text messages and monthly voice calls were made in addition to the standard care.

- *Secondary Behavioural Reinforcers:* Transactional goal setting and social support.

The control group were expected to receive only the routine or standard care for clients on ART.

#### 3.2.1.2 *Evaluation of the Integrated Mobile Phone Intervention for Monitoring Adherence*

To evaluate the integration of mobile technology into routine nursing practice, in order to improve and support adherence to ARTs in HIV infected clients in Accra, Ghana, a randomised controlled trial was used with three phases.



Phase one had three time points (baseline, month three and month six) and three objectives namely:

1) To assess adherence to treatment among HIV infected clients in Accra, Ghana before during and after an integrated mobile phone technology intervention to support adherence;

2) To identify the demographic, clinical variables and support measures that may predict ART adherence in HIV infected clients;

3) To evaluate the effectiveness of using mobile phone interventions to promote ART adherence among HIV infected clients.

Primary endpoints measured were adherence level based on self-reporting, visual analogue pill counting and pill identification. Secondary endpoints were CD4 counts and body mass index (BMI).

### 3.2.2 Phase 2: Qualitative evaluation

In the second phase, qualitative data was obtained using interviews and focus group discussions to address objective four namely:

4) To evaluate the experiences of HIV infected clients and the perspectives of significant others in integrating mobile phone interventions in ART adherence support.

### 3.2.3 Phase 3: Recommendations for integrating mobile phones to support ART adherence

The third phase involved a critical review of the outcome of the study and existing evidence to address objective five namely:

5) To make recommendations for integrating mobile phone interventions in adherence monitoring strategies in the health sector. The contextual meanings of outcomes alone were insufficient grounds for suggesting the need to develop a guideline for an intervention in which a cost benefit analysis was not integrated. Therefore, reviewing existing documents, particularly guidelines and reports related to the outcomes of the study, was relevant to shaping the discourse.

## 3.3 RESEARCH APPROACH

The research approach used for this study is explanatory sequential mixed method research. The mixed methods research situated in the pragmatic paradigm was therefore identified as the most appropriate approach to be used to address the 5 objectives of the study. The process of quantitatively measuring

adherence while qualitative data is obtained at the end of the trial to provide context and meaning to the adherence outcome (Fetters, Curry, and Creswell (2013) is referred to as an *explanatory sequential design*.

The research approach has specific research designs which are the systematic plans that are termed the 'blue prints' of the research. The design outlines, among other things, the subject, setting, measurements, period and procedure of the study (Creswell & Garrett, 2008; Suresh, 2015). The choice of study design is relative to the study objective and the philosophical underpinning. The research may be designed as quantitative, qualitative or mixed methods (Creswell, 2013).

Quantitative studies generally focus on numerical measurement of variables, establishing relationships between variables and making deductive inferences (Creswell, 2013; Polit & Beck, 2013). Qualitative research, on the other hand, inductively generates knowledge using processes that obtain subjective information within the natural setting and context of the phenomenon being studied (Speziale, Streubert, & Carpenter, 2011). Combining the two approaches in the same study is referred to as mixed methods.



Mixed method research is a type of study that blends quantitative and qualitative methods to investigate problems using the best techniques (Creswell, 2013; Johnson, Onwuegbuzie, & Turner, 2007; Teddlie & Tashakkori, 2011). Mixed methods have been critiqued for making qualitative methods inferior and confusing paradigms. However, the strength of mixed methods enables researchers to combine the different approaches. Research problems and questions are addressed by what (Teddlie and Tashakkori (2011) refer to as methodological eclecticism and paradigm pluralism. Combining methods and

philosophical underpinnings to explore phenomena creates opportunity for a diversity of inference and a plethora of outcomes. Mixed methods also permits the synthesis of knowledge based on deductive and inductive reasoning (Creswell, 2013; Creswell & Clark, 2007; Teddlie & Tashakkori, 2011). Mixed methods are normally underpinned by a pragmatic philosophical paradigm.

### 3.4 RESEARCH PARADIGM

In this study a pragmatic paradigm informed the research approach and design. The principles of determinism, objectivity, quantification, reliability and generalisability were applied. Consistent with the explanatory sequential design, adherence outcomes were first measured quantitatively then interpretive qualitative data was obtained to enrich the findings. The meaning of adherence behaviour with IMPI from different perspectives was explored. Individual interviews and group discussions were conducted in a natural setting to obtain in-depth information on adherence behaviour. Document review was done to extract existing information on adherence interventions which informed the decision as to whether developing a guideline within the context of this study was relevant.



Philosophers in examining knowledge pose questions; (Creswell (2003) referring to his 1994 work argued that researchers ask questions relating to ontology, epistemology, axiology, rhetoric and methodology. The ontological view questions what constitutes knowledge and the epistemological view explores the nature of knowledge. He further claimed that the values of the knowledge refer to the axiology while the way it is written is the rhetoric. The way knowledge is investigated, Creswell argued, refers to the methodology. These broad perspective of knowledge have influenced the discourse in social literature

regarding which paradigms are most appropriate for investigating and interpreting what is known (Creswell & Garrett, 2008; Teddlie & Tashakkori, 2011).

Debates about merging paradigms in a single study have dominated the literature and the use of pragmatic paradigms which are a hybrid of the two dominant ideologies have become acceptable to some philosophers and researchers (Creswell, 2013; Creswell & Clark, 2007; Teddlie & Tashakkori, 2011). Creswell and Garrett (2008) argued that integrating different paradigms and methodologies in a study allows for the addressing of questions and decision making from a wide range of alternatives.

The stance in the early stages of the knowledge debate was to maintain single paradigms. The dominant philosophical ideologies were positivism and constructivism. While other ideologies have emerged, pragmatism provided synergism of the two dominant paradigms amidst arguments of their incompatibility. However, pragmatism has gained grounds and is currently applied in many fields of study including health. Broom and Willis (2007) assert that two main ideological orientations (positivist and the interpretivist) have dominated the debate on the health research paradigm.



A positivist paradigm is a philosophical orientation that seeks to understand reality on the assumption that phenomena are ordered and nothing occurs by chance (Pearson, Field, & Jordan, 2009; Polit & Beck, 2004). The positivist paradigm applies standardised procedures to observe phenomena constructed on theoretical ideas and then tests hypotheses and provides explanations grounded in observable and measurable outcomes (Pearson et al., 2009).

Interpretivists argue that knowledge is derived from the subjective interpretation of phenomena contextualised within a naturalistic setting (Broom & Willis, 2007). Interpretivists apply qualitative approaches to knowledge development while positivists utilise quantitative methods. The pragmatic approach blends quantitative and qualitative approaches in the same study.

### 3.5 RESEARCH SETTING

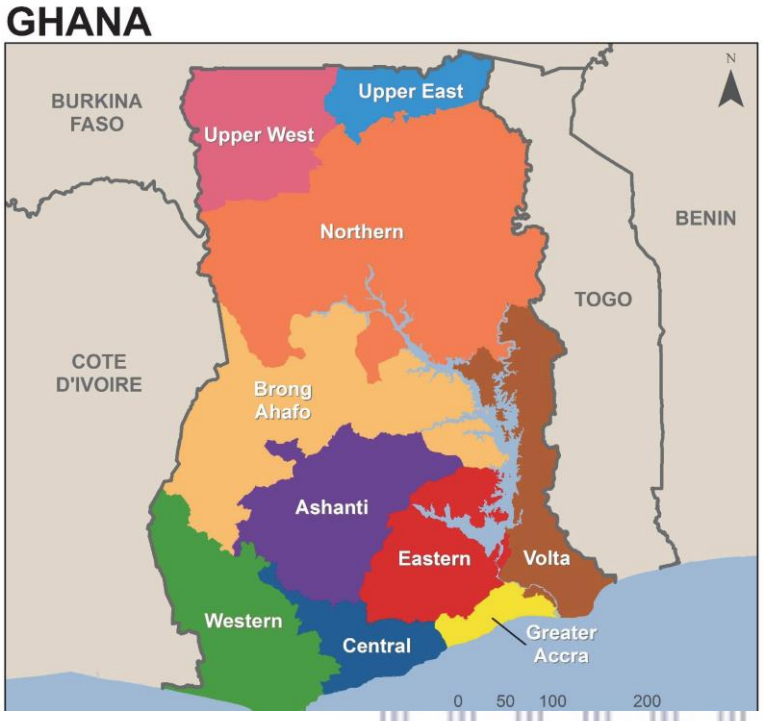
Ghana is a former British colony that gained independence on 6 March, 1957 with Dr Osagyefo Kwame Nkrumah as its first president. Since then there have been periods of political stability and upheavals. However, after 1992 constitutional governance and democracy has been sustained.

Ghana has a total land area of 238,538 square kilometres with a population of 24.2 million. It is bordered by Burkina Faso in the north, Cote d'Ivoire to the west and Togo to the east. The southern boundary is covered by the Gulf of Guinea, a coastline that stretches for about 560 kilometres. Ghana comprises ten regions (depicted in figure 4) namely; Upper West, Upper East, Northern, Brong Ahafo, Ashanti, Western, Central, Eastern, Volta and the Greater Accra region (Wikipedia-contributers, 2016).



The Greater Accra Region has a population of approximately 4,010,054 (16.3%) of the total population of Ghana (GSS, 2012). The Greater Accra Region is made up of metropoles (2), sub-metros (7), municipalities (3) and district assemblies (3). The location of health facilities are also informed by the structure of the local government system. There are several public and private health facilities in the region with 319 health facilities currently providing HCT/ PMTCT service and 24

ART sites. The HIV prevalence rate is 1.5% with a total of 12,077 new infections as at the year 2011 (NACP, 2014b).




***Source:(GSS et al., 2015)***

***Figure 4 Map of Ghana***



The two health institutions selected for this study are located within the Greater Accra region. All the hospitals are in urban centres and have ART clinics. One of the institutions serves as a teaching hospital and is classified under tertiary health care. It has a bed capacity of 2,000 and 17 clinical and diagnostic departments/units. The average daily attendance is estimated at 1,500 clients while client admissions are about 250 daily. A total of 22, 480 clients attended the ART clinic in 2013, of this number, new clients were 1,054 with an estimated daily attendance of 250 clients (KBTH, 2013).

The other institution is a secondary (level 'A') facility which is a referral point for all district hospitals in the Greater Accra region. It occupies a total land area of

about 15.65 acres. It has a bed capacity of 194 and an average outpatient attendance of 388 clients daily (Osei-Tutu & Anto, 2016). The hospital was expanded to a 420 facility and was commissioned on 30 November 2016 (Abubakar, 2016).

## 3.6 METHODOLOGY

The methodology section includes the description of the study relative to the various phases of the study. Information relating to the method, population, sampling, procedure, analysis, data quality and ethics was discussed.

## 3.7 PHASE 1: RANDOMISED CONTROLLED TRIAL

This phase involved undertaking a randomised, controlled trial to assess adherence to treatment among HIV infected clients in Accra, Ghana, before during and after an integrated mobile phone technology intervention, to support adherence and to evaluate the effectiveness of using mobile phone interventions to promote ART adherence among HIV infected clients. In addition, the trial will enable the identification of the demographics, clinical variables and support measures that may predict ART adherence in HIV infected clients. The study method, population, sampling, instruments, data collection and analysis are described in this section.



### 3.7.1 Study Method

A randomised control trial (RCT) is a quantitative analytical experimental study design where respondents are randomly assigned to groups using predefined criteria (Okeh & Ugwu, 2009). The groups may or may not receive an intervention or the interventions may vary depending on the study design. Okeh and Ugwu (2009) indicated that a RCT requires that analysis is done per group allocation no

matter the intervention condition (intention to treat analysis). Additionally, the analysis of findings should indicate differences between groups noting the size of the difference.

There are different approaches in group allocation relative to the study design and objectives. However, in this study the two-arm equal group assignment was employed. Eligible respondents were randomised into two groups; an intervention and a control group in a ratio of 1:1. Baseline information was obtained from clients and hospital records. Outcomes were measured in both groups at three months and six months.

### 3.7.2 Population and Target Population

The target population in this study was all HIV/AIDS positive clients receiving antiretroviral therapy in Greater Accra within the study period. There were an estimated 75,762 adults on ART in 2013 out of which 3,150 were from the Greater Accra region.



### 3.7.3 Sample and Sampling Procedure

Clients infected with HIV within the Greater Accra Region were eligible. However, to enhance access to clients; the samples were drawn from two (2) major public health facilities in Accra. The output from the sample size calculation can be seen below.

A sample size of 320 respondents was expected to be recruited using a two-tailed significance level of 95% and power of 80%, a ratio of 1:1 in the groups, an expected adherence rate of 85% (lowest adherence score reported) in the non-exposed group which is expected to increase to 95% (required adherence level) in the exposed group.

***Table 4: Sample size calculation***

| **Sample Size: Cross-Sectional, Cohort, & Randomised Clinical Trials** | | | |
|---|---|---|---|
| Two-sided significance level(1-alpha): | | | 95 |
| Power(1-beta, % chance of detecting): | | | 80 |
| Ratio of sample size, Unexposed/Exposed: | | | 1 |
| Percent of Unexposed with Outcome: | | | 85 |
| Percent of Exposed with Outcome: | | | 95 |
| Odds Ratio: | | | 3.4 |
| Risk/Prevalence Ratio: | | | 1.1 |
| Risk/Prevalence difference: | | | 10 |
| | **Kelsey** | **Fleiss** | **Fleiss with CC** |
| Sample Size – Exposed | 142 | 141 | 160 |
| Sample Size-Non-exposed | 142 | 141 | 160 |
| Total sample size: | 284 | 282 | 320 |

CC = continuity correction *Results from Open Epi Version 2, open source calculator*



The sample size estimation was based on the Open Source Statistics for Public Health version 2 open source calculator as shown in Table 4. A non-response rate and lost-to-follow up of 10% estimated a sample size of 352 respondents to be a representative sample size. Nevertheless, 362 respondents were recruited into the study at baseline out of 400 respondents who were willing to participate in the study.

The eligibility criteria included; HIV seropositive status, age - 18 years and above, willingness to participate, receiving ARV, access to a mobile phone, ability to use a basic mobile phone application with training and should not be on Tuberculosis treatment or have any other co-morbidities requiring long-term treatment. Respondents were excluded if they did not have access to a mobile phone, or could not use a mobile phone after training, their CD4 count test result was not accessible, their mobility was impaired or they were undergoing treatment for Tuberculosis.

*The permuted block randomisation* sampling technique was used as this was a small trial and simple randomisation might have resulted in the numbers allocated to each group not being well balanced.

The sample size of the study was estimated at 352 with four blocks yielding 88 blocks with six permutations per block. An Excel spreadsheet was used to create the blocks and generate random numbers. The numbers were then ordered, written out and then sealed in envelopes accordingly. In addition, two colour codes for treatment, which were hidden from the investigator and the research assistants collecting data, were included in the sealed envelope, for easy assignment to a group. As the number of respondents indicating a willingness to participate in the study increased to 400, the number of blocks was adjusted to 100 but only 362 became eligible and were retained.

Permuted block randomisation is one of the methods of allocating subjects into study groups that have equal block sizes based on permutations. The allocation ratio determines the possible block sizes and permutations. In case of a 1:1 ratio allocation, probable permutations are multipliers of the number of groups expected therefore there may be 2, 4, and 6… block sizes. In the case of a four blocks size there are six possible permutations possible (Efird, 2011). Zhao and Weng (2011) argue that increasing block sizes also reduces predictive probabilities.



### 3.7.4 Instruments

Data was collected using structured interviewer administered questionnaires. Baseline assessment included socio-demographic characteristics (age, sex, level of education, marital status, employment status and religion); clinical variables

(including stage of HIV, duration of illness, CD4 count, type of medication and weight) and use of mobile phone technology (Appendix C).

The multi-method adherence tool (Appendix D1-4) developed by (Steel et al. (2007) was used to measure adherence levels. The multi-method scale is designed to be administered by the care provider. The tool consists of four subscales, namely: a self-reporting scale, a visual analogue scale, a pill identification test scale and a pill count with a relevant scoring criterion scale. There is an additional subscale which is not scored that measures adherence support.

- The self-reporting subscale consists of four items that examine adherence from clients' responses over a four week period.
- The visual analogue scale estimates clients' personal assessment of pill taking behaviour on a scale of zero to ten with zero indicating poor adherences and ten implies optimum adherence.
- The pill identification test scale assesses familiarity with pills based on the ability to name pills, indicate doses, timing and additional instructions.
- The pill count scale requires estimating adherence based on the number of pills dispensed at previous clinic visits and the number of pills remaining.
- The adherence support scale measures were evaluated on a four point Likert scale which assessed whether support measures were available, not helpful, somewhat helpful or very helpful. Additionally, this subscale assessed the factors affecting pill taking on a four point Likert scale. The support measures evaluated were modified to reflect literature perspectives.

### 3.7.5 Validity and Reliability of the Instrument

The Multimethod adherence tool is an instrument developed and validated for measuring adherence in clinical settings and has reported good reliability and validity.

*Validity:* Validity was measured by ensuring items in the construct adequately measured the concept of adherence. The types of validity of interest in this study were face validity, content validity and construct validity.

Face validity was established through a peer review by my supervisor, peers and four independent reviewers who noted that the items measured the construct and concept in the study.

***Table 5: Summary of psychometric properties of research instrument***

| **Tool/subscales** | **Author** | **Description** | **Reliability** |
|---|---|---|---|
| Multimethod Adherence tool | Steel et al (2007) | Consist of 4 constructs for measuring adherence and adherence support measures | r = .52 |
| - Self-report | Miriosky adopted by Steel et al (2007) | Consist of four questions with two categorical responses on pill taking behaviour | r = .53 |
| - Visual Analogue scale | Steel et al (2007) | Estimation of pill behaviour on a 10 point scale with 1 as least. | r = .42 |
| - Pill identification test | Steel et al (2007) | Identification of pill name, dose, timing and additional instruction (4) items | unknown |
| - Pill count | Steel et al (2007) | Computation of pill dispensed less pill taken | r = .52 |

Content validity involves critical appraisal of constructs and items within appropriate theoretical concepts. Expert groups are sometimes used to evaluate and score the items particularly when an instrument is new (Wood, Kerr, & Ross-Kerr, 2010).

Construct validity is an approach used to determine if the concepts being measured are related theoretically as is operationalised within the study (Wood et al., 2010). There are three approaches recommended by (Walz, Strickland and

Lenz 1991) cited in (Wood et al. (2010) namely: use of contrasted groups (comparing criterion score with study outcome), manipulating variables in experiments and a multitrait-multimethod approach (using different tools that measure the same concept).

The design of the current study met most of the conditions proposed by (Walz et al 1991) and (Steel et al 2007) who piloted the Multimethod tool and reported strong correlation with Medication Event Monitoring (MEM) on the subscale and overall scores: Visual analogue scale (r = .42); Pill count (r = .52) and Multimethod (r = .52) but noted the sample size (n = 33) was relatively small. The self-report subscale made up of the Miriosky-4 scale had the highest correlation co-efficient (r = .53). Table 5 summarises the psychometric properties of the multimethod adherence tool.

In addition, this study used a two arm experimental group and multimethod tool which measured the same construct at four levels before adding up the total scores.



*Reliability:* Reliability consists of three concepts, inter-rater reliability, test-retest reliability and internal consistency, though only internal consistency was calculated. According to (Pallant (2011) reliability of the research instruments is determined by its stability and consistency. Stability is tested by repeated measurement in the same population while consistency examines relations between items that measure the same construct. Cronbach's alpha coefficient is the most commonly used indicator for determining scale consistency. The Cronbach alpha values are influenced by the number of items in the scale, therefore the lower the number of items the smaller the alpha values. Cronbach's

alpha values range from zero (least) to one (highest) with .7 considered acceptable, however, for items less than ten it is recommended that inter-item correlation is reported(Pallant, 2011).

Internal consistency was calculated using Cronbach's alpha coefficient which can detect a relationship between items in the constructs measured. A pre-test to validate the instruments in a cross-sectional study ( N = 318) revealed weak to moderate consistency of the tool (Dzansi, Lartey, & Chipps, 2015). Only the pill count score did not correlate to the other scores (detail results are presented below).

***Table 6: Internal consistency of tool***

| Subscale | Number of item | Cronbach's Alpha |
|---|---|---|
| Baseline self-report | 4 | .33 |
| Self-report subscale scores included | 4 | .69 |
| Pill identification test | 4 | .10 |
| PIT one item deleted | 3 | .34 |
| PIT at follow up | 2 | .63 |
| Pill count baseline | 2 | .47 |
| Pill count follow-up | 2 | .78 |
| Visual analogue scale | 1 | - |



However, on completion of the current study, the Chronbach alpha was calculated and demonstrated poor internal consistency (Table 6).

#### 3.7.5.1 *Pre-test: Validating the multimethod adherence tool*

The reliability of the instrument was also tested through a pre-test among 318 respondents in a cross-sectional study using convenience sampling.

The Cronbach alpha for the four item scale was .70 with a standardised value of α = .72 (N = 309). Item two (2) and four (4) had a relatively higher correlation $r_s$ (309) = .59, p < .05 compared with the other items in the scale as shown in table 7. Stability of alpha values were observed to decrease α = .65 (N = 274) after retest (two weeks) using the same respondents.

***Table 7: Self-reporting scale inter-item correlation***

| **Variables** | **Outcome** | | | |
|---|---|---|---|---|
| Items | 1 | 2 | 3 | 4 |
| 1. Do you sometimes find it difficult to remember to take your medicine? | - | | | |
| 2. When you feel better, do you sometimes stop taking your medicine? | .38 | - | | |
| 3. Thinking back over the past four days, have you missed any of your doses? | .26 | .31 | - | |
| 4. Sometimes if you feel worse do you stop taking the medication? | .39 | .59 | .43 | - |

*Cronbach's alpha = .70 (N = 309) decreased to α = .65 at retest*



Pill identification tests with the four items recorded a low internal consistency α = .41 but deleting item one (name of drug) increased the internal consistency α = .98 (N = 306) for the three items. There was perfect inter-item correlation following retest analysis based on the three items only.

***Table 8: Pill identification test inter-item correlation***

| Items | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| 1. Name of drug | - | | | |
| 2. Knows number of pills per dose | -.16 | - | | |
| 3. Knows timing of dose | -.18 | .92 | - | |
| 4. Knows additional information | -.18 | .92 | 1 | - |

*Cronbach's alpha = .41 (four items), after deleting item 1 α = .98 (N = 306)*

The results summarised in Table 9 revealed the average adherence score and the reliability coefficient for each of the four subscales that measured adherence at two week intervals. Visual analogue scores increased slightly from ($M$ = 85.5, $SD$ = 8.5) to ($M$ = 87.1, $SD$ = 7.7) with the scale demonstrating very strong positive correlation outcome $r_s$ (274) = .84, $p$ < .01.

**Table 9 : Test retest correlation of subscales of the multimethod adherence tools**

| **Variables** | **Outcome** | | | | |
|---|---|---|---|---|---|
| *Measurements* | *M* | *SD* | *N* | *Test* $r_s$ | *P - value* |
| Self-reporting score [a] | 96.2 | 9.14 | 274 | .75** | .01 |
| Self-reporting [b] | 97.8 | 6.75 | 274 | | |
| Visual analogue score [a] | 85.5 | 8.55 | 274 | .84** | .01 |
| Visual analogue [b] | 87.1 | 7.76 | 274 | | |
| Pill Identification test (4 items) [a] | 88.0 | 5.48 | 274 | .72** | .01 |
| Pill identification test (4 items) [b] | 88.9 | 5.74 | 274 | | |
| Pill Identification test (3 items) [a] | 99.1 | 6.70 | 274 | .63** | .01 |
| Pill Identification test (3 items) [b] | 99.6 | 4.26 | 274 | | |
| Pill count score [a] | 98.8 | 1.42 | 193 | .08 | .218 |
| Pill count score [b] | 98.6 | 2.89 | 193 | | |
| Overall adherence [a] | 94.9 | 4.48 | 193 | .79** | |
| Overall adherence Score [b] | 95.6 | 3.77 | 193 | | |

*** Correlation is significant at the .01 level (2-tailed).*

[a] *Initial test score*

[b] *retest score*



The results also show the low adherence score obtained if the four item pill identification adherence subscale is used although a significant positive strong correlation $r_s$ (274) = .72, $p$ < .01 was recorded following test-retest. However, the three item pill identification outcome $r_s$ (274) = .63, $p$ < .01 had a relatively lower association on retest compared with the four items scale. Pill count recorded high adherence levels ($M$ = 98.8, $SD$ = 1.4) at initial assessment but scores ($M$ = 98.6, $SD$ = 2.9) reduced marginally after the retesting. In

addition, there was no significant association between the first and second adherence test scores with a very weak correlation coefficient $r_s$ (193) = .08, $p$ = .218. The overall adherence levels increased slightly (1%) and there was strong significant positive association between the scores at time one and two $r_s$ (193) = .79, $p$ < .01.

### 3.7.6 Data Collection Procedure

The data collection describes the preparations before commencement of data gathering, the recruitment process and the procedures employed.

#### 3.7.6.1 *Preparation for data collection*

Permission letters supported by an ethical approval letter were sent to the two hospitals. Clinicians (doctors, nurses, pharmacist, laboratory technicians and biostatistician) within the unit where data was being collected were informed about the study procedure and their role in ensuring the integrity of the data.



Research assistants were recruited and trained to ensure the protocol was understood. A three-man steering committee consisting of the first supervisor and two mentors was formed. A data management committee was also put in place to monitor the data collection. A one-day training session was organised to train all members of the research team.

A statistician (data manager) guided the researcher in generating codes for group assignment. Additionally, light green and orange stickers were obtained and kept in sealed envelopes with the random numbers written on it. This was done to minimise the complexity of group assignment as some of the random numbers were on occasion similar. Questionnaires were printed and research codes written on each questionnaire. Computers, mobile phones, notebooks and other

resources were procured and checked. Space for conducting interviews was sought to ensure client privacy. Pre-recruitment education was done for a period of one month to enable clients to have adequate information before deciding whether to enrol in the study.

#### 3.7.6.2 *Recruitment and data collection*

Recruitment of respondents and baseline data collection occurred concurrently. Prospective respondents were informed about the study's purpose and expectations using the client information sheet. A general education session was given early in the morning, on clinic days, to enable respondents to make their decisions about enrolment. Clinic records of respondents who expressed interest were obtained to determine eligibility. Respondents who met the criteria were taken through the informed consent process; the consent form was endorsed by respondents and witnessed by the research assistant.



Respondents who met the criteria were asked to randomly pick one of the sealed envelopes. The recruitment assistant recorded the respondent's name, hospital number, telephone number and research code. The respondent proceeded to the interview room where their weight and height were checked prior to administration of the questionnaire.

The questions were read by a research assistant for responses (interviewer administered). The questionnaire included a pill count requiring the pills to be counted. Patient records were checked for pills dispensed during the previous clinic visit, research assistants were required to note the name of the pill, dosage, date supplied and the date of next visit to the clinic. Additionally, the following data was obtained from the clients' record: latest CD4 count, latest viral load and

stage of illness. The folder number and code on the sealed envelope were recorded on the questionnaire. Respondent's name, research code, folder and telephone numbers and relevant demographic data were written in a notebook as a backup record for follow-up. The follow-up clinic visit dates were scheduled to coincide with the first and second follow-up interviews whenever possible.

All the respondents recruited went through a similar process on each clinic day until the desired sample size was obtained over a one month period. The research coordinator, who did not participate in recruitment or data collection, received the envelopes opened and recorded the group assignment on the questionnaire and in the notebook. Respondents in the intervention group were taken through the goal setting and planning sessions individually. Two clinical assistants (peer educators who were HIV positive but worked in the unit as volunteers) were assigned to send weekly text messages and make monthly voice calls and to prompt respondents to set alarms at medication time.



All the respondents were called and reminded of their first and second follow-up visits which occurred during the third and sixth months respectively. During these visits, the respondents had their weight and height checked and questionnaires administered as previously described. The questionnaires were labelled with the group code, at the end of each clinic day, by the research coordinator referring to their existing records. These processes were followed to protect data quality and reduce bias associated with randomised control trials. Efforts were made to ensure that members of the team who were involved in implementing interventions did not participate in administration of the questionnaires.

### 3.7.7 Data Analysis

Data was gathered in different stages therefore measures were in place to ensure data integrity. This section provides vivid description of how data was analysed.

#### 3.7.7.1 *Data Preparation*

The analysis involved all randomised clients irrespective of their study outcome. However, respondents randomised in error and those who did not meet the inclusion criteria specified in the protocol were excluded in analysis.

Questionnaires were crosschecked to ensure they were completed in full; incomplete questionnaire and those which could not be validated were excluded. A codebook was created and the variables were defined and labelled with appropriate coding instructions. Data entry was done using Epidata and SPSS software version 20. Variables such as BMI and pill count score were computed in Microsoft Excel using the computational formulas



- *BMI= Weight in kilogram divided by height per metre squared;*
- *Pill count score % Adherence =Pills dispensed minus pills returned divided by pills expected to be taken multiplied by 100.*

Descriptive exploration of data was done on variables to identify outliers. Checks for consistency between variables were also carried out. Where data errors appeared to have been made, but the true values could not be determined, a decision of exclusion was taken prior to breaking the study code.

Significance testing for all statistical tests was two sided with an alpha level of $p \leq .05$ being statistically significant. The 95% confidence interval was used were appropriate. The Cohen (1988) effect size standard namely: small effect (.1), medium effect (.3) and large effect (.5), were applied in estimating the effective

size for the independent *t* test. The dependent variables were; self-reporting score, visual analogue score, pill identification test score, pill count score and overall adherence score. The independent variables were; demographic characteristics (age, gender, education, marital status and employment status), clinical variables (BMI and CD4 count level) and time (time 1, 2, and 3).

#### 3.7.7.2 *Analysis of demographic and clinical variables*

Categorical demographics variables (marital status, education, employment status and religion) were analysed between the groups using Chi-Square test of independence and Fisher's exact test, were appropriate. Continuous variables (including height, weight, age and CD4 count) were assessed for normality. Between-group comparisons for normally distributed data were done using the independent 't' test while skewed data was compared using the Mann Whitney U test.



##### *3.7.7.2.1 Analysis of Adherence outcomes*

Adherence scores for the self-reporting scale and the pill identification test were computed by transforming scores into numerical variables (the addition of the raw scores divided by the number of items multiplied by 100). The percentages obtained were then ranked into ordinal scale with three levels namely: highly adherent (95% and above), moderately adherent (75% to 94.9%) and low adherence (less than 75%) based on the criteria for scoring on the multimethod adherence tool. The scores for the pill count and visual analogue scales were also converted to percentages in a similar pattern: highly adherent (95% and above), moderately adherent (75% to 94.9%) and low adherence (less than 75%).

Overall adherence scores were computed adding up the four subscales (self-reporting, visual analogue, pill identification test and pill count and divided by four) then all the scores were transformed to ordinal scale with a score of 95% and above as highly adherent (value = 3); moderately adherent 75-94% (value = 2) and low adherence less than 75% (value = 1). This was consistent with the coding frame suggested by (Steel et al. (2007) but modifications were done to make the estimation of adherence score easier and more accurate.

Data on adherence outcomes was collected at three different stages from the same respondents. The effects of baseline characteristics (independent variables) on adherence outcomes (dependent variable) were examined using regression techniques. Regression analysis done for continuous variables relevant to study objective and outcomes namely: CD4 count, BMI, VAS, pill count scores were included as dependent variables in the linear regression model. Socio-demographic factors (age, sex education, marital status, employment, religion) and time were also included in the model as covariates.



Linear mixed model regression analysis adjusted for covariates was done to determine the effect of intervention across the three timelines and the groups. The same procedure was employed in determining predictors of adherence. The Linear mixed model is robust to any violations of normality, linearity, multi-colinearity and homoscedasticity.

Logistic regression was done for binary outcomes (categorical variables) consistent with the principles underlying such regression analysis. Descriptive statistic and frequencies were run for variables for which regression was not possible due to the violation of logistic regression rules.

### 3.7.8 Ethical considerations in the randomised controlled trial

*Permission*: The protocol was submitted for review and approved by the Senate Research Ethics Committee, University of the Western Cape South Africa and the Institutional Review Board of the Noguchi Memorial Institute for Medical Research of the University of Ghana, Legon. In addition, four independent reviewers and mentors from the Fogarty AIDS International Training and Research Program (AIRTP) reviewed the protocol prior to providing funding. Permission letters were written to obtain clearance from the administrators of the two institutions.

*Privacy and anonymity:* The privacy of respondents was protected by conducting interviews in a private room at the clinic. The identity of respondents was protected by using codes and folder numbers in place of names. The time of the phone calls was decided in conjunction with respondents to limit intrusion into their privacy. Calls were made by the clinical assistants (peer educator/volunteers) with whom respondents had interacted with prior to enrolling in this study. Text messages were coded to prevent any suspicion and maintain the privacy of the participants' HIV status. The questionnaires, which were labelled with codes, were also separated from the consent form. Research assistants were trained to be well versed in the research process to avoid breaching the privacy of respondents.



*Informed Consent:* Respondents were taken through a rigorous consent process and were asked to sign a consent form only if they understood the purpose, procedure and the benefits or risks associated with participation. The information sheet was used to explain the research process and clients signed the forms in writing or by thumbprints.

*Non-maleficence:* There was direct no harm caused by the study to respondents and any such harm would have been unintended. However, for clients who did not present their pills for counting there were some feelings of guilt which were allayed by encouragement. All respondents had an equal opportunity to enrol in the study despite the eligibility criteria.

The use of random numbers and colour codes ensured the concealment of subject allocation and in addition the investigator did not participate in the data collection process. The use of a trial committee facilitated monitoring for possible ethical breaches. The research assistants were trained to enhance their competence while investigators were supported by supervisors and mentors to improve competency in implementing the intervention.

The provision of tokens to participants, to cover transport costs, was not disclosed prior to the interview and respondents were encouraged not to inform their peers about the tokens the received, so that no financial incentive to join the study was perceived.



*Beneficence:* Respondents had direct interaction with the research team and messages and voice calls times were determined by mutual agreement reached at the goal setting stage. The monitoring of adherence was a motivational experience considering that respondents in the control group also benefited from voice calls after terminating the study. Respondents also received some rewards in the form of snacks and transportation tokens.

*Respect:* The respondents' rights to enrol, withdraw or decline from participating in the study were communicated to them and respected.

*Confidentiality:* Measures were put in place to ensure that personal records and questionnaires were protected. Documents with personal details such as the field notebook were kept in safe custody while files were password protected. Respondents were assured that the use of data for academic purposes would in no way result in their personal details being exposed to anybody. All clients' identities will also be protected when information is disseminated through the publication of this thesis.

Ethics are the moral values and principles integrated in the research process that ensures adherence to professional, legal, and social obligations to the study's subjects (Polit & Beck, 2013). The essence of ethics in the research process is to protect the respondent without compromising the quality of the research process. The approaches and procedures employed in research ought to integrate human rights issues, safety, social responsibility and professional standards in a holistic manner (Resnik, 2011).



In this regard the ethical principles applied in this study were consistent with the standards guiding RCT. Sarker (2014) noted that respondents in RCT are expected to have the right of choice when deciding whether to enrol in a study. Subjects are not to be coerced directly or indirectly to participate in the study (Wood et al., 2010).

Informed consent should be granted on the basis that a respondent has a clear understanding of the purpose of the research and its procedures and an appreciation of the benefit to risk ratio (Nardini, 2014; Sarker, 2014; Wood et al., 2010). Misconceptions and ambiguities should be clarified before any endorsement of the forms (Nardini, 2014). Consent must be given voluntarily and

the right of withdrawal must be freely available. Respondents must also be given equal opportunity especially when beneficial interventions are involved and the study process ought to be devoid of bias (Sarker, 2014; Wood et al., 2010). The principles of blinding randomisation and competence are considered integral ethical issues influencing RCT (Nardini, 2014).

## 3.8 PHASE 2: QUALITATIVE STUDY

The second phase of the study sought to evaluate the experiences of HIV infected clients and the perspectives of significant others in integrating mobile phone interventions in ART adherence support. The focus was to explore clients' experiences associated with HIV diagnosis and treatment, adherence to treatment and their opinions on using integrated mobile phone interventions. The perspective of professionals (experts) and policy on integrating mobile phone interventions was also examined.

### *3.8.1* Study Methods



Descriptive exploratory qualitative methods were used to obtain in-depth information in three qualitative studies:

1) HIV infected clients' experiences of using a mobile phone in supporting medication adherence;

2) Experts' (health professionals at policy and implementation level for HIV care) experiences of using a mobile phone in supporting medication adherence; and

3) Existing adherence guidelines. Individual interviews, focus group discussions and document review were the main methods used to obtain the data. Thematic and narratives analysis was done to generate themes, categories and

subcategories. The three studies are described separately but the data analysis, rigour and ethics of the three studies are discussed together.

### *3.8.2* Study 1: Interviews

The population for the three studies included stakeholders involved in policy planning, implementation and evaluation on ART. Information on existing ART adherence guidelines was also targeted for extraction.

#### 3.8.2.1 *Participants and sampling*

Two groups were interviewed:

a) Participants were clients with HIV/AIDS receiving ART and using mobile phones as a medication support measure (n=10) that were purposively recruited from the treatment group of the randomised control trial. Six client participants out of ten who consented were interviewed. The sample size for the client participant interview was determined by data saturation. The criteria for participation included; use of alarms for medication adherence, receiving weekly text messages and monthly voice calls for the six month duration of the intervention.

b) Three stakeholder representatives (experts) were also purposely selected from The Ghana AIDS Commission, another from The Korle Bu Fevers Unit and one from the National AIDS Control programme. However, only two granted interviews and one sent a copy of the ART guidelines instead.

#### 3.8.2.2 *Interview guide*

The main tools for collecting data were semi-structured interviews, guides that had main questions and probes. Field notes and journals were used to record unspoken gestures and words and record the atmosphere of the face-to-face interactions.

There were two semi-structured interview guides: one for client interviews and the other for interviews with experts. Participating clients provided information about their disease and treatment history, adherence behaviour and perspectives on using mobile phones to promote adherence.

The expert interview guides explored the existing adherence measures, challenges and perspective on using mobile phones in the mainstream health delivery system. It also explored their preparedness for such interventions and willingness to integrate mobile phones into existing policies.

#### 3.8.2.3 *Preparation for Data Collection*

Interview guides were cross checked. Participants were contacted via phone to confirm schedules. In the case of stakeholder interviews, letters were sent to the directors of the various institutions outlining the purpose of the interview and feedback was received indicating the relevant persons assigned to grant the interview. The personnel were then contacted and an interview date and venue scheduled. The questions were sent with the letters to give them adequate time to prepare for the interviews.



#### 3.8.2.4 *Data collection Interview*

Participants were informed about the rationale for the study and the interview and information sheet were used to reinforce information about the study. Consent forms were signed and participants were asked to express any concerns as their voices were to be recorded. Code names were assigned to each participant to protect their privacy on the audio recordings. The questions were asked per the interview guide but with flexibility where required. The trends in the questioning and probing were determined by the responses of the participants, but efforts

were made to focus the interviews on the objectives of the study. The interviews lasted for 20 to 30 minutes and were mainly conducted in the local Ghanaian language. Participants were given an opportunity to ask questions and answers were given to them. At the end of each interview participants were thanked for their participation.

Expert participants were scheduled an appointment following an official letter that was sent to their respective institutions. The letter indicated the purpose of the interview and interview guides were sent ahead of the interview date to allow for adequate preparation. Interviews were held in the offices of the interviewees. The preliminary outcomes of the study were disseminated and their perspectives on integrating mobile phones in adherence monitoring explored. The interviews were conducted in English and most of the conversations, which were also recorded, lasted for approximately 30 minutes. The audio recordings were then transcribed for analysis.



### 3.8.3 Focus group discussion

#### 3.8.3.1 *Participants and sampling*

Participants in the focus group discussions were purposively selected from the intervention groups if they used the alarm on their mobile phones received weekly text messages and voice calls. A total of 20 participants were enrolled in the three (3) focus groups. Focus group one and three had six participants while group two had 8 participants.

#### 3.8.3.2 *Focus group discussion guide*

The semi-structured interview guide used for the focus group discussion elicited information relating to medication taking behaviour, phone use and

recommendations for integrating mobile phones as adherence support measures in clients with HIV/AIDS. There were probes to clarify and focus the conversation or discussion.

#### 3.8.3.3 *Focus Group Discussion*

Three sessions of focus group discussions were held each facilitated by a research assistant with the researcher in attendance. Participants were informed about the discussions and appointments scheduled. Calls were made to remind participants about the sessions. The facilitator typically posed the questions and the participants discussed their perspective on the various issues. Responding and commenting on issues raised was voluntarily. However, occasionally some questions were directed at specific participants based on their comments or specific circumstances. Participants were free to pose questions that were discussed among the group. The discussions were in Akan, an indigenous Ghanaian language which enabled participants to freely express themselves. The discussions lasted for about one to two hours and were recorded for transcription and analysis.



### 3.8.4 Document review

From a number of reports and guidelines on ART, four documents were purposely selected but only three were used to extract information on policy and treatment guidelines that answered research questions. A quick check of the outline was done to identify sections and further reading on adherence to treatment. The guidelines on when to start ART and on pre-exposure prophylaxis for HIV' (WHO, 2015a) was excluded after an initial reading of the document as it was observed that similar information could be extracted from the other reports. The three documents reviewed were:

- Consolidated guideline on the use of antiretroviral drugs for treatment and prevention of HIV infection (WHO, 2015),
- Guidelines for antiretroviral therapy in Ghana (NACP, 2014), and
- Consolidated guideline on the use of antiretroviral drugs for treatment and prevention of HIV infection (WHO, 2013).

The criteria for choosing documents were based on relevance and the researcher's discretion. The aim was to extract information on estimated adherence levels, measures for adherence monitoring and an explicit mention of integration of mobile phones in adherence monitoring. These were informed by the qualitative interview themes as well.

#### 3.8.4.1 *Document review guide*

A document review guideline was developed to guide the extraction of information from the various documents that were reviewed. The document review guide was aimed at exploring existing policies on adherence to determine specific policies or guidelines on using mobile phones to support adherence. The guide was structured to elicit information based on the preliminary codes of the interview and focus group outcomes including adherence levels, adherence measures, mobile phone use and other relevant information.



#### 3.8.4.2 *Document Review process*

Three reports on antiretroviral therapy from WHO were downloaded from the open access web resource of the organisation. These were: '*Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV'* (WHO, 2015a), *Policy brief: consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: what's new'* (WHO, 2015c) and '*Consolidated guideline on the use of antiretroviral drugs for treatment and prevention of HIV infection'* (WHO, 2013). '*The guideline on when to start*

*antiretroviral therapy and on pre-exposure prophylaxis for HIV'* (WHO, 2015a) was excluded after an initial reading of document.

The *2014 Annual Report* published in August 2015 and '*Guidelines for antiretroviral therapy in Ghana'* (2014) were requested and received from the Director of NACP, Ghana. The researcher had read previous reports and guidelines of the NACP in Ghana but decided to include only the 2014 guideline in the review because it was an update on the previous guidelines. Three documents were therefore considered for the review with reference to the research objectives, questions and preliminary codes from interviews and focus group discussions.

### *3.8.5* Data Analysis

Data analysis in qualitative studies follows different patterns. An integrative approach was used for analysing all the different forms of data collected, because the information obtained explored similar perspectives. The preliminary code from the interview transcript was the same as the focus groups but with some minimal variations. Equally the information sought from the documents reviewed was derived from initial findings from interviews. The analysis of the individual interviews involved coding by line and paragraph and classification of the codes into categories and themes. Verification of codes and categories with previous interviews was done to determine relatedness or uniqueness in pattern. Creswell (2009) cited Tesch's comprehensive guidelines for transcribing and analysing in-depth interview data which was used in this study. (Creswell, (2009)

#### 3.8.5.1 *Step 1: Transcripts*

The researcher listened to the audio recordings and transcribed the interviews which were in English. Assistance was sort to translate and transcribe the interviews which were in an indigenous language. The researcher ensured that the transcriptions were accurate and truly reflected the totality of the participants' view of the experience. There were six transcripts from patient interviews, two expert interviews and three focus group transcripts. The transcripts were also exported into ATLAS, Ti 7 software. Documents reviewed were later exported to the software and considered as transcripts for coding.

#### 3.8.5.2 *Step 2: Extracting significant concepts and statements by coding*

Prior to using software for the coding, the researcher and trained research assistants read the transcripts to gain an understanding and then coding and naming of the units per the content they represented was done. To get a sense of the whole, the researcher read and re-read each of the transcripts and used markers to code concepts and statements within the narrative content. Ideas were jotted down and the underlying meanings of each coded word were written in the margins of the transcripts.

#### 3.8.5.3 *Step 3: Theme clusters*

The manual codes were counterchecked by the research team and the coded concepts and statements were sorted and listed into categories after the researcher re-read the interviews to get an understanding of the recurrent concepts and their full meaning. The coding frame was then created and each transcript in the software was coded using the selected codes.

After all the transcripts were coded and clustered the statements without codes were re-examined and assigned codes as appropriate. The clusters were used to develop the matrix where similar topics were clustered together as themes. Each significant statement and theme from the interviews were then typed out and labelled as the first level of the analysis.

#### 3.8.5.4 *Step 4: Themes categorization*

The researcher went back to the data with the list of clustered themes and searched for commonalities across participants and looked at how the themes were patterned and interrelated within the data. The software was used to identify patterns and relationship between the various clusters, sub-categories, categories and themes. The report was then generated with segmentation of the codes, quotes, memos and themes.

#### 3.8.5.5 *Step 5: Exhaustive description*

The researcher found the most descriptive wording for the codes and put them into categories by grouping codes and themes that related to each other. Subcategories were then drawn between the main categories for easy identification and description.

#### 3.8.5.6 *Step 6: Category labelling*

The categories that emerged were reviewed and labelled appropriately.

#### 3.8.5.7 *Step 7: Category grouping*

The researcher then grouped the categories into major categories with their subcategories using the Atlas Ti network menu.

#### 3.8.5.8 *Step 8: Description of the categories*

Finally, each category was described and supported with the verbatim quotations from the participants in a literal style. Field notes taken by the researcher were used to describe unstructured observations made during the interviews. This provided additional context for interpretation of the data.

The group transcripts were critically evaluated for differences and similarities in ideas about the use of mobile phones as expressed by participants in the group. The stakeholder interviews were also analysed by extraction of main ideas in the narratives with contextual comparison of the different perspectives.

### *3.8.6* Rigour in the qualitative studies

Rigour refers to criteria used for establishing that the trustworthiness of qualitative data is demonstrated through the researcher's attempts and efforts to confirm information disclosed and to ensure that the information accurately represents the participants' views (Speziale et al., 2011). This is achieved by ensuring credibility, dependability, conformability, and transferability in data management.



#### 3.8.6.1 *Credibility*

Credibility focuses on the truth and value relating to the findings of the study. The approach in this study was integrative, to enable a diversity of perspectives which would inform the in-depth descriptions required. Data was obtained using different approaches namely; individual interviews, focus group discussions, document reviews and field observations. The researcher and the team were able to adequately interact with the participants as they were familiar with the socio-cultural context and some of the research assistants were themselves living

with HIV/AIDS. Supervisors, peers and team members reviewed and checked the protocols and processes. Ethical clearance was obtained from the relevant institutions and the protocols were also checked by blinded reviewers.

The qualitative aspects of this study were meant to enrich the quantitative outcomes and provide depth and meaning to the findings. In view of this, the information obtained was within a specified context but did not limit the expression required to get the truth from the participants. There were additional probes and subsequent interviews reflected the information previously obtained to ensure they were correctly interpreted. All research assistants were adequately trained to ensure the data collected was credible.

#### 3.8.6.2 *Dependability*

Dependability in qualitative research refers to stability and consistency of data over time and varying conditions (Polit & Beck, 2013). To be certain of stability and consistency in this study, the researcher recorded all interviews using audio tape, wrote field notes, and kept a self-reflection diary, together with verbatim transcripts coded for verification. The researcher described the research process and procedures that were used in the study so that the supervisors and the internal and external reviewers could determine their acceptability or otherwise. The researcher is keeping all recordings and all other information and decisions regarding the study under lock and key.

To ensure the objectivity or neutrality of this study, the researcher ensured that the study findings reflected the experiences and ideas of the participants, rather than those of the researcher.

In this study, beliefs underpinning decisions that were made and methods that were adopted are acknowledged in the research report. The researcher being a registered nurse monitored personal biases about care giving and involved other people in data collection to limit potential bias.

A pilot study was done to test the interview guide, to determine that all equipment required such as the tape recorder worked properly and to estimate the length of time required to complete an interview.

#### 3.8.6.3 *Confirmability*

This refers to the data correctly representing the information participants provided. There were no biases or subjectivity in the study. The findings represent the participants' perspective of their experience in using mobile phones to improve adherence, participants were allowed to validate interview findings during the focus group sessions. Participants were given the identity numbers and the audiotape recordings of each participant. The outcomes of the interviews were further integrated in the stakeholder interviews to confirm or clarify issues raised by the participants. Questions and observations that were made were discussed with the research team and mentors.



#### 3.8.6.4 *Transferability*

Transferability involves the extent to which the findings of a qualitative study can be of use to others (Noble & Smith, 2015). Significant details of the study's settings and documentation as well as decisions, choices, and subjective interpretations of the data have been provided by the researcher to facilitate the transferability of the study. Accurate records were kept of all interviews and interactions with each participant precisely because the careful recording of data

was crucial to the study. The essence of seeking to integrate mobile phones in adherence monitoring requires that research data is representative of the specific population to which inferences pertain.

### *3.8.7* Ethical considerations during qualitative studies

The participants were given the opportunity to enrol voluntarily in the study and no coercion as used. The participant information sheet (Appendix A) was used to explain the study procedure and consent obtained.

Anonymity involved the protection of the institution and participants from easily being associated with the outcomes. It was impossible for others to identify participant data and both the participants and research team were given an undertaking that no information they provided would be accessible to anyone. Pseudonyms and number codes were used during interviews and focus group discussions. Code numbers were used to identify participants in the audiotapes, field notes and transcripts. The in-depth interviews and the transcribing of the interviews were done by the researcher's assistants and reviewed by researchers who were known to participants from the initial stages of the study.



Participants were respected at all times. The data that was collected for this study will be confidentially secured for five years thereafter a decision whether to discard it will be taken. Access to the full audio records and transcriptions are only available to the researcher and the supervisor. Except for the data that is to be disseminated, no other content will have any information linking participants to it.

The researcher has an obligation to minimise harm and maximise profit for the good of participants and society (Polit & Beck, 2013). Considering the nature of

HIV and its associated stigmas, the possibility of emotional discomfort was anticipated during the interview sessions and, in light of this, professional help was made available. However, no requests for help were recorded. Participants were given compensation for transport and airtime (mobile phone credit) costs incurred and snacks.

Documents reviewed were either retrieved from the official website of the institution or received from authors directly. Some of the reports and documents were available, for academic purposes, without having to seek permission. All documents reviewed were duly referenced as required.

## 3.9 PHASE 3: RECOMMENDATIONS FOR INTEGRATION OF MOBILE PHONE ADHERENCE STRATEGIES

To make recommendations for integrating mobile phone interventions in health service adherence and monitoring strategies, an integrated synthesis of quantitative results, qualitative outcome and evidence from existing literature and guidelines on adherence interventions was conducted by the researcher. This was followed by a process to receive feedback and input from experts and key service providers to enhance the quality of recommendations.



### 3.9.1 Process

Information for the recommendations was extracted from the results of the quantitative outcomes and the qualitative findings. A narrative review of the literature was conducted to examine evidence on adherence interventions (reported in Chapter two).

A dissemination session was organised and field notes were taken on the comments from the participants. The dissemination sessions were attended by

the research team, health professionals and some clients. Informal discussions of the outcomes were held with peers and significant others to enrich the recommendation process. The personal and professional experiences of some of the researchers in working with individuals infected with HIV were also helpful in making suggestions for integrating mobile phones in adherence strategies. These experiences, which were mainly anecdotal in nature and spontaneously offered, were documented in a journal for easy recall.

### 3.9.2 Data Synthesis

The findings were read through three times, to ensure that the researcher was thoroughly acquainted with the findings, while identifying probable patterns. The research objectives were compared with the findings, checked for consistency, and scrutinised for issues that were unrelated to the objectives of the study. Patterns in quantitative results and qualitative outcomes were critically evaluated for differences and similarities. Existing literature was compared with the findings of the study for relatedness and variations. Recommendations from similar studies and organisations, such as WHO, were reviewed and considered in making decisions regarding what could be implemented. Patient preference, resource availability and cultural contexts formed the background to the recommendations that were derived from this study. The information available was synthesised interpretively to deduce the implication of the study relating to clinical practice, education and policy.



## SUMMARY OF THE CHAPTER

This chapter gave detailed description of the methodology used in the study and the pragmatic philosophical approach was explained. The research setting,

population and sampling were described for each phase of the study. The instruments for data collection, validity/rigor, the procedure, and ethical considerations were also discussed.

# CHAPTER 4: INTERVENTION DEVELOPMENT AND IMPLEMENTATION

## 4.1 INTRODUCTION

Adherence to ART medication by HIV infected clients was contextualised within the behavioural perspective with an underlying assumption that motivational activities would facilitate adherence to ART. Using an alarm as a reminder, motivational text messages and voice calls were considered primary behavioural reinforcers while transactional goal setting and social support were secondary reinforcers of adherence behaviour. The intervention was to reflect the pragmatic nature of adherence behaviour resulting in the outcome being measured both objectively and subjectively. This chapter discusses the intervention development, implementation and evaluation process of the intervention using the logic model.

## 4.2 THE INTEGRATED MOBILE PHONE INTERVENTION FOR MONITORING ADHERENCE EVALUATION



The Integrated Mobile Phone Intervention for Monitoring Adherence (IMPIMA) was implemented in Accra, Ghana among clients living with HIV/AIDS visiting two hospitals. The protocol for the intervention was approved on 6 November 2013 and the process of planning training and soliciting requirements for the study was initiated. The validation of the data collection instrument was done over a period of three months. Recruitment of participants for the main study started in June 2014. The intervention was done concurrently with recruitment which commenced in July 2014 and continued until the desired sample size was realised three months later. The study was closed in October 2015 with an extended period of voice calls to the control group to ensure fairness.

### 4.2.1 Assumptions underpinning IMPIMA

Programme theorists argue that programmes that are implemented to elicit change have two theoretical components: change and action. In view of this, programme planners ought to put in place definite activities which must occur for the desired outcome to be observed (Funnell & Rogers, 2011). The way to develop an intervention is by determining the action and change required. The evaluation framework is based on the aim of the intervention [outcome], the objectives [outputs of intervention] and the activities [inputs, processes] of the intervention.

The logic model by its nature is one of the ideal frameworks that incorporate planning and evaluating, from a programme theory perspective. The logic model that takes into account the input, process, output and outcome of the intervention programme (Funnell & Rogers, 2011). In this study, we adopted the programme theory perspective to plan the mobile phone interventions programme (Table 10).



### 4.2.2 Aim, objectives and activities of IMPIMA

#### 4.2.2.1 *Aim of IMPIMA*

The IMPIMA programme was designed with the aim of improving the quality of life and decreasing the morbidity and mortality rate among HIV infected clients in Accra, Ghana.

#### 4.2.2.2 *Objectives of IMPIMA*

Improve adherence to ART among HIV infected clients in Accra, Ghana using mobile phones as an adherence support measure.

#### 4.2.2.3 *Activities of IMPIMA*

1) Use primary reinforcers to improve adherence

- Set alarms for medication reminders;
- Voice and text messages to motivate adherence.

2) Use secondary reinforcers to improve adherence
- Transactional goal setting;
- Social support.

***Table 10:*** *Intervention planning and evaluation mapping*

| **Intervention Planning** | **Evaluation planning** | |
|---|---|---|
| **Aim** | **Indicator** | **Measure** |
| Improve quality of life<br><br>Decreased morbidity and mortality | Viral load<br><br>Quality of life | CD4 count<br><br>No long term Quality of Life measures were done |
| **Objective** | **Indicator** | **Measure** |
| Improve adherence | Adherence in HIV infected clients at baseline assessment, at 3 and sixth month<br>Adherence in HIV infected clients in intervention and control groups | Improvements in adherence scores:<br>• Self-report<br>• Visual analogue assessment<br>• Pill identification<br>• Pill count and<br>• Overall adherence score |
| **Activities** | **Indicator** | **Measure** |
| Use primary reinforcers | Mobile phone usage practices among HIV infected clients?<br>Influence of phone alarm, text messaging and voice calls on adherence | Alarm usage<br><br>Messages and calls received |
| Use secondary reinforcers | Experiences of HIV infected clients and professionals | In-depth information on the clients' perspective of the intervention. |
| **Implementation** | **Indicator** | **Measure** |
| Inputs<br><br>Processes: | King's Transactional model | |

## 4.3 PLANNING USING THE LOGIC MODEL

### 4.3.1 Inputs

The success of any intervention depends on the resources available and how these resources are used to facilitate programme implementation. The inputs for the IMPIMA programme were human and material resources (Figure 5).

#### 4.3.1.1 *Human Resources*

To ensure that the appropriate strategy for protecting data quality was employed it was necessary to ensure that committees were in place to supervise and implement the intervention. The Trial Steering Committee (TSC) was constituted to monitor and supervise the development and implementation of protocols at all stages of the study. The members of the TSC included two academic faculty members and one professional (including supervisor) and one member from the sponsoring institution.



The Trial Management Committee (TMC) was made up of the principal investigator, the coordinator, research assistants, peer volunteers and a statistician (data manager). The TMC members undertook a six hour training session on the implementation of protocols to ensure strict adherence.

In field training was put in place whenever there a skills gap was identified. The trial coordinator was an experienced nurse with a postgraduate qualification and over five years of experience in working with people living with HIV.

The two research assistants were newly qualified undergraduate students who were undergoing their internship in the unit and at the time of recruitment had spent six months in the unit. Two undergraduate final year nursing students also

participated in collecting the baseline data, all these personnel went through training. The peer volunteers (referred to as clinic assistants in protocol) assisted with peer education, scheduling of appointments and other activities relating to care and support at the clinic. Two of the volunteers were trained to deliver messages and make voice calls per the protocol requirements. They were also trained to facilitate the individual interviews and focus group discussions under the supervision of the research coordinator and the principal investigator.

The Data Management Committee (DMC) which included a statistician and research assistants, for handling data, was put in place to ensure the integrity of data through the monitoring of data collection, data transformation and reporting. However, the statistician was often unavailable hence the principal investigator assumed most of the responsibility with assistance from the other statisticians as and when they were available.

#### 4.3.1.2 *Material Resources*



Materials required to ensure implementation of the intervention were sourced with funding from the Fogarty International AIDS Training and Research Program (AITRP). Two laptop computers and two desktop computers were acquired and used for data storage and management. Modems were also acquired for data transmission. Modems for bulk SMSs were also obtained which had the capacity to store and deliver a maximum of 500 messages at the click of a button. The modems had built in software that allowed for the use of an Excel spreadsheet to store contacts. The bulk SMS device had to be connected to a computer to work. The contact list had be created and selected whenever messages were to be sent. The device had a feedback system that was activated to deliver reports.

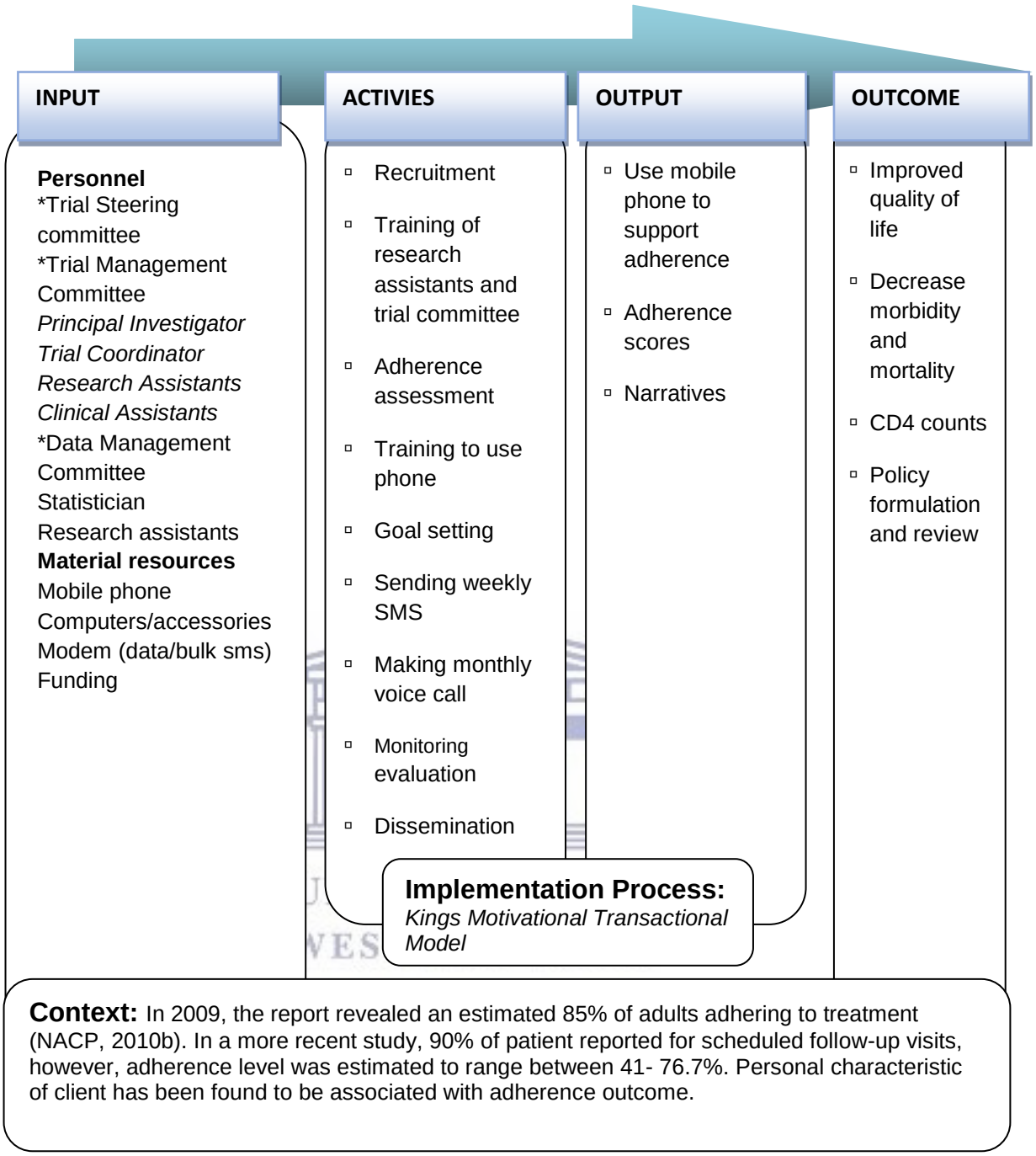



*Figure 5: The application of logic model for evaluation of intervention*

Analogue and Android phones were acquired for voice calls and were also used as a backup for SMS delivery when the modems were not functioning correctly. A wireless telephone (landline) was also used as a back up to the communication devices.

Airtime, for the mobile phones and modems, was purchased using recharge cards to ensure the continuous functioning of the system. Respondents used their own phones which had alarm, SMS and voice call functionality. Funds were disbursed to all respondents at baseline and then again at the two follow-up visits to pay for their transportation.

### 4.3.2 Activities

#### 4.3.2.1 *Alarm intervention*

Respondents in the intervention group had a one-on-one interaction with clinic assistants. Their medication dosage was determined and their ability to use the necessary functions of the phone assessed. Each respondent was then assisted to programme their phone in accordance with times that they took their medication. The frequency of the alarms varied, once or twice daily, according to the medication schedules of the respondents. The alarm was programmed to ring until stopped or set to snooze.



#### 4.3.2.2 *Text messaging (SMS)*

Text messages were sent out weekly, depending on specific preferences, for six months. During the first meeting to determine adherence needs and goals, respondent also discussed the scheduling of messages with the research team. The clinic assistants presented a schedule of days and time from which respondents could choose their preferred time to receive messages. Since there was no clinic on Tuesdays and Thursdays the respondents opted to receive the messages on these days, preferably in the evening.

The mobile phone numbers were entered into the spread sheet according to the subgroups and the chosen day and time to make it easier to send the messages

in bulk The messages were copied from MS Word and pasted or typed into the 160-character space provided in the text box, the relevant contacts were selected and then the send button pressed. Reports were instantly generated on the status of the delivery of the message – either delivered or pending.

The content of the messages was mainly motivational with no mention of medication. Coded words such as 'song' were used in the messages but the clients were aware that the word "song" represented the medication. This was explained to respondents at the initial meeting. Some examples of the messages sent are:

> *'Starting anything new could be difficult but I know you can do it. Yes, you can'*
>
> *'We agreed to stick together to meet our goal. This is just a reminder of our commitment'*
>
> *'Does the way you feel make you think of giving up? Please don't give up'*
>
> *'We may be making steady progress listening to the song and keeping the promise. It's time to share our achievements as well'.*



The messages, sent in the last week of the third and sixth months, gave a clue about the next appointment. No response to the messages was expected from the respondents, but they could reply to the message or ask questions if they wished to.

#### 4.3.2.3 *Voice calls*

Voice calls were made every month to give encouragement to respondents and to find out if they had any concerns. The calls lasted an average of two minutes depending. Based on the preferences of respondents during the goal setting stage, the primary language of communication for the voice calls was the

indigenous language, Akan. Voice calls were also made during the third and sixth months to remind respondents of their upcoming clinic appointments. The control group was also called during the third and sixth months to remind them about their clinic appointments. The rationale was to improve study retention in all the groups. Once the contact list was created respondents were called every month, on either a Tuesday or Thursday, until the study closed. Respondents were free to call the helpline at any time if they had any problems or issues.

#### 4.3.2.4 *Preparation for Intervention:*

The activities undertaken to ensure successful implementation of the intervention were the development and review of the protocol, pre-testing to validate the research instrument and the planning and implementation of the intervention. The protocol was reviewed by blinded reviewers prior to the allocations of funds. The protocol was approved by two institutional review boards which contributed to ensuring the integrity of the intervention.



The instrument for assessing adherence outcomes was pre-tested to ensure its validity and reliability. The necessary amendments emanating from the pre-test were made to the instrument. Approval was then sought from one of the review boards for the qualitative data collected to be included at the end of the intervention. Approval was given and the resources needed acquired. The TMC members were trained on how to recruit respondents, the nature of the study and how to limit bias in recruitment and delivery of the intervention.

Recruitment was done based on random assignment to groups as describe in the methodology section. Baseline information was obtained from clients prior to group assignment to limit any bias. The framework of the intervention required

that adherence assessment be done first, then goals set and thereafter individual gaps in technology bridged. The interventions delivered were alarm, text messages and voice calls (integrated mobile phone interventions).

### 4.3.3 Implementation Process

The implementation of the intervention was done using King's Transactional model while the logic model was used to evaluate the overall programme.

#### 4.3.3.1 *Application of conceptual frameworks in implementing intervention*

The model was applied within the basic assumptions postulated by (King, 1981). The transaction between the intervention group and the research team was to use mobile phone alarms, weekly text messages and monthly voice calls to support adherence to ART.

The main goal was to evaluate the integration of mobile technology to improve adherence to ARTs. The study was adequately communicated to clients who made their decisions to enrol in the study freely and independently.



The implementation of the intervention required regular engagement, taking action, making judgement and providing continuous feedback as depicted in figure 6.

Collective decisions were made regarding how and when interventions were to be delivered.

It was important to establish a relationship with the respondents that allowed for interaction, communication and feedback to meet the transactional goals. The interaction with respondents was face-to-face and involved the following:

a. Identifying the need for the relationship to provide adherence support using mobile phone interventions

b. Setting mutual adherence goals

c. Identifying the following as key in meeting adherence goals from the respondents' perspective

    i. Self-determination

    ii. Access to a mobile phone

    iii. Willingness to set alarms, read messages and receive calls

    iv. Availability of support from family and significant others

d. Applying the following strategies in meeting adherence goals

    i. Empowering respondents to set alarms based on daily dosage of ART.

    ii. Sending of coded communication text messages weekly for a period of six months.

    iii. Making of monthly voice calls for six months.

    iv. The evaluation of outcomes was based on:

- Baseline information adherence scores, clinical variables and socio-demographic variables
- Comparative inferential statistical analysis of outcome in intervention and control group
- In-depth individual and focus group interview to appreciate the pattern and meaning of adherence behaviour in intervention group
- Undertaking a comprehensive evaluation of the entire intervention using the logic model.

The transaction with the control group involved interactions that led to client recruitment, baseline and follow-up assessments but actions, judgements and feedback were focused on standard care. Feedback was not regular except to remind group members about follow-up interview dates.

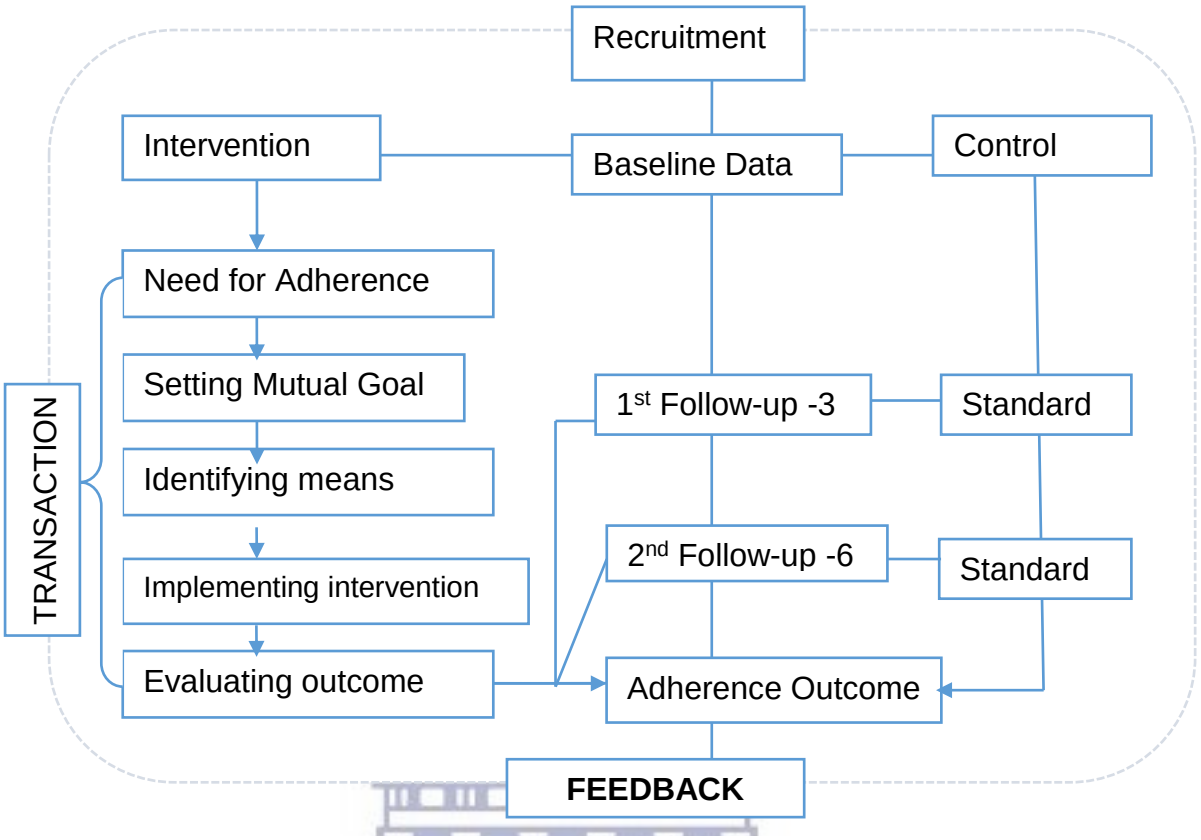



*Figure 6 Transactional model implementation in integrated mobile phone*



#### 4.3.4 Process evaluation

There were common challenges with the intervention which were identified during the implementation.

##### 4.3.4.1 *Protocol violations*

Protocol violation occurred in relation to SMS and voice call delivery. Tracking of SMS delivery was only done 12 weeks after commencing the intervention. The delivery report showed that out of the 181 messages sent about 54 were pending. The messages were resent to those respondents for whom delivery had not been confirmed. During a feedback session some respondents reported switching off their phones but messages were received once they had turned their phones on again.

A failure of bulk SMS system was detected which caused messages to be delivered ten at a time, this led to the use of analogue messaging. This process could have resulted in the omission of some numbers considering the tedious nature of sending messages manually.

In the initial stages, when voice calls were made by research assistants, participants reported discomfort with this. Sometimes participants declined to speak and pretended they were unaware of as to why they were being communicated with. Later following the use of peer volunteers this was no longer a problem as participants were familiar with the peer volunteers. Some respondents could not be reached via phone unfortunately this was not well tracked and recorded therefore only subjective data was obtained.

The inability to use the automated SMSs software for bulk messaging also contributed to weakness in the message tracking system.

Other issues associated with intervention integrity were:



- A high attrition rate, especially in the control group, which has been explained in the first section of the results.
- An inability of some respondents to read messages due to literacy issues and what the researchers chose to refer to as ‘text prompt fatigue’
- The multimethod adherence tool used to assess adherence was weak. Although the self-reporting, visual analogue, pill count and pill identification tests were used to generate data for comparison, each subscale had a different levels of measurement (nominal and numerical). This led to the transformation of scores at different stages of analysis.
- A shortage of reagent for the CD4 count estimation resulted in a reduction in the number of CD4 results available for analysis
- The rationing of ART due to shortages led some participants to engage in pill hording practices in anticipation of a pill shortage

- Response bias emanated from using the same scale and asking the same questions repetitively thus allowing clients to anticipate questions and give repetitive responses.

### 4.3.5 Outcome

The primary outcome indicator for the intervention was adherence scores. The secondary indicators were BMI, CD4 counts levels and narratives from interviews and focus group discussions. This is the focus of the next chapter.

## 4.4 CHAPTER SUMMARY

In this chapter the intervention was evaluated with the logic model. The processes used in the design of the intervention were described. The element of the logic model; input, output and outcomes were described noting possible violations of study protocol. The next chapter consists of the report of the quantitative results.

# CHAPTER 5: RESULTS OF QUANTITATIVE EVALUATION - RANDOMISED CONTROLLED TRIAL

## 5.1 INTRODUCTION

This chapter presents the findings on the randomised Controlled trial of the outcomes of the integration of mobile technology to improve adherence to ART in clients with HIV (IMPIMA). This evaluation addressed the following objectives of the study: i) To assess adherence to treatment among HIV infected clients in Accra, Ghana before during and after an integrated mobile phone technology intervention to support adherence; ii) To identify the demographic, clinical variables and support measures that may predict ART adherence in HIV infected clients; and iii) To evaluate the effectiveness of using mobile phone interventions to promote ART adherence among HIV infected clients.



The trial in summary assigned a total of 362 respondents into the two groups on a ratio of 1:1. Baseline information was obtained on both groups and they were followed-up at the third and sixth month. The multi-method adherence tool was used to measure adherence in both groups after the alarm, weekly text messages and monthly voice calls were received by the Intervention group. Study enrolment and demographic profiles of respondents were described first. Subsequently baseline adherence assessment outcomes were reported with reference to the entire sample and the two groups. The assessment included measurement of self-reporting, visual analogue outcome, pill identification test, pill count, overall adherence and adherence support measures. Respondents' competency to use a mobile phone was also assessed and reported. The rest of

the sections reported outcomes of the same measurement at post intervention (third month and sixth month). The predictors of adherence were also explored. Details of the findings are set out below.

## 5.2 STUDY ENROLMENT AND RETENTION

Recruitment of respondents was done using a simple random sampling technique. Respondents were first screened for eligibility (n = 400) from the two study sites (Site A = 310, site B = 90 respondents). A total of 362 respondents met the criteria, and were recruited into the study and their baseline data was

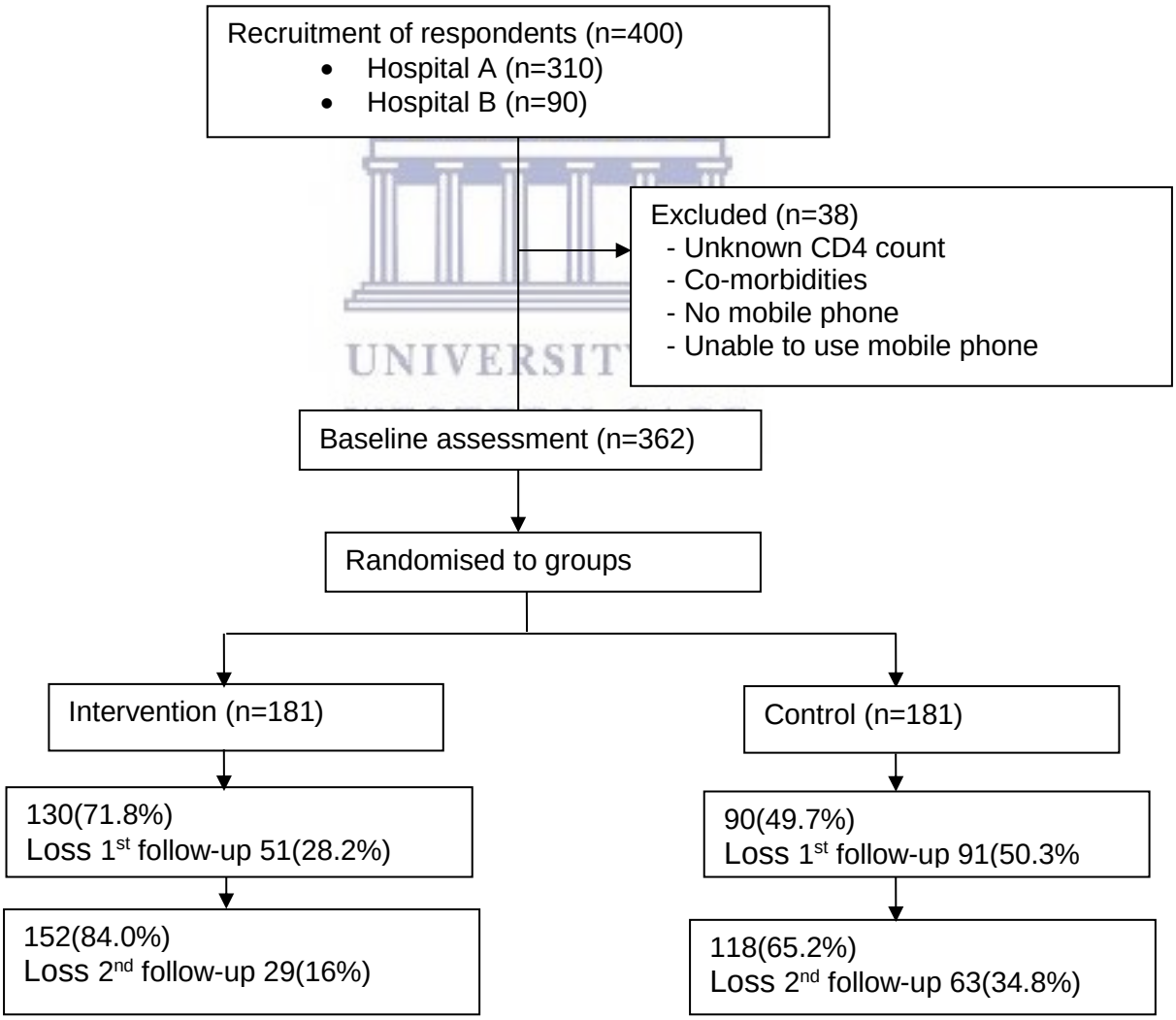



*Figure 7: Recruitment and retention flow chart*

obtained. Respondents were subsequently randomly allocated to two groups Intervention and Control (n = 181 in each arm).

The allocation to group as described in methodology was concealed. Random numbers and colour code used to assign respondents to the respective groups. Loss to follow-up occurred during the first and second follow-up as shown in Figure 7. Retention was lowest at the first follow-up but improved at second follow up for both groups since most of the respondent had clinic appointment with this period. Retention was also lower in the Control group at both follow-ups (n = 90, 49.7% and n = 181, 49.7% respectively). Out of 362 respondents at baseline, 142(39. %) were lost to follow-up at month three while 92 (25%) were lost at month six (second follow-up). The respondents who did not turn up for follow-up did not provide any reasons for not showing up. None of the respondents were reported dead during the study period per the available records.



## 5.3 DEMOGRAPHIC PROFILE OF PARTICIPANTS AT BASELINE

Demographic data on age, gender, education level, marital status, employment and religion were obtained from eligible respondents at baseline only. Descriptive statistics for frequency distribution and mean scores were calculated for the 362 respondents. Table 11 illustrate characteristics of the groups generally and the homogeneity in the groups at baseline.

The mean age of the 362 respondents was 44.4 (*SD* = 9.82), the youngest respondent was 20 years while the oldest was 74years. There was no significant difference in the mean age of the respondents in the Intervention (*M* =44.7*, SD* =

9.1) and Control (*M* =44.2*, SD* = 10.5) groups *t* (360) = .433, *p* =.66 indicating that with respect to age the groups were equal at baseline.

There were more female respondents (n = 228, 63%) than males 134(37%) in the overall sample and no significant differences between the Intervention and Control Groups. Most of the respondents (306, 84.5%) had at least basic education, although 35 (9.7%) reported that they had not received any formal education. In comparing differences in education among the Intervention and Control groups, no significance differences were observed $X^2$ = (2, n =362) = 2.48, *p* = .29.

***Table 11: Demographic profile of respondents***

| Variables | Intervention =(181) M(SD) | Control (n=181) M(SD) | Total (N=362) M(SD) | Test | *p*- |
|---|---|---|---|---|---|
| Age | 44.7(9.1) | 44.2(10.5) | 44(9.82) | t =.433 | .66 |
| | n(%) | n(%) | n(%) | | |
| Sex | | | | | |
| *Male* | 66(49.3%) | 68(50.7%) | 134(37%) | $X^2$=.47 | .83 |
| *Female* | 115(50.4% | 113(49.6) | 228(63%) | | |
| Education | | | | | |
| *Tertiary* | 7(33.3%) | 14(66.7%) | 21(5.8%) | $X^2$=2.4 | .29 |
| | 156(51.0% | 150(49.0% | 306(84.5% | | |
| *None* | 18(51.4%) | 17(48.6%) | 35(9.7%) | | |
| Marital status | | | | | |
| *Married* | 91(50.3%) | 90(49.7%) | 181(50%) | $X^2$=.01 | .91 |
| *Not married* | 90(49.7%) | 91(50.3%) | 181(50%) | | |
| Employment | | | | | |
| *Formal* | 48(53.9%) | 41(46.1%) | 89(24.6%) | $X^2$=1.7 | .42 |
| *Informal* | 116(50.0% | 116(50.0% | 232(64.1% | | |
| *Unemployed* | 17(41.5%) | 24(58.5%) | 41(11.3%) | | |
| Religion | | | | | |
| *Christian* | 161(48.8% | 169(51.2% | 330(91.2% | $X^2$=2.1 | .14 |
| *Muslim* | 20(62.5%) | 12(37.5%) | 32(8.8%) | | |

Independent t test and chi-square test, Significant at p<.05

Married respondents were similar in both groups (n = 181, 50%) with no significant differences between the two groups $X^2$ = (1, n = 362) = .011, $p$ = .91 as depicted in Table 11.

Employment was measured in three categories: formal employment in the private or public sector with regular income, informal employment which implied that the individual was self- employed or engaged in work with an undefined income, and lastly no employment. The results indicated that nearly two thirds 232 (64%) were working in the informal sector. Comparing respondents working in the formal sector, it was observed that the Intervention group had slightly more respondents (n = 48, 54%) than the Control group (n = 41, 46%), but no significant differences existed in the employment status in the two groups $X^2$ = (2, n = 362) = .1.746, $p$ = .42.

The two main religious groups represented in this study were Christians and Muslims. The majority of respondents 330 (91%) were Christians. Although the number of Christians and Muslims in each group varied, the differences were not statistically significant $X^2$ = (1, n=362) = 2.194, $p$ = .14.

## 5.4 CLINICAL PROFILE OF RESPONDENTS AT BASELINE

The clinical profile of the respondents was described in terms of direct and indirect variables associated with the disease process. Clinical data (physiologic indicators) such as CD4 count, Body Mass Index (BMI), duration of illness and stage of illness were obtained at baseline. Psychosocial variables related to health service such as travel time to the clinic, schedule of follow up visits, proximity of other ART clinics, status disclosure and how the medication is stored

were also measured and analysed as clinical data, these are displayed in Table 12.

Baseline CD4 count results obtained from respondents' records revealed an average of 522 cells per cubic millimetre of blood (*SD* = 290, n = 326) for the sample (Table 12). No significant difference was observed in Intervention (*M* = 550, *SD* = 302) and Control (*M* = 494, *SD* = 276) groups for CD4 count results (*t* (324) = 1.75, *p* = .08).

***Table 12 : Clinical profile of respondents***

| ***Variable*** | ***Outcome*** | | | | |
|---|---|---|---|---|---|
| | Intervention M(SD) | Control M(SD) | Total | test | *p* value |
| CD4 | 550(302.3) n =162 | 494(276.2) n =164 | 522(290) N =326 | t = 1.75 | .08 |
| BMI | 24.4(4.30) | 24.7( 4.67) | 24.5(4.48) | *t* = -.778 | .44 |
| Duration of illness | 60 (45.7) | 72 (39.6) | 68.7(42.7) | *U* = 16142 | .81 |
| Travel time | 64.2(51.2) | 75.2(60.7) | 69.7(56.4) | *U* = 14588 | 06 |
| | n (%) | n (%) | n(%) | | |
| Disease stage | | | | | |
| *Stage I* | 23(50%) | 23(50%) | 46(12.7%) | $X^2$= 1.96 | .74 |
| *Stage II* | 51(52.6%) | 46(47.4%) | 97(26.8%) | | |
| *Stage III* | 43(44.8%) | 53(55.2%) | 96(26.5%) | | |
| *Stage IV* | 15(46.9%) | 17(53.1%) | 32(8.8%) | | |
| *Unknown* | 49(53.8%) | 42(46.2%) | 91(25.1%) | | |
| Follow up | | | | | |
| *<3 months* | 21(56.8%) | 16(42.2%) | 37(10.2%) | $X^2$ = 2.78 | .42 |
| *3 months* | 68(45.6%) | 81 (54.4%) | 149(41.3%) | | |
| *4 months* | 75(51.4%) | 71(48.6%) | 146(40.4%) | | |
| *Unsure* | 17(58.6%) | 12(41.4%) | 29(8%) | | |
| Near clinics | | | | | |
| *Yes* | 49(50.5%) | 48(49.5%) | 97(26.8%) | $X^2$ = .014 | .90 |
| *No* | 132(49.8%) | 133(50.2%) | 265 (73.2% | | |

*T test; Mann Whitney test; Chi Square test; * Significant at p<.05 two tailed*

Though it was approaching significance, the magnitude of difference (mean difference = 55.9, 95% CI: -7.13 to 119.02). The weight and height of respondents were used to estimate the BMI of the respondents at baseline using standard computational formula (BMI = weight in kilogram/ height in metre$^2$). The results depicted in Table 12 show the average BMI of respondents in the sample was 24.5 (*SD* = 4.48). The average BMI for groups differ, however, the difference was not significance comparing the Intervention (*M* = 24.4, *SD* = 4.30) and Control (*M* = 24.7, *SD* = 4.67) groups (*t* (360) = - .778, *p* = .44).

Results also showed that respondents in the sample reported that they had on average been living with the disease for 68.7 months (*SD* = 42.7), approximately five years and seven months. The observed means of the duration of illness for Intervention (*M* = 60, *SD* = 45.7) and Control (*M* = 72, *SD* = 39.6*)* groups showed marginal differences that were not statistically significant *U* =16142, *Z* = -.21, *p* = .81



Respondents were asked to indicate the time spent in minutes when travelling from their residence to the clinic. This was to determine if respondents travelled long distances or spent many hours travelling to access services. The results indicated a wide range of travel time with a minimum travel time of 10 minutes and a maximum time of eight (8) hours travel time for the overall sample. As shown in Table 12, the average time travelled in minutes among the 362 respondents was 69.7 minutes (*SD* = 56.4) approximately one hour. Although results showed the Control group spent more time travelling (*M* = 75.2, SD = *60*.7) the difference was not statistically significant *U* = 14588, *Z* = -1.84, *p* = .06.

More than two thirds of respondents (265, 73%) did not live close to an ART clinic and had to travel to access services at other clinics.

A diagnostic staging of the disease also showed that respondents were at different stages of the illness. Comparisons of the stage of illness revealed 49 (54%) of respondents in the Intervention group did not have a diagnostic staging of the disease indicated in their patient records. Just over half of the respondents 53 (55%) in the Control group were in stage III compared with the Intervention group (n= 43, 45%), but no statistical differences were observed between the groups $X^2$ = (4, n = 362) = 1.96, $p$ = .74.

Out of the 362 respondents, 210(58%) had disclosed their status to their spouse (Figure 8)

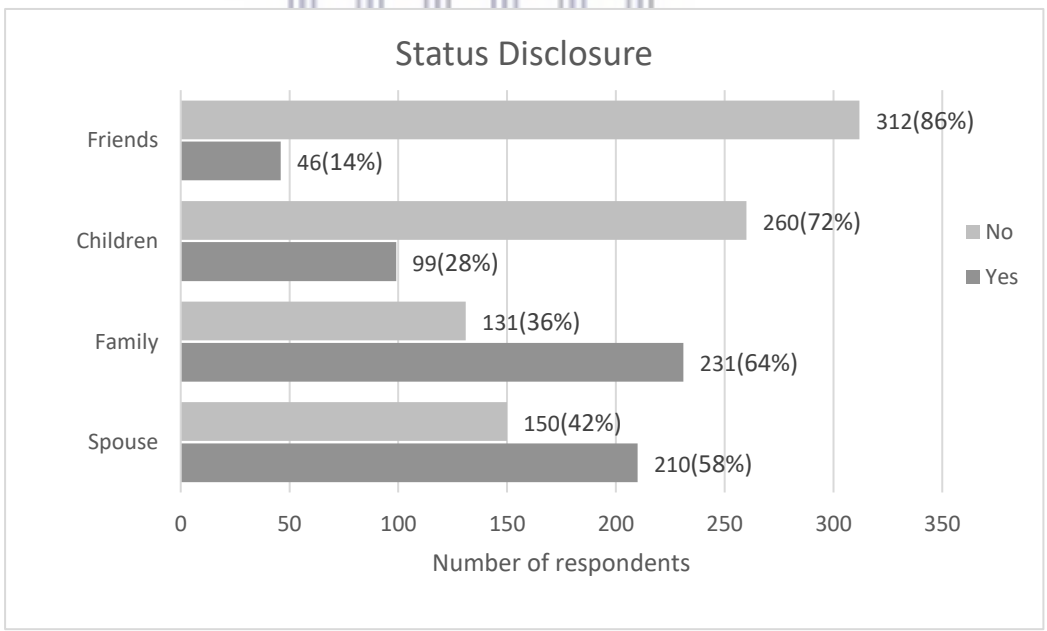



***Figure 8: HIV status disclosure***

The majority 312 (86%) had not disclosed their status to their friends. Similarly, 260 (72%) of the 362 respondents had not disclosed their status to their children.

Status disclosure was not significantly different in the groups. Out of the 181 respondents in each group, 108 (51%) in the Intervention group 102 (49%) in the Control group disclosed their status to their spouse. No significant group differences were observed $X^2$ = (2, n = 362) = 2.59, $p$ = .27. There was no observed difference between the Intervention (n = 120, 52%) and Control (n = 111, 48%) groups with regards to status disclosure to family $X^2$ = (1, n = 362) = .97, $p$ = .38. Some respondents in the Intervention (n = 53, 29%) and Control (n = 46, 26%) groups disclosed their status to their children but no significant observed difference occurred between the groups $X^2$ = (2, n = 362) = 1.07, $p$ = .58. A few of the respondents disclosed their status to friends in the Intervention (n = 23, 12.7%) and Control (n = 23, 12.7%) groups, however, significant group differences were not seen $X^2$ = (2, n = 362) = 1.01, $p$ = .60.

Respondents reported no specific location for storing their medication, with significant differences between Intervention and Control groups $X^2$ = (5, n = 362) = 11.2, $p$ = .05. Some of the places for storing their medication were: special pill containers, purses, cupboards, bags, under their pillows and other places; results are shown in figure 5.3. Out of the 362 respondents, 140 (39%) locked up their medication in cupboards while 26 (7%) kept their medication under their pillows. Some stored their medication in places such as on top of their fridge or in polythene bags as illustrated in figure 9.

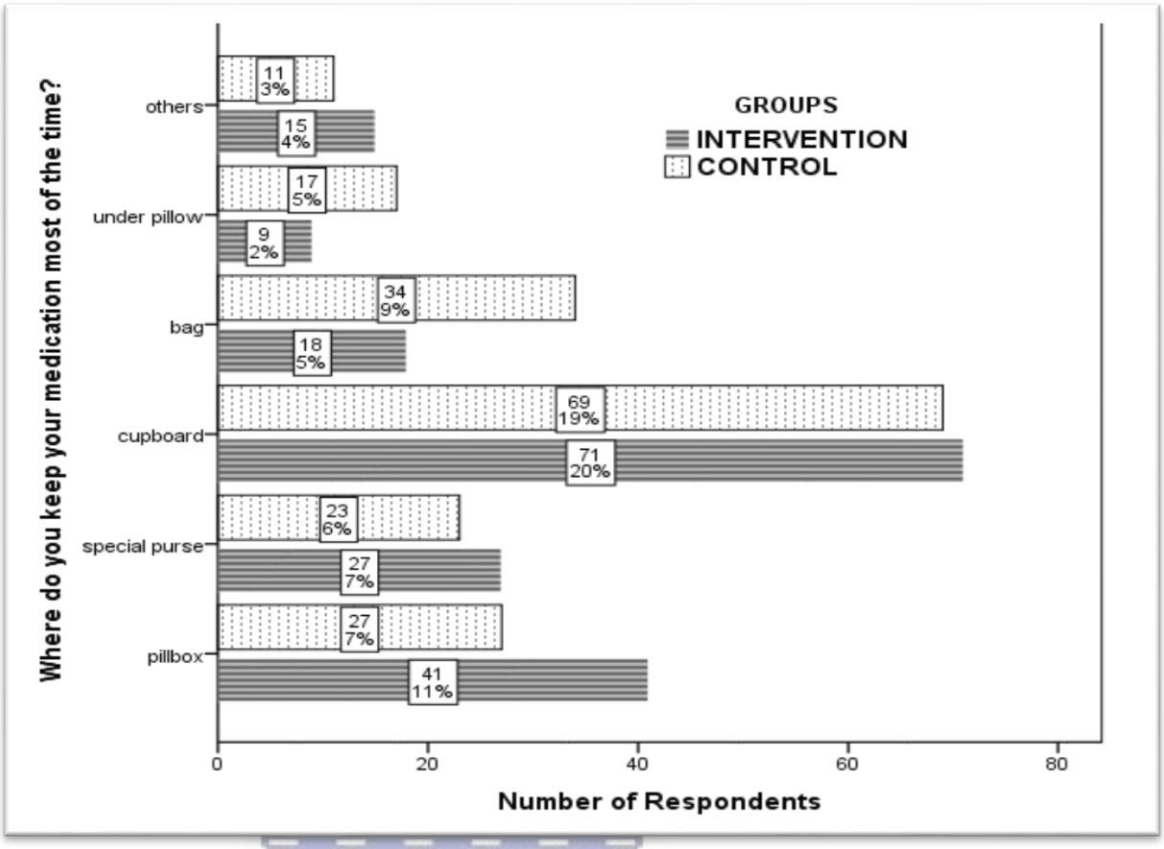



***Figure 9 : Sample reports of places for storage of pills***



## 5.5 BASELINE ADHERENCE LEVELS AMONG RESPONDENTS

In this study, adherence levels were measured with the Multi-method adherence tool. There were four subscales that independently measured adherence, namely: self- report, visual analogue scale, pill identification tests and pill count. The mean score for each subscale summed to obtain overall adherence score. Ordinal score was derived by recoding means as follows: low adherence (75% or less), moderate adherence (75.1-94.9%) and high adherence (95% or more) as recommended by the tool developers with some modification. The tool also consisted of items that assessed adherence support measures and factors influencing adherence. Results of general adherence outcome were reported in

mean percentage scores as presented in Table 13 and proportion of ordinal ranks per subscale and study arm as shown in table 5.4.

***Table 13 : Baseline Adherence level among respondents***

| *Variables* | **Intervention** *(n=181)* *M(SD)* | **Control** *(n=181)* *M(SD* | **Total** *(N=362)* *M(SD* | Test | *p*-value |
|---|---|---|---|---|---|
| Self-report | 95.7(8.05) | 96.1(7.74) | 95.9(7.89) | *U* = 16132 | .74 |
| VAS | 84.6(8.79) | 83.9(8.66) | 84.3(8.72) | *U* =15448 | .32 |
| Pill Id Test | 88.2(4.69) | 88.7(6.19) | 88.5(8.72) | *U* = 15514 | .19 |
| Pill Count | 99.1(1.37) | 99.2(1.65) | 99.2(1.52) | *U* =15403 | .27 |
| Overall score | 91.9(3.87) | 91.8(3.95) | 99.1(3.91) | *U* = 16327 | .96 |

*Mann Whitney test * Significant at p<.05 two tailed*

The results in Table 13 indicate that out of the 362 respondents who were assessed at baseline for adherence, the overall adherence score (*M* = 91.9, *SD* = 3.91) was below 95% and was not statistically significant *U* = 16327, *Z* = -.05, *p* =.96. The respondents scored higher on pill count (*M* = 99.2, *SD* = 1.52) but outcomes were not significantly different in Intervention (*M* = 99.1, *SD* = 1.37) and Control (*M* = 99.2, *SD* = 1.65 groups *U* = 15408, *Z* = -1.09, *p* =.27 while the lowest score was obtained on the visual analogue scale (*M* = 84.3, *SD* = 1.52). No significant differences were observed in the Intervention (*M* = 84.6, *SD* = 8.78) and Control (*M* = 83.9, *SD* = 8.66) groups with regards to the visual analogue scale *U* = 15448, *Z* = -1.09, *p* =.27. The specific tools are discussed below.

### 5.5.1 Baseline Adherence Level: Self report (SR)

The self- reporting scale (SR) is a four item dichotomous variables assessment tool that was used to examine pill taking behaviour based on the individuals' evaluation. The three ranked levels of adherence were low, moderate and high adherence and results are shown in Table 14 indicate. Results revealed that the majority of respondents 272 (75%) were 'highly adherent' to treatment at baseline; 135 (49.6%) in the Intervention group and 137 (50.4%) in the Control group. Out of the 26 (7%) respondents with low adherence scores, 15 (58%) were the Intervention group and 11 (42%) in the Control group. The differences observed in the groups with regards to self- reported adherence levels were not statistically significant at baseline $X^2$ = (2, n = 362) = .639, $p$ = .74 among the two groups. Notably, respondents with high and moderate adherence were slightly more in the Control group. Similarly, the Control group's mean score was just 0.4% more than the Intervention group's score.



### 5.5.2 Baseline Adherence Level Visual Analogue Scale

The VAS is a self- rating scale that scores adherence on a scale of zero to ten with ten as the highest score. The rated scores were converted into percentages and then classified into ordinal scales of low, moderate and high adherence. The observed outcome depicted in table 5.4 shows 288 (79.6%) of the respondents moderately adhere to treatment. There were equal number of respondents in the moderate adherence category (n = 144, 50%) in each study arm. Low adherence was observed in 45 (12.4%) out of the 362 respondents with 22 (48.9%) in Intervention group and 23 (51.1%) in the Control group. The comparison of the

two study arms revealed no statistically significant differences existed among the visual analogue scores of the groups ($X^2$ = (2, n = 362) = .057, $p$ = .97).

### 5.5.3 Baseline adherence for Pill Identification Test (PIT)

The Pill Identification Test (PIT) measures the ability of respondents to identify pill names, pill dose, timing and additional instructions. The respondents were shown the pills, asked to identify them and describe how they should be taken. The yes and no responses were transformed to percentage scores and ranked in three levels; high, moderate and low adherence as described earlier. The mean score for PIT was 88.5% (*SD* = 8.72) out of expected 95% and above.

***Table 14 : Baseline Adherence levels with ordinal scale***

| *Variable* | Categories | Intervention *(n=181)* n(%) | Control *(n=181)* n(%) | Total *(N=362)* N(%) | Test | *p*-value |
|---|---|---|---|---|---|---|
| Baseline Self report | *High* | 135(49.6%) | 137(50.4%) | 272(75.1%) | $X^2$ = .693 | .74 |
| | *Moderate* | 31(48.4%) | 33(51.6%) | 64(17.7%) | | |
| | *Low* | 15(57.7%) | 11(42.3%) | 26(7.2%) | | |
| Visual Analogue | *High* | 15(51.7%) | 14(48.3%) | 29(8%) | $X^2$ = .057 | .97 |
| | *Moderate* | 144(50%) | 144(50%) | 288(79.6%) | | |
| | *Low* | 22(48.9%) | 23(51.1 | 45(12.4%) | | |
| Baseline Pill Id Test | *High* | 18(38.8%) | 29(61.7%) | 47(13%) | $X^2$ = 3.12 | .21 |
| | *Moderate* | 155(52%) | 143(48%) | 298(82.3%) | | |
| | *Low* | 8(47.1%) | 9(52.9%) | 17(4.7%) | | |
| Pill count | *High* | 178(50.3%) | 176(49.7%) | 354(97.8%) | $X^2$ = .511 | .72 |
| | *Moderate* | 3(37.5%) | 5(62.5%) | 8(2.2%) | | |
| Baseline overall score | *High* | 127(49.8%) | 128(50.2%) | 255(70.4%) | $X^2$ =1.04 | .59 |
| | *Moderate* | 54(50.9%) | 52(49.1%) | 106(29.3%) | | |

Chi square test, * Significant at p<.05 two tailed

As shown in Table 14, the majority of respondents 298 (82%) moderately adhered to ART at baseline assessment on PIT score (Intervention group, n = 155, 52%; Control group, n = 143, 48%). Low adherence was recorded in 17 (4.7%) of respondents while 47 (13%) were highly adherent. The two groups were compared for differences in PIT adherence scores at baseline using the Chi Square test. No significant differences existed between the Intervention and Control group adherence outcomes $X^2$ = (2, n = 362) = 3.12, $p$ = .21. Excluding the name of the pill in the pill identification test increased adherence scores for PIT as will be shown in subsequent sections when between and within subject analysis is done.

### 5.5.4 Baseline Adherence with Pill count scores

Respondents' pills were counted and an adherence score estimated with reference to the date pills were dispensed, numbers of pill dispensed, and follow up date indicated in patient's hospital record. Pill count scores were derived from computing the percentage dispensed and pills returned. Table 13 shows an average adherence score of 99 (*SD* =1.5) out of a possible 100. The ordinal ranks of low adherence (75% or less), moderate adherence (75.1-94.9%) and high adherence (95% or more) show that respondents were 'highly adherent' with regards to the pill count score. Highly adherent respondents in the Intervention group were 178 (50.3%) and 176 (49.7%) in the Control group. The group comparison for homogeneity revealed that no statistically significant differences existed between the Intervention and Control group pill count scores at baseline $X^2$ = (2, n = 362) = .511, $p$ = .72.

### 5.5.5 Overall adherence scores at Baseline

The overall score was derived arithmetically by adding up the score of the four subscales (SR, VAS, PIT and Pill count) in percentage scores. The ordinal scale was ranked based on the criteria used for the subscales. Table 14 depicts that nearly three quarters 255 (70%) were highly adherent at baseline but the mean adherence score of 91.9% (SD = 3.95) was observed with minimum score of 76 and maximum of 100. The Intervention group recorded 127 (49.8%) respondents obtaining overall adherence score that was at least 95% and the Control group had 128 (50.2%). The overall adherence assessment outcome did not differ ($X^2$ = 1.04, $p$ = .59) at baseline.

### 5.5.6 Baseline adherence support measures

Adherence support measures assessed were adherence counselling, visits from health workers, support from family, spouses, peer groups, religious groups and NGO's. Additionally, measures such as use of medication charts, wallets, alarms, text message reminders and voice calls from health workers were also assessed. Respondents were required to indicate whether support was available, helpful or not helpful as depicted in the results (Table 15 and Figure 10).

Adherence counselling was the most helpful measure reported among the respondents (n = 355, 98%). Some respondent noted spousal (n =141, 39%) and family (n = 135, 37%) support was also helpful. The assessment of adherence counselling as helpful was similar in the Intervention 117(49.9%) and Control 178 (50.1%) groups. No significant statistical differences were observed in the groups ($X^2$ = 1.0, $p$ = .61). The majority of respondents (n = 357, 97%) reported that they

had no visits from health workers although this was one of the adherence support measures.

Out of the five respondents who had visits from health workers, two noted that they were not helpful. Respondents also mentioned that support from friends (n = 354, 98%), religious groups (n = 350, 97%) and peer groups (n = 358, 99%) was mostly absent.

***Table 15: Baseline adherence support measures***

| **Variables** | **Outcome Intervention** *(n=181)* *n(%)* | **Control** *(n=181)* *n(%)* | **Total** *(n=362)* *N(%)* | **Test** | **p-value** |
|---|---|---|---|---|---|
| Adherence counselling | | | | | |
| *Absent* | 3(1.7%) | 3(1.7%) | 6(1.7%) | $X^2 = 1$ | .61 |
| *Not helpful* | 1(0.6%) | 0(0%) | 1(0.3%) | | |
| *Helpful* | 177(97.8%) | 178(98.3%) | 355(98.1%) | | |
| Visit from health workers | | | | | |
| *Absent* | 180(99.4%) | 177(97.8% | 357(98.6%) | $X^2 = 2.60$ | .11 |
| *Not helpful* | 1(0.6%) | 1(0.6%) | 2(0.6%) | | |
| *Helpful* | 0(0%) | 3(1.7%) | 3(0.8%) | | |
| Support from friends | | | | | |
| *Absent* | 174(96.1%) | 180(99.4%) | 354(97.8%) | $X^2 = 4.77$ | .09 |
| *Not helpful* | 2(1.1%) | 0(0%) | 2(0.6%) | | |
| *Helpful* | 5(2.8%) | 1(0.6%) | 6(1.75%) | | |
| Support from family | | | | | |
| *Absent* | 111(61.3%) | 115(63%) | 226(62.4%) | $X^2 = 1.26$ | .53 |
| *Not helpful* | 0(0%) | 1(0.6%) | 1(0.3%) | | |
| *Helpful* | 70(38.7%) | 65(35.9%) | 135(37.3%) | | |
| Support from spouse | | | | | |
| *Absent* | 106(58.6%) | 111(61.3%) | 217(59.9%) | $X^2 = 1.46$ | . 48 |
| *Not helpful* | 1(0.6%) | 3(1.7%) | 4(1.1%) | | |
| *Helpful* | 74(40.9) | 67(37%) | 141(39%) | | |
| Support religious group | | | | | |
| *Absent* | 177(98.9%) | 173(95.6%) | 350(97.3%) | $X^2 = 3.81$ | .15 |
| *Not helpful* | 0(0%) | 3(1.7%) | 1(0.3) | | |
| *Helpful* | 0(0%) | 1(0.6%) | 9(2.5%) | | |
| Support PLWA groups | | | | | |
| *Absent* | 181(100%) | 177(97.8%) | 358(98.9%) | $X^2 = 4.05$ | .13 |
| *Not helpful* | 0(0%) | 3(1.7%) | 3(0.8%) | | |
| *Helpful* | 0(0%) | 1(0.6%) | 1(0.3%) | | |

*Chi square test, * Significant at p<.05 two tailed*

Other measures such as use of text messaging had one respondent in the Control group rating it as helpful and the rest 361 (99.7%) indicating this support measure was not available to them. Similarly, 359 (98.9%) were not using alarms as an adherence support measure at baseline assessment.

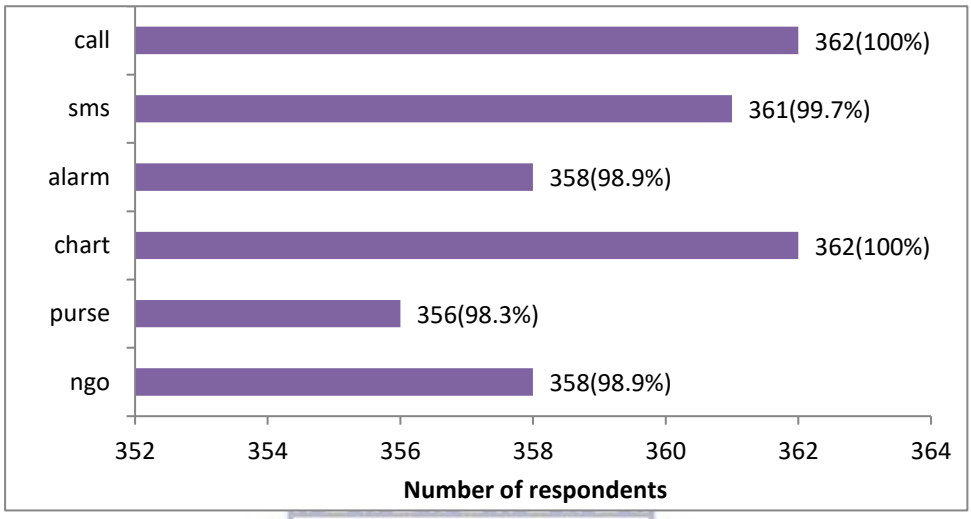



***Figure -10 Adherence support measure NOT available at baseline***



## 5.6 FACTORS ASSOCIATED WITH ADHERENCE LEVELS AT BASELINE

The factors associated with different adherence level (low, moderate or high) were compared irrespective of group among the 320 respondents. Age, gender, education, religion, employment and follow up visits were considered co-variants that may influence low, moderate or high adherence on each of the subscales (self- report, visual analogue, pill identification test and pill count score) and overall adherence scores at baseline. The Chi square test was applied with a two-tailed test and p-value of .05.

### 5.6.1 Respondents perspectives on factors influencing adherence

The last section of the multimethod assessment tool consists of constructs that measure factors influencing adherence. Table 16 shows the respondents'

perspective on how work, numbers of pills, dosing schedules, mood and related factors influence their medication regime.

***Table 16 : Respondents' perspective on factors influencing adherence***

| Variables | Intervention n=181 n(%) | Control n=181 n(%) | Total N=362 n(%) | Test | *p*-value |
|---|---|---|---|---|---|
| Work schedule | 15 (8.3%) | 11(6.1%) | 26 (7.2%) | $X^2 = 0.7$ | .54 |
| Number of pills | 2(1.1%) | 4(2.2%) | 6(1.7%) | $X^2 = .689$ | .49 |
| Number of times | 2(1.1%) | 6(3.3%) | 8(2.2%) | $X^2 = 2.07$ | .17 |
| Forgetfulness | 16(8.8%) | 22(12.1%) | 38(10.5%) | $X^2 = 1.06$ | .39 |
| Feeling better | 4(2.2%) | 1(0.6%) | 5(1.4%) | $X^2 = 1.83$ | .37 |
| Feeling sick | 3(1.7%) | 9(5%) | 12(3.3%) | $X^2 = 3.10$ | .14 |
| Absence of reminders | 7(3.9%) | 2(1.1%) | 9(2.5%) | $X^2 = 2.85$ | .17 |
| Presence of people | 27(14.9%) | 24(13.2%) | 51(14.1%) | $X^2 = .225$ | .65 |
| Fear of being seen | 38(21%) | 26(14.3%) | 64(17.7%) | $X^2 = 2.73$ | .13 |
| Meal time | 10(5.5%) | 13(7.2%) | 23(6.4%) | $X^2 = .418$ | .66 |
| Sleep | 13(7.2%) | 10(5.5%) | 23(6.4%) | $X^2 = .418$ | .66 |
| Feeling sad/unhappy | 25(13.8%) | 24(13.2%) | 49(13.5%) | $X^2 = .024$ | .88 |

*Chi square test (Fisher's exact) significant at p<.05*



The majority of the respondents noted work (n = 335, 92.8%), pill number (n = 355, 98%) pill time (n = 353, 98%) forgetfulness (n = 324, 89.5%) feeling better (n = 335, 92.8%) and feeling sick (n = 335, 92.8%) did not affect their medication schedules.

As shown in Table 16, out of the 362 respondents, 64 (18%) indicated that the fear of being seen by other people, influences when and how they take their medication. There were no significant differences between the Intervention (n = 38, 21%) and Control (n = 26, 14.3%) groups in relation to their perspective on being seen while taking medication $X^2$ = (1, n = 361) = 2.73, $p$ = .13. A few respondents noted that the presence of other people (n = 51, 14%), feeling sad (n

= 49, 13.5%), forgetfulness (n = 38, 10.5%) and sleep (n = 23, 6.4%) affected their medication schedule.

### 5.6.2 Factors Associated with Baseline Self- Reporting Scale

In determining the factors that may be associated with low adherence, moderate adherence or high adherence among the 362 respondents, the Chi square test was applied to test for significant differences between the different demographic variables. As seen in Table 17, being male (n = 101, 37%) or female (n = 171, 63%) did not determine respondents' high adherence to ART $X^2$ = (8, n = 362) =.150 .972.

***Table 17 : Factors associated with adherence level self- reporting***

| | Variable | | | | | Test | *p-value* |
|---|---|---|---|---|---|---|---|
| | | *Low* | *Moderate* | *High* | Total | | |
| Gender | Male | 10(38.5%) | 23(35.9%) | 101(37.1%) | 134(37%) | $X^2$=.150 | .97 |
| | Female | 16(61.5%) | 41(64.1%) | 171(62.9%) | 228(63%) | | |
| | Total | 26(7.2%) | 64(17.7%) | 272(75.1%) | 362(100%) | | |
| Education | Tertiary | 1(3.8%) | 5(7.8%) | 15(5.5%) | 21(5.8%) | $X^2$=1.6 | .81 |
| | Basic/advanced | 23(88.5%) | 51(79.7% | 232(85.3%) | 306(84.5%) | | |
| | No education | 2(7.7%) | 8(12.64%) | 25(9.2%) | 35(9.7%) | | |
| | Total | 26(7.2%) | 64(17.7%) | 272(75.1%) | 362(100%) | | |
| Relationship | Married | 18(69.2%) | 34(53.1%) | 129(47.4%) | 181(50%) | $X^2$=4.82 | .09 |
| | Not married | 8(30.8%) | 30(46.9%) | 143(52.6%) | 181(50%) | | |
| | Total | 26(7.2%) | 64(17.7%) | 272(75.1%) | 362(100%) | | |
| Employment | Formal | 5(19.2%) | 13(20.3%) | 71(26.1%) | 89(24.6%) | $X^2$=5.35 | .25 |
| | Informal | 19(73.1%) | 39(60.9%) | 174(64%) | 232(64.1%) | | |
| | None | 2(7.7%) | 12(18.8%) | 27(9.9% | 41(11.3%) | | |
| | Total | 26(7.2%) | 64(17.7%) | 272(75.1%) | 362(100%) | | |
| Religion | Christian | 24(92.3%) | 57(89.1%) | 249(91.5%) | 330(91.2%) | $X^2$=3.09 | .21 |
| | Moslem | 2(7.7%) | 7(10.9%) | 23(8.5%) | 32(8.8%) | | |
| | Total | 26(7.2%) | 64(17.7%) | 272(75.1%) | 362(100%) | | |
| Visit | <3 months | 4(15.4%) | 5(7.8%) | 28(10.3%) | 37(10.2%) | $X^2$=4.88 | .56 |
| | 3 months | 11(42.3%) | 30(46.9%) | 108(39.9%) | 149(41.3%) | | |
| | 4 months | 8(30.8%) | 27(42.2%) | 111(41%) | 146(40.4%) | | |
| | Undefined | 3(11.5%) | 2(3.1%) | 24(8.9%) | 29(8%) | | |
| | Total | 26(7.2%) | 64(17.7%) | 272(75.1%) | 361(100%) | | |

Chi square test, * Significant at p<.05 two tailed

The majority of respondents who were not married (single, divorced, widowed) 143 (53%) were 'highly adherent' contrasting with those who were married 129 (47%). Nevertheless, results showed relationship status had no influence on low, moderate or high adherence $X^2 = (8, n = 362) = 4.82$, $p = .09$. Similarly, employment, religion and how often respondents reported for follow up visits did not significantly influence their adherence level when a self- reported scale was used for assessing adherence.

### 5.6.3 Factors Associated with Baseline Visual Analogue Scale

The influence of age, gender, education, relationship status, employment, religion and frequency of follow up visits on level of adherence was explored using the Chi square test for significance.

***Table 18 : Factors associated with baseline Visual Analogue scale***

| | Variable | | | | | Test | *p*-value |
|---|---|---|---|---|---|---|---|
| | | Low n=45 | Moderate n=288 | High n=29 | Total N = 362 | | |
| Age | 20-29 | 6(13.3%) | 14(4.9%) | 4(13.8%) | 24(6.6%) | $X^2$=14.99 | .06 |
| | 30-39 | 9(20.0%) | 74(25.7%) | 6(20.7%) | 89(24.6%) | | |
| | 40-49 | 17(37.8%) | 121(42.0%) | 7(24.1%) | 145(40.1%) | | |
| | 50-59 | 7(15.6%) | 56(19.4%) | 6(20.7%) | 69(19.1%) | | |
| | 60 and above | 6(13.3%) | 23(8.0%) | 6(20.7%) | 35(9.7%) | | |
| Gender | Male | 16(35.6) | 108(37.5%) | 10(34.5%) | 134(37%) | $X^2$=.150 | .93 |
| | Female | 29(64.4%) | 180(62.5%) | 19(65.5%) | 228(63%) | | |
| Education | Tertiary | 1(2.2%) | 17(5.9%) | 3(10.3%) | 21(5.8%) | $X^2$=4.87 | .30 |
| | Basic/advance | 37(82.2%) | 244(84.7%) | 25(86.2%) | 306(84.5%) | | |
| | No education | 7(15.6%) | 27(9.4%) | 1(3.4%) | 35(9.7%) | | |
| Relationship | Married | 22(48.9%) | 143(49.7%) | 16(55.2%) | 181(50%) | $X^2$=.346 | .84 |
| | Not married | 23(51.1%) | 145(50.3%) | 13(44.8%) | 181(50%) | | |
| | Total | 45(12.4%) | 288(79.6%) | 29(8%) | 362(100%) | | |
| Employment | Formal | 9(20%) | 72(25%) | 8(27.6%) | 89(24.6%) | $X^2$=1.25 | .87 |
| | Informal | 30(66.7%) | 183(63.5%) | 19(65.5%) | 232(64.1%) | | |
| | None | 6(13.3%) | 33(11.5%) | 2(6.9%) | 41(11.3%) | | |
| Religion | Christian | 41(91.1%) | 260(90.3%) | 29(8.8%) | 330(91.2%) | $X^2$=3.09 | .21 |
| | Muslim | 4(8.9%) | 28(9.7%) | 0(%0) | 32(8.8%) | | |
| Visit | <3 months | 4(8.9%) | 25(8.7%) | 8(27.6%) | 37(10.2%) | $X^2$=15.3 | .02* |
| | 3 months | 19(42.4%) | 119(41.5%) | 11(37.9%) | 149(41.3%) | | |
| | 4 months | 21(46.7%) | 115(40.1%) | 10(34.5%) | 146(40.4%) | | |
| | Undefined | 1(2.2%) | 28(9.8%) | 0(0%) | 29(8%) | | |

Chi square test, * Significant at p<.05 two tailed

The low, moderate and high adherence categories were used for comparison. Results displayed in table 5.8 show that, although the majority of respondents were moderately adhering to treatment, this was not associated with being male or female, having high or no education, being employed and religious affiliation. However, a statistically significant outcome was observed with regards to the frequency of follow up visits $X^2$ = (8, n = 362) = 15.3, *p* = .02.

### 5.6.4 Baseline Pill Identification Test

The pill identification adherence level and its association with gender, education, relationship status and employment were explored.

***Table 19 : Pill identification adherence level and its association***

| | Variable | *Low n=17* | *Moderate n=298* | *High n=44* | Total n= 362 | Test | *p-value* |
|---|---|---|---|---|---|---|---|
| Gender | Male | 6(35.3%) | 109(36.6%) | 19(40.4%) | 134(37%) | $X^2$=.281 | .87 |
| | Female | 11(64.7%) | 189(63.4% | 28(59.6%) | 228(63%) | | |
| | Total | 17(4.7%) | 298(82.3%) | 47(13%) | 362(100%) | | |
| Education | Tertiary | 2(11.8%) | 11(3.7%) | 8(17%) | 21(5.8%) | $X^2$=26.4 | .01* |
| | Basic/advance | 10(58.8%) | 257(86.2%) | 39(83%) | 306(84.5%) | | |
| | No education | 5(29.4%) | 30(10.1%) | 0(0%) | 35(9.7%) | | |
| | Total | 17(4.7%) | 298(82.3%) | 47(13%) | 362(100%) | | |
| Relationship | Married | 10(58.8%) | 144(48.3%) | 27(57.4%) | 181(50%) | $X^2$=1.91 | .38 |
| | Not married | 7(41.2%) | 154(51.7%) | 20(42.6%) | 181(50%) | | |
| | Total | 17(4.7%) | 298(82.3%) | 47(13%) | 362(100%) | | |
| Employment | Formal | 4(23.5%) | 67(22.5%) | 18(38.3%) | 89(24.6%) | $X^2$=8.03 | .09 |
| | Informal | 13(76.5%) | 194(65.1%) | 25(53.2%) | 232(64.1%) | | |
| | None | 10(0%) | 37(12.4%) | 4(8.5%) | 41(11.3%) | | |
| | Total | 17(4.7%) | 298(82.3%) | 47(13%) | 362(100%) | | |

*Chi square test, * Significant at p<.001 two tailed*

As depicted in table 19, there were significant differences in adherence based on education level with the proportion of respondents with no education (29.4%) being higher in the low adherence categories compared to other adherence categories. Respondents with more education had proportionally higher representation in moderate and high adherence categories on pill count score ($X^2$

= 26.4, *p*< .01). The other variables do not demonstrate any significant association in adherence level categories for pill count scores.

### 5.6.5 Factors Associated with Adherence Level for Baseline Pill Count Score

Low, moderate and high adherence to ART estimated with pill count was assessed for association with demographic variables namely, gender, education, employment and regularity of follow up visits. Table 20 shows that the outcomes had no statistically significant association with reference to the variables included in the model.

***Table 20 : Factors associated with Pill Count Score***

| | Variable | | | | Test | *p-value* |
|---|---|---|---|---|---|---|
| | | *Moderate* | *High* | Total | | |
| Gender | Male | 2(25%) | 132(37.3%) | 134(37%) | $X^2$=.507 | .48 |
| | Female | 6(75%) | 222(62.7%) | 228(63%) | | |
| | Total | 8(2.2%) | 354(97.8%) | 362(100%) | | |
| Education | Tertiary | 1(12.5%) | 20(5.6%) | 21(5.8%) | $X^2$=.789 | .67 |
| | Basic/advanced | 6(75%) | 300(84.7%) | 306(84.5%) | | |
| | No education | 1(12.5%) | 34(9.6%) | 35(9.7%) | | |
| | Total | 8(2.2%) | 354(97.8%) | 362(100%) | | |
| Employment | Formal | 2(25%) | 87(24.6%) | 89(24.6%) | $X^2$=1.60 | .45 |
| | Informal | 4(50%) | 228(64.4%) | 232(64.1%) | | |
| | None | 2(25%) | 39(11%) | 41(11.3%) | | |
| | Total | 8(2.2%) | 354(97.8%) | 362(100%) | | |
| Visit | <3 months | 0(0%) | 37(10.2%) | 37(10.2%) | $X^2$=4.48 | .21 |
| | 3 months | 2(25%) | 147(40.2%) | 149(40.4%) | | |
| | 4 months | 4(50%) | 142(40.2%) | 146(40.4%) | | |
| | Undefined | 2(25%) | 27(7.6%) | 29(8%) | | |
| | Total | 8(2.2%) | 353(97.8%) | 361(100%) | | |

Chi square test, * Significant at p<.05 two tailed

Moderate and high adherence scores for pill count were not related to being male or female, having education, employment or visiting the clinic more regularly.

### 5.6.6 Factors Associated with Adherence Level for Baseline Overall Adherence

The overall adherence outcome was compared for association with some demographic characteristics of respondents. The aim was to find out if scoring low, moderate or high on overall adherence assessment was associated with age gender, education, relationship, employment, religion and frequency of follow up visits. Results showed that no significant associations were observed within adherence levels except that high adherence levels were associated with education levels of respondents $X^2$ = (1, n = 361) = 5.01, $p$ = 03 (table 5.11).

***Table 21 : Baseline Overall Adherence Score association with demographic profile***

| | Variable | | | | Test | *p-value* |
|---|---|---|---|---|---|---|
| | | *Moderate* | *High* | Total | | |
| Age | 20-29 | 11(10.4%) | 13(5.1%) | 24(6.6%) | $X^2$ =14.99 | .09 |
| | 30-39 | 21(19.8%) | 67(26.3%) | 88(24.4%) | | |
| | 40-49 | 37(34.9%) | 108(42.4%) | 145(40.2%) | | |
| | 50-59 | 23(21.7%) | 46(18%) | 69(19.1%) | | |
| | 60 and above | 14(13.2%) | 21(8.2%) | 35(9.7%) | | |
| Gender | Male | 39(36.8%) | 95(37.3%) | 134(37%) | $X^2$=.007 | .93 |
| | Female | 67(63.2%) | 160(62.7%) | 227(62.9%) | | |
| Education | Formal | 90(84.9%) | 236(92.5%) | 326(90.3%) | $X^2$=5.01 | .03* |
| | No education | 16(15.1%) | 19(7.5%) | 35(9.7%) | | |
| | Relationship | | | | | |
| | Married | 55(30.6%) | 125(69.4% | 180(49.9%) | $X^2$=.246 | .62 |
| | Not married | 51(28.2%) | 130(71.8%) | 181(50.1%) | | |
| Employment | Formal | 22(20.8%) | 67(26.3%) | 89(24.6%) | $X^2$=2.77 | .25 |
| | Informal | 68(64.2%) | 163(63.9%) | 231(64%) | | |
| | None | 16(15.1%) | 25(9.8%) | 41(11.4%) | | |
| Religion | Christian | 97(91.5%) | 232(91%) | 329(91.1%) | $X^2$=.026 | .87 |
| | Moslem | 9(8.5%) | 23(9%) | 32(8.9%) | | |
| | Total | 106(29.4%) | 255(70.6%) | 361(100%) | | |
| Visit | <3 months | 10(9.4%) | 27(10.6) | 37(10.2%) | $X^2$=3.17 | .73 |
| | 3 months | 49(46.2%) | 99(39%) | 148(41.1%) | | |
| | 4 months | 42(39.6%) | 104(40.9%) | 146(40.6%) | | |
| | Undefined | 5(4.7%) | 24(9.4%) | 29(8.1%) | | |

*Chi square test (Fisher's exact) * Significant at p<.05 two tailed*

Additional modelling was done with a binary logistic regression to determine the likelihood of education, regularity of clinic appointments and employment to

predict adherence levels (moderate and high). The model was statistically significant $X^2$ = (3, n = 361) = 7.98, *p*< .05. The model explained between 22% (Cox and Snell R square) and 31% (Nagelkerke R squared) of variation in adherence level and correctly classified 70.6% of the cases. Results displayed in Table 22 further reveal that education significantly predicts adherence levels (*OR* = 2.16, CI = 1.06, 4.39, *p* <.05). Moderately adhering to ART increases the odds for individuals who have been through formal education by 2.16.

***Table 22 : Binary regression predictors of overall adherence level***

| Predictors | B (S.E.) | Wald | df | 95% C.I. | Odds ratio | *p-value* |
|---|---|---|---|---|---|---|
| Education | .769(.362) | 4.507 | 1 | [1.06, 4.39] | 2.16 | .03* |
| Follow-up schedule | .232(.235) | .980 | 1 | [.796, 1.99] | 1.26 | .32 |
| Employed | -.303(.203) | 2.218 | 1 | [.496, 1.10] | .74 | .14 |
| Constant | .655(.534) | 1.502 | 1 | | 1.92 | .22 |

** Significant at p<.05 two tailed*

## 5.7 UTILISATION OF MOBILE PHONE AMONG CLIENTS WITH HIV



Mobile phone use was assed among respondents at baseline, irrespective of group assignment, to determine the knowledge, skills and practices of respondents in the use of mobile phones. The purpose was to assess gaps and preferences which informed the planning of mobile phone intervention during the study. Self-constructed questionnaires were used to obtain information from the 362 respondents.

### 5.7.1 Mobile phone use and practices

Respondents were asked to indicate if they shared their mobile phone with other people, the applications they use on their phones, their preferred language of

communication, the usage of their phones to support medication adherence and the training needs in respect of using the alarm, reminders, SMS and voice calls. The majority of respondents 338 (93%) out of the 362 reported they did not share their phone with anybody.

Some of the respondents (n = 77, 21%) reported using their mobile phone to facilitate taking their medication, but the majority (n = 285, 79%) did not. More than half of those using their mobile phone to support medication adherence, were in the Intervention group (n = 48, 62%) while 29 (38%) were in the Control group. The difference observed was significant $X^2$ = (1, n = 360) = 5.95, $p$ = .02.

### 5.7.2 Use of Alarm and Reminders

The majority of the respondents (n = 272, 75%) did not use the alarm applications. The number of respondents using the alarm application on their phone in the Intervention (n = 47, 52%) and Control (n = 43, 48%) groups varied but was not significant $X^2$ = (1, n = 360) = .237, $p$ = .63). 227 (63%). Out of the 362 respondents 251 (69%) noted that they required training to use the alarm application.

Most of the respondents did not use the reminder applications on their phones. More than half of respondents using reminders were in the Control group. Respondents also indicated that they required training to use the reminder application on their phone (n = 220, 61%).

### 5.7.3 Use of Text Messaging Application

Out of the 362 respondents 250 (69%) said they did not use the text message application on their phones. The most common language in which respondents sent or received messages was English (n = 241, 67%).

***Table 23 : Differences between Intervention and Control group in phone usage***

| Variable | Response | Intervention (n = 181) | Control (n = 181) | Total | Test | *p -value* |
|---|---|---|---|---|---|---|
| Use alarm | Yes | 47 (52.2%) | 43(47.8%) | 90(24.9%) | $X^2$ =.237 | .63 |
| | No | 134(49.3%) | 138(50.7%) | 272(75.1%) | | |
| Use reminder | Yes | 28(%) | 33(54.1%) | 61(16.9%) | $X^2$ =.493 | .48 |
| | No | 153(84%) | 148(49.2%) | 301(83.1%) | | |
| Use text | Yes | 52(46.4) | 60(53.6%) | 112(30.9%) | $X^2$ =.827 | .36 |
| | No | 129(51.6%) | 121(48.4%) | 250(69.1) | | |
| Use call | Yes | 105(46.3%) | 122(53.7%) | 227(63.1%) | $X^2$ =3.98 | .05* |
| | No | 76(57.1%) | 57(42.9%) | 133(36.9%) | | |
| Call language | English | 44(46.3%) | 51(53.7%) | 95(26.3%) | $X^2$ =.754 | .38 |
| | Others | 137(51.5%) | 129(48.5%) | 266(73.7%) | | |
| Sms language | English | 116(48.1) | 125(51.9%) | 241(66.6%) | $X^2$ =2.03 | .36 |
| | Others | 23(60.5%) | 15(39.5%) | 38(10.5%) | | |
| | Can't read | 42(50.6%) | 41(49.4%) | 83(22.9%) | | |
| Phone for medication | Yes | 48(62.3%) | 29(37.7%) | 77(21.3%) | $X^2$ =5.95 | .02* |
| | No | 133(46.7%) | 152(53.3%) | 285(78.9%) | | |
| Training alarm | Yes | 57(51.4%) | 54(48.6%) | 111(30.7%) | $X^2$ =.117 | .73 |
| | No | 124(49.4%) | 127(50.6%) | 251(69.3%) | | |
| Training reminder | Yes | 75(52.8%) | 67(47.2%) | 142(39.2% | $X^2$ =.742 | .39 |
| | No | 106(48.2%) | 114(51.8%) | 220(60.8%) | | |
| Training text | Yes | 72(51.4%) | 68(48.6%) | 140(38.7%) | $X^2$ =.186 | .67 |
| | No | 109(49.1%) | 113(50.9%) | 222(61.3%) | | |
| Training call | Yes | 64(52%) | 59(48%) | 123(34%) | $X^2$ =.308 | .58 |
| | No | 117(49%) | 122(51%) | 239(66%) | | |

*Chi Square test*significant at p<.05*

Some respondent (n = 83, 23%) noted receiving messages but not being able to read them. Less than half (n = 140, 39%) of respondents admitted they required training to use the text message application.

A comparison of the use of the text message application among the groups showed that respondents in the Intervention group did not differ significantly from the Control group $X^2$ = (1, n = 360) = .827, $p$ = .36. No significant differences were observed with regards to the language of text message $X^2$ = (1, n = 360) = 2.03, $p$ = .36 and training needs $X^2$ = (1, n = 360) = .186, $p$ = .67.

### 5.7.4 Use of Voice Calls

The voice call was the most used application among respondents, with 227 (63%) of respondent reporting its use. There were more respondents using voice calls in the Control group (n = 122, 54%) compared with the Intervention group (n = 105, 46%). No significant differences were observed among respondents with regards to the use of voice calls by the Intervention and the Control groups $X^2$ = (1, n = 360) = 3.98, $p$ = .05 as indicated in Table 23. The respondents also reported using mainly their indigenous language (n = 266, 74%) for voice communication with only 95 (26%) using English language.



## 5.8 PREDICTORS OF MOBILE USE USAGE IN HIV CLIENTS

Four binary regression analyses were performed with alarms, reminders, text messaging and voice call usage as dependent variables to determine which socio-demographic factors influenced the use of mobile phone among respondents. The independent variables included age, sex, education, marital status and employment. The results have been summarised in Table 24.

### 5.8.1 Predictors of Alarm usage

The model for predictors of alarm use (Yes NO) among respondents for age, sex, education, marital status and employment as predictors was statistically significant $X^2(5, n = 362) = 30.4$, $p < .01$ but explained only 8% (Cox and Snell R square) and 12% (Nagelkerke R squared) of variation in alarm use. The model correctly classified 75% of the respondents reporting alarm use. Results displayed in Table 24 further show that age significantly predicts use of alarms (*OR* = 1.56*, 95%* CI = 1.2, 2.3, $p$ <.01). It also revealed that the likelihood of using alarms among respondents increased by 1.6 times if the person was younger. Additionally, being employed contributed to the use of alarms (*OR* = 1.76*,* CI = 1.11, 2.80, $p$ <.05) among respondents. Being employed resulted in a 1.7 chance of using the alarm as a reminder for adherence.

### 5.8.2 Predictors usage of reminders

The binary regression outcome (Yes NO) for use of reminders among respondents was statistically significant $X^2(5, n = 362) = 24.5$, $p < .01$. Variation in the use of reminders was explained by 7% (Cox and Snell R square) and 11% (Nagelkerke R squared) with the model correctly classifying 83% of the cases. Age significantly predicted use of reminders among respondents (*OR* = 1.59*,* CI = 1.17, 2.14, $p$ <.05). This indicates that the likelihood of using reminders increased 1.5 times among respondents who were younger. Education significantly predicted use of reminders by the respondents (*OR* = 2.57*,* CI = 1.13, 5.80, $p$ <.05).

### 5.8.3 Predictors of using Text message Application

Modelling for use of text messaging (Yes NO) with binary logistic regression was also significant $X^2(5, n = 362) = 37.1$, $p < .01$. The differences in using a text messaging application were explained by 9.7%% (Cox and Snell R square) and 13.7% (Nagelkerke R squared) and the model correctly classified 72% of the cases. Age (*OR* = 1.48, CI = 1.16, 1.88, $p < .05$), education (*OR* = 3.13, CI = 1.52, 6.48, $p < .05$) and employment (*OR* = 1.61, CI = 1.05, 2.45, $p < .05$) significantly predicted use of text message among respondents. The result indicates that the likelihood of using text messaging increased by 1.48 times in younger respondents, while those who have some level of education had a 3.13 likelihood of using text messaging. Respondents with employment also had a 1.61 probability of using a text message application.

**Table 24 : *Predictors of Mobile phone use***

| | Predictors | B (S.E.) | Wald | df | Odds ratio | 95% C.I. | *p-value* |
|---|---|---|---|---|---|---|---|
| Use of Alarm | *Age* | .444(.134) | 11.2 | 1 | 1.56 | [1.19, 2.03] | .01** |
| | *sex* | .300(.280) | 1.14 | 1 | 1.35 | [.779 - , 2.34] | .28 |
| | *Education* | .572(.354) | 2.61 | 1 | 1.77 | [.886, 3.54] | .11 |
| | *Marital status* | .472(.261) | 3.28 | 1 | 1.60 | [.962, 2.67] | .07 |
| | *Employed* | .566(.237) | 5.71 | 1 | 1.76 | [1.11, 2.80] | .02* |
| | *Constant* | -3.53(.955) | 13.67 | 1 | .029 | | .01** |
| Reminders | *Age* | .462(.153) | 9.07 | 1 | 1.59 | [1.18, 2.14] | .03* |
| | *sex* | .012(.329) | .001 | 1 | 1.01 | [.531, 1.93] | .97 |
| | *Education* | .942(.416) | 5.12 | 1 | 2.56 | [1.13, 5.80] | .02* |
| | *Marital status* | .404(.299) | 1.83 | 1 | 1.51 | [.834, 2.69] | .18 |
| | *Employed* | .453(.274) | 2.74 | 1 | 1.57 | [.920, 2.69] | .09 |
| | *Constant* | -3.03(1.05) | 8.33 | 1 | .049 | | .04 |
| Text | *Age* | .389(.124) | 9.93 | 1 | 1.48 | [1.16, 1.88] | .02* |
| | *sex* | .476(.263) | 3.28 | 1 | 1.61 | [.961, 2.69] | .07 |
| | *Education* | 1.14(.371) | 9.50 | 1 | 3.13 | [1.52, 6.48] | .02* |
| | *Marital status* | -.003(.245) | .000 | 1 | .997 | [.617, 1.61] | .99 |
| | *Employed* | .475(.215) | 4.86 | 1 | 1.61 | [1.05, 2.45] | .03* |
| | *Constant* | -4.27(.977) | 19.1 | 1 | .014 | | .01 |
| Voice call | *Age* | .220(.107) | 4.25 | 1 | 1.25 | [1.01, 1.54] | .04* |
| | *Employed* | .378(.191) | 3.92 | 1 | 1.46 | [.1, 2.12] | .05 |
| | *Constant* | -191(.488) | 15.4 | 1 | .147 | | .01 |

* Significant at p<.05 two tailed **Significant at p<.001 two tailed

### 5.8.4 Predictors of using voice calls

The use of voice call (YES, NO) was included as a dependent variable with two covariates (age and employment) to determine likelihood of predictive characteristics. The model was statistically significant $X^2$ (2, n = 360) = 8.85, $p$ < .05 but explained only 2.4 % (Cox and Snell R square) and 3.3% (Nagelkerke R squared) of the differences in cases while classifying 64.4% correctly. Age (*OR* = 1.25, CI = 1.01, 1.54, $p$ <.05) and employment (*OR* = 1.46, CI = 1, 2.12, $p$ <.05) were significant in determining use of voice calls. As age increased, the likelihood of using voice calls increased by 1.25 times while for employment it increased by 1.46 times as shown in Table 24.

## 5.9 EFFECTS OF MOBILE PHONE INTERVENTION ON ADHERENCE AMONG RESPONDENTS

Effects of alarm use, weekly text messaging and monthly voice calls on adherence levels at month three and month six were explored using different statistical techniques.



Chi square test of significance was done to explore relationship in adherences outcome for each subscale of the multimethod adherence tool relative to the two groups. Descriptive statistics with frequencies and percentages were reported as observed for the three levels (low, moderate, and high) of adherence outcome expected.

Linear mixed modelling was applied in estimating the effect on the scores for Self-report, Visual analogue Pill identification test, Pill count and Overall adherence (dependent variables). The model allowed for a comparison of the

Intervention and the Control groups across the three timelines for between groups and within subject outcomes (fixed factors). Socio-demographic variables were also included in the model as fixed factors using the Maximum Likelihood method. The adherence scores were estimated in percentages with low adherence being scores of less than 75%, moderate adherence between 75% to 94.9% and 95% and above as high adherence.

### 5.9.1 Evaluating Difference in Adherence: Self-report

The self- report assessment outcome was compared using the Chi square test of significance to determine differences between the adherence scores at baseline and the two follow-ups in the groups. Results in Table 25 below, show that the adherence outcome in the Intervention and Control groups did not differ at baseline.

A total of 272 (75%) of respondents were highly adherent at baseline with 137 (50.4%) in the Control group. However, the difference in assessment of adherence at baseline using the self- report scale was not significant $X^2$ = (2, n = 362) = .693, $p$ = .71.

The follow up assessment at month three showed that 123 (61.5%) respondents in the Intervention group were highly adherent to treatment compared with 77 (38.5%) in the Control group. The results showed a near difference in adherence outcome between the two groups $X^2$ = (2, n = 220) = 5.82, $p$ = .06 as shown in Table 25

***Table: 25 Self Reporting adherence score***

| Variable | Outcome | | | | |
|---|---|---|---|---|---|
| | Intervention | Control | Total | Test | p value |
| Baseline SR | | | | | |
| High | 135(49.6%) | 137(50.4%) | 272(75.1%) | $X^2$ = .639 | .71 |
| Moderate | 31(48.4%) | 33(51.6%) | 64(17.7) | | |
| Low | 15(57.7%) | 11(42.3%) | 26(7.2%) | | |
| Total | 181(50%) | 181(50%) | 362(100%) | | |
| 3rd Month SR | | | | | |
| High | 123(94.6%) | 77(61.5%) | 200(90.9%) | $X^2$ = 5.82 | .06 |
| Moderate | 7(5.4%) | 12(13.3%) | 19(8.6%) | | |
| Low | 0(0%) | 1(1.1%) | 1(0.5%) | | |
| Total | 130(59.1%) | 90(40.9%) | 220(100%) | | |

Chi Square test* Significant at p<.05 two tailed

The self-report adherence scores as shown in Figure 11 revealed mean adherence increased by 3.1% in the Intervention group and 0.9% in the Control group at month three (*Time 2*). All respondents (n = 270) scored 100% on the self-report adherence at the month six assessment.

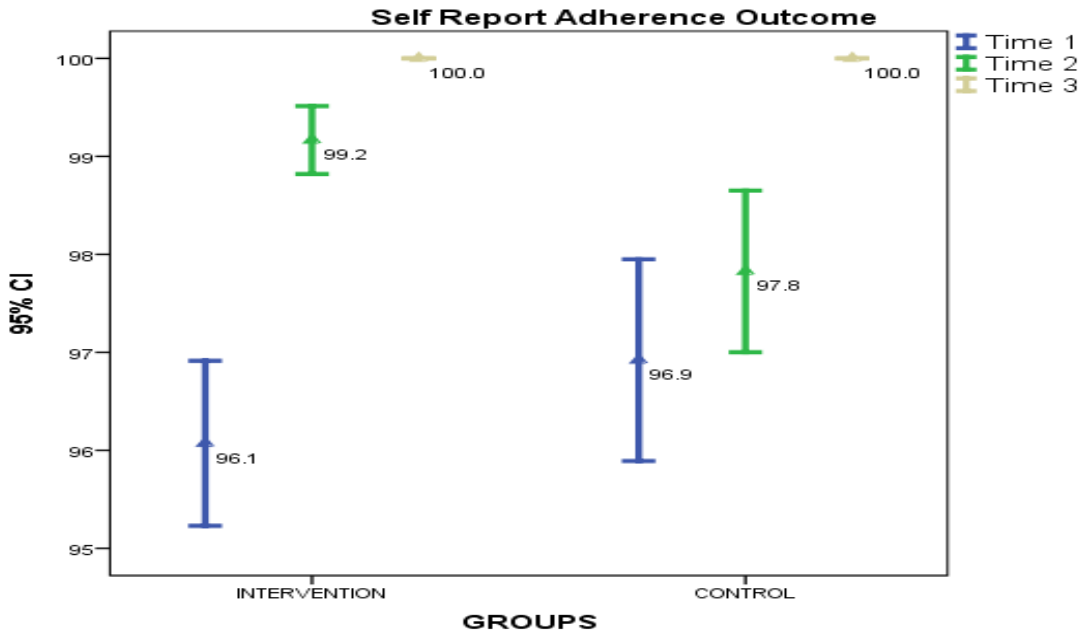



***Figure 11: Mean adherence score for self-report in Intervention and Control groups***

Further analysis of the using linear mixed modelling was done with self-report as the dependent variable. Time, group, age, gender, education, marital status, employment, religion and follow up visit schedule as fixed factors. Maximum likelihood method was used to fit the model. As illustrated in Table 26, the Intervention group self-report adherence score at time 2 increased (*M = 99.3, SE* = .28, *CI* = 98.8, 99.9*)* compared with the Control group (*M = 97*, *SE = .34*, *CI = 97.2, 98.5)* the difference was statistically significant *F (1, 255)* = 11.2, *p* < .01 for between group comparison.

Pairwise comparisons of within subject adherence outcome for self-report adherence scores showed that respondents, irrespective of group, recorded significant increase in scores. The Intervention group outcome at *Time 1 & 2* (*Mean difference* = -3.61, *SE* = .369, *CI* = -4.34, -2.89, *p* < .01), *Time 1 & 3 2* (*Mean difference* = -4.29, *SE* = .353, *CI* = -4.98, -3.59, *p* < .01) showed significant increases in self-report score but *Time 2 & 3* (*Mean difference* = -.675, *SE* = .383, *CI* = 4.06, 8.45, *p = .08*) result was not significant.



***Table 26: Comparing self-report adherence score in the Intervention and Control group***

| | Intervention | | Control | | | |
|---|---|---|---|---|---|---|
| | *M(SE)* | 95% CI | *M(SE)* | 95% CI | *F* test | *p*-value |
| Self-Report | | | | | | |
| Time 1 | 95.7(.239) | [95.2, 96.2] | 96.1(.240) | [95.6, 96.5] | 1.04 | .31 |
| Time 2 | 99.3(281) | [98.8, 99.9] | 97.8(.340) | [97.2,98.5] | 11.2 | .01 |
| Time 3 | 100(.260) | [99.5, 100] | 99.9(.296) | [99.4, 100] | .007 | .93 |
| Intervention | | | | | 86.4 | .01** |
| Control | | | | | 53.1 | .01** |

*F test ** Significant at p<.01 two tailed*

Significant results were obtained in the Control group at *Time 1 & 2* (*Mean difference* = -1.79, *SE* = .416, *CI* = -2.61, -.973, $p < .01$), *Time 1 & 3* (*Mean difference* = -3.91, *SE* = .380, *CI* = -4.66, -3.16, $p < .01$) and *Time 2 & 3* (*Mean difference* = -2.12, *SE* = .451, *CI* = -3.01, -1.24, $p < .01$). The respondents' rating of self-adherence improved from baseline to month six in both groups although expectations were that only Intervention group scores would increase as depicted in Table 26.

### 5.9.2 Evaluating difference in adherence for Visual Analogue outcome

The descriptive outcome of the ordinal scale for VAS (Table 27) showed that the majority 288 (79.6%) of respondents were moderately adherent to treatment with 144 (50%) respondents in each group at baseline. At the first follow up, of the 176 (80%) respondents who were moderately adherent, 108 (61. 4%) were in the Intervention group while 68 (38.6%) were in the Control group.



***Table 27 : Differences in adherence VAS at three time intervals***

| Variable | categories | Intervention n(%) | Control n(%) | Total |
|---|---|---|---|---|
| Baseline VAS | Low | 22(48.9%) | 23(51.1%) | 45(12.4%) |
| | Moderate | 144(50%) | 144(50%) | 288(79.6%) |
| | High | 15(51.7%) | 14(48.3%) | 29(8%) |
| | Total | 181(50%) | 181(50%) | 362(100%) |
| Third Month | Low | 20(50%) | 20(50%) | 40(18.2%) |
| | Moderate | 108(61.4%) | 68(38.6%) | 176(80%) |
| | High | 2(50%) | 2(50%) | 4(1.8%) |
| | Total | 130(59%) | 90(41%) | 220(100%) |
| Sixth month | Low | 51(56.7%) | 39(43.3%) | 90(33.3%) |
| | Moderate | 101(58.4%) | 72(41.6%) | 173(64.1%) |
| | High | 0(0%) | 7(100%) | 7(2.6%) |
| | Total | 152(56.3%) | 118(43.7%) | 270(100%) |

Two hundred and seventy (270) respondents were assessed at the second follow up (month six) out of which 152 (56.3%) were in the Intervention group and 118 (43.7%) in the Control group. Most of the respondents (n = 173, 64%) were moderately adherent to ART at the second follow up using the VAS ordinal scale. More than half of respondents 101 (58.4%) were in the Intervention group and 72 (41.6%) were in the Control group. Further analysis was performed to determine the actual effect of the intervention across timelines.

Results of the linear mixed model regression analysis to determine the outcome of mobile phone intervention measured using the VAS were critically examined. VAS scores were included as dependent variables while time, group, time & group and intercept were the fixed factors.

As shown in Figure 12 no significant differences were observed in the Intervention (*M* = 84.4, *SE* = .648, *CI* = 83.4, 85.9*)* and Control (*M* = 82.46*, SE* = .648, *CI* = 82.6, 85.1*)* group scores at baseline *F (*360, n = 362) = .614, *p* = .434). Out of the 181 respondents in each group, 130 (72%) of respondents in the Intervention group returned for evaluation at *Time* 2.

The adherence scores of the 90 (50%) of respondent in the Control group who returned compared with the Intervention group, showed that the Intervention group (*M* =83.4*, SE* =.789, *CI* = 82.2, 85.3*)* scored slightly higher in adherence than the Control group (*M* = 82, *SE* = .947, *CI* = 80.1-83.8*)* but the difference was not significant *F (*218, n = 362) = 1.99, *p* = .160). Adherence scores decreased in the Intervention (*M* = 77.7*, SE* = .813, *CI* = 75.9, 79.1*)* and Control (*M* = 77. 3*, SE* = .923, *CI* = 77.2, 81*)* groups at the second follow up (time three) but significant

differences were not observed between the groups *F (*267, n = 362) = 1.93, *p* = .16).

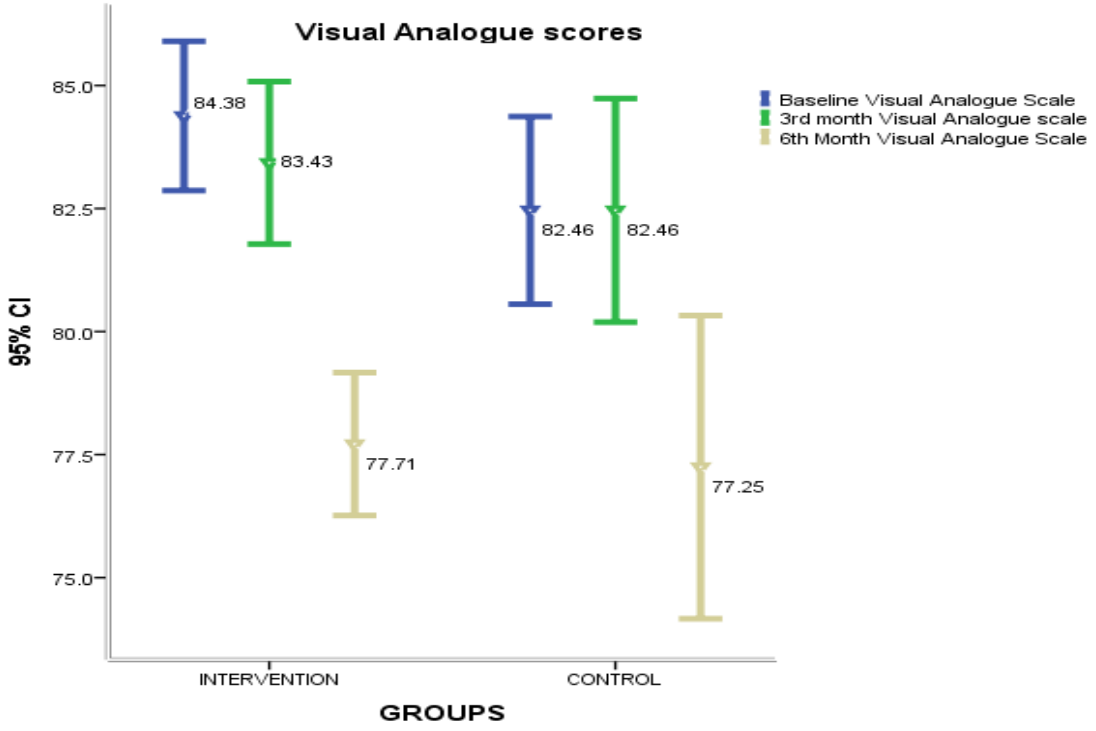



***Figure 12 : Visual Analogue adherence score for the three time points and group***



Pairwise comparisons within subjects were estimated based on marginal means with baseline VAS score as the dependent variable.

***Table 28 : Mixed model linear regression comparing groups adherence***

| | Intervention *M(SE)* | 95% CI | Control *M(SE)* | 95% CI | *F* test | *p*-value |
|---|---|---|---|---|---|---|
| Visual Analogue | | | | | | |
| Time 1 | 84.6(.648) | [83.4, 85.9] | 83.9(.648) | [82.6, 85.2] | .614 | .43 |
| Time 2 | 83.8(.789) | [82.2, 85.3] | 82(.947) | [80.2, 83.9] | 1.99 | .16 |
| Time 3 | 77.5(.813) | [75.9, 79.1] | 79.2(.923) | [77.4, 81] | 1.93 | .17 |
| Intervention | | | | | 25.7 | .01** |
| Control | | | | | 8.74 | .01** |

*F test ** Significant at p<.01 two tailed*

Results of the Intervention group showed decrease in scores at *Time 1* and *3* (Mean difference = 7.13, *SE* = 1.03, *CI* = 5.09, 9.17); then *Time 2* and *3* (Mean difference = 6.26, *SE* = 1.11, *CI* = 4.06, 8.45). The differences were statistically significant *F (*549, n = 362) = 25.7, *p* <.01.

In the Control group there was similar decline in adherence levels among respondents between *Time 1* and *3* (Mean difference = 4.70, *SE* = 1.13, *CI* = 2.49, 6.9.2) and *Time 2* and *3* (Mean difference = 2.81, *SE* = 1.30, *CI* = .244, 5.37). The results demonstrated significant statistical difference in adherence scores *F (*377, n = 362) = 25.7, *p* = 03 as seen in Table 28. Notably adherence mean scores decreased overtime, as shown in Figure 12, attributable to attrition effects. The expectation that adherence would improve only in the Intervention group was therefore not achieved.

### 5.9.3 Evaluating Difference in Adherence for Pill Count Score



Respondents' pills were counted during each visit to monitor adherence behaviour within the three measurement times (baseline, third and sixth month). The descriptive results and linear regression outcomes were presented. The aim was to determine the differences in adherence from time one to three and compare outcomes for the groups and subjects.

Results revealed that respondents were mostly highly adherent at baseline (n =354, 97.8%) with regards to pill count outcomes. Out of the 219 respondents who returned for time two, 218 (99.5%) were highly adherent with most of them being in the Intervention group (n = 129, 59%). None of the respondent in the Control group reported moderate adherence behaviour. Adherence patterns in time three showed that all respondents were highly adherent although more than half were in the Intervention group (n = 152, 56%) while 118 (44%) were in the Control group.

The linear mixed modelling enabled the comparison of pill count percentage scores between the groups and within subjects at each time point. The results have been displayed in figure 5.7 and table 5.19.

Comparing the Intervention (*M* = 99.14, *SE* = .113) and Control (*M* = 99.3, *SE* = .113) group scores at baseline, no differences were observed in the adherence

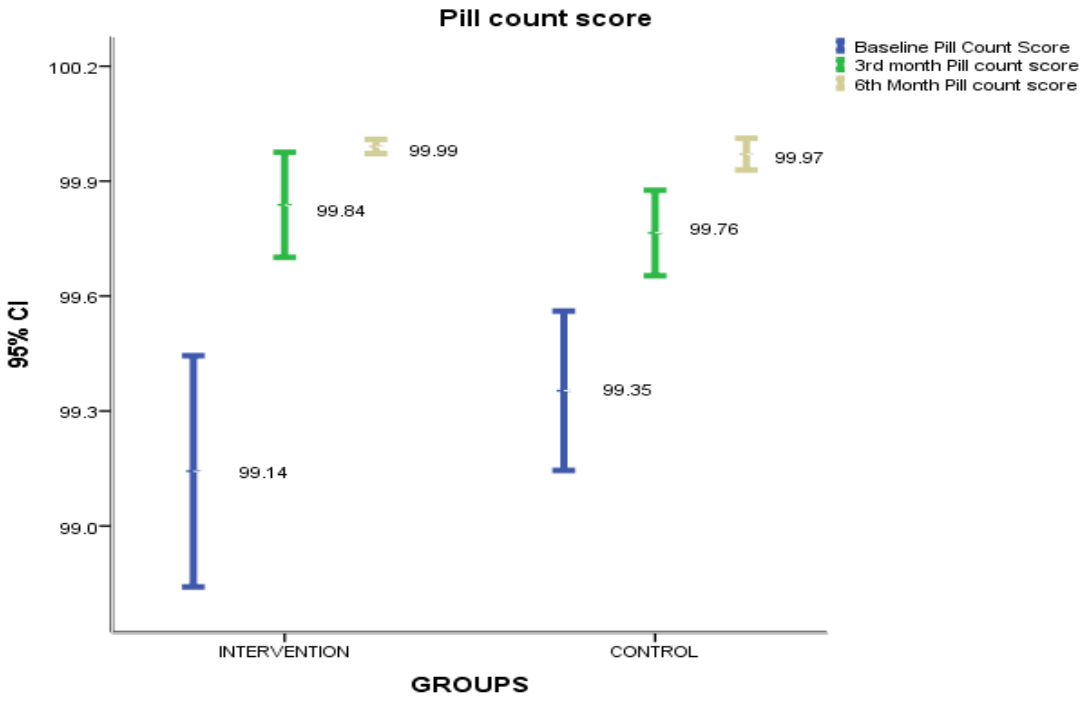



***Figure 13 : Pill count score from time 1 to 3***

behaviour *F (*363, n = 362) = .128, *p* = .72) although the Control group's mean score was higher by 21% as shown in Table 29. Similarly, adherence scores at time two for the Intervention (*M* = 99.8, *SE* = .056) and Control (*M* = 99.9, *SE* = .068) groups did not demonstrate that differences existed in adherence outcome between the groups *F (*202, n = 362) = .834, *p* = .36). At time three, the Intervention (*M* = 99.9 *SE* = .020) and Control (*M* = 99.9 *SE* = .022) group scores were also not statistically significant *F (*263, n = 362) = .003, *p* =.96).

However, pairwise comparisons within subjects revealed the Intervention group adherence scores at *Time 1and 2* (*Mean difference* = -.85, *SE* = .135, *CI* = -.951, -.419) and *Time 1and 3* (*Mean difference* = -.805, *SE* = .114, *CI* = -1.03, -.581) were significantly different *F (*368, n = 362) = 28.4, *p* <. 01. The *Time 2 and 3* scores (*Mean difference* = 7.13, *SE* = 1.03, *CI* = 5.09-9.17) were nearly significant *p* = .06. The results showed that adherence scores of each respondent increased from baseline through the third and sixth months and they demonstrated high adherence to treatment.



***Table 29 Differences in pill count score***

| | Intervention *M(SD)* | 95% CI | Control *M(SD)* | 95% CI | *F* test | *p*-value |
|---|---|---|---|---|---|---|
| Pill Count | | | | | | |
| Time 1 | 99.1(.113) | [98.9, 99.4] | 99.2(.113) | [98.9, 99.4] | .128 | .72 |
| Time 2 | 99.8(.056) | [99.7, 99.9] | 99.7(.068) | [99.6, 99.9] | .834 | .36 |
| Time 3 | 99.9(.020) | [99.9, 100] | 99.9(.022) | [99.9, 100] | .003 | .96 |
| Intervention | | | | | 28.4 | .01** |
| Control | | | | | 26.4 | .01** |

*F test * Significant at p<.05 two tailed ** Significant at p<.001*

Although pill count adherence scores were expected to remain stable or decrease in the Control group the results showed that adherence scores for *Time*

*1and 2* (Mean difference = -.547, *SE* = .140, *CI* = -.823, -.271) improved. *Time 1and 3* (Mean difference = -.750, *SE* = .114, *CI* = -.974, -.525) and *Time 2 and 3* scores (Mean difference = -.202, *SE* = .074, *CI* = -.349, -.056) adherence scores also improved significantly *F (*387, n = 362) = 26.4, *p* <.01 as depicted in Table 29.

The outcome obtained from counting the pills and estimating percentage adherence showed that generally adherence was high among all the respondents and consistently improved marginally for each respondent from baseline assessment, through month three and month six irrespective of the group assignment. The effects of the mobile phone intervention on adherence outcome therefore were not conclusive considering that the observed change occurred in both groups.

### 5.9.4 Evaluating difference in adherence: Pill identification test



The ability to identify the pill name, pill dose, pill time and pill instructions were evaluated among the Intervention and Control groups at baseline, first follow-up which occurred at month three and at the second follow-up at month six. Results presented in Table 30 show that using the PIT adherence score at baseline, there was moderate adherence to treatment (n = 298, 82%) with about 155(52%) in the Intervention group.

Comparing outcomes at the third month showed most of the respondents (n = 185, 84%) were moderately adherent. No significant changes occurred in the adherence outcome in both groups $X^2$ = (2, n = 220) = 2.14, *p* = .34. Nevertheless, the Intervention group had more respondents being moderately

adherent (n = 112, 60.5%) compared with the Control group (n = 73, 39.5%). No respondent recorded low adherence at month six.

***Table 30: showing adherence score for Pill identification test***

| Variable | Outcome Intervention | Control | Total | Test | *p*-value |
|---|---|---|---|---|---|
| Baseline PIT | | | | | |
| *High* | 18 (38.3%) | 29(61.7%) | 47(13%) | $X^2 = 3.12$ | .21 |
| *Moderate* | 155(52%) | 143(48%) | 298(82.3%) | | |
| *Low* | 8(47.1%) | 9(52.9%) | 17(4.7%) | | |
| *Total* | 181(50%) | 181(50%) | 362(100%) | | |
| 3rd Month PIT | | | | | |
| *High* | 18(52.9%) | 16(47.1%) | 34(15.5%) | $X^2 = 2.14$ | .34 |
| *Moderate* | 112(60.5%) | 73(39.5%) | 185(84.1%) | | |
| *Low* | 0(0%) | 1(100%) | 1(0.5%) | | |
| *Total* | 130(59.1%) | 90(40.9%) | 220(100%) | | |
| 6th Month PIT | | | | | |
| *High* | 1 (100%) | 0(0%) | 1(0.4%) | $X^2 = .779$ | .38 |
| *Moderate* | 151 (56.1%) | 118(43.9%) | 269(99.6%) | | |
| *Total* | 152(56.3%) | 118(43.7%) | 270(100%) | | |

Chi square test *Significant at p<.05

One respondent in the Intervention group was highly adherent apart from that all the respondents remained moderately adherent (n = 269, 99.6%) with 151 (56%) in the Intervention group and 118 (44%) in the Control group. The 12% difference in the number of respondents in the two groups had no significant statistical indication for change in adherence score at month six.

The validation of the multimethod adherence tool as presented in the methodology section revealed that indicating name of pill decreases the adherence score. In view of this, only scores based on the other three items was computed and included in the linear mixed model for Pill identification test effects. The outcome of pill identification test presented in Figure 14 show increases in adherence scores in the Intervention group from 99.2 (*SE* = .122, *CI* = 99, 99.5) at *Time 1* to 100 (*SE* = .144, *CI* = 99.7, 100) in *Time 2 & 3*. Similarly, the Control group obtained 99.5 (*SE* = .123, *CI* = 98.7, 99.2) adherence score at *Time 1* 99.8

(*SE* = .174, *CI* = 99.5, 100) at *Time 2* and 100 (*SE* = .151, *CI* = 99.6) 100 at *Time 3.*

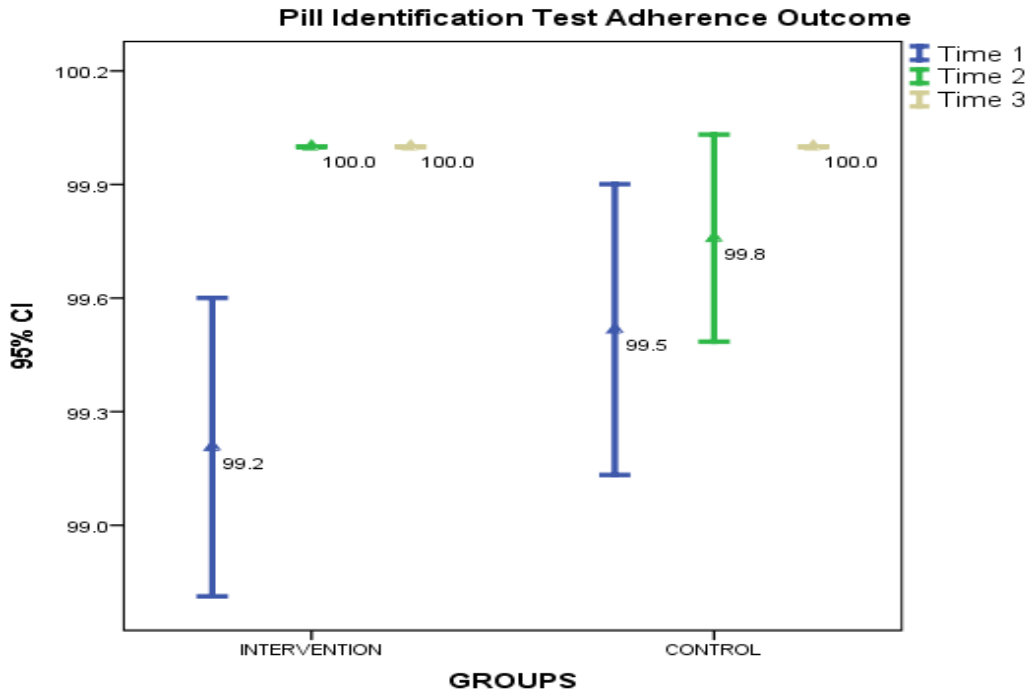



***Figure 14 Pill identification test outcome based on three items of the scale***

The observed difference in PIT scores for the Intervention (*M* = 99.7, *SE* =.077, *CI* = 99.6, 99.9) and Control (*M* = 99.6, *SE* =.087, *CI* = 99.4, 99.8) groups based on estimated marginal means was not statistically significant *F* (1, 255) = 1.77, p = .18). Time (1, 2, 3) as a fixed factor was significant with observed differences occurring between Time 1 and 2 (mean difference = -.790, *SE* = .142, *CI* -1.06, -.511 *p* < .01) Time 1 and 3 (mean difference = -.880, *SE* = .133, *CI* -1.14, -.620, *p* < .01) but not Time 2 and 3 (mean difference = -.090, *SE* = .151, *CI* -.387, .270 *p* = .55). Results further show that adherence scores increased in each respondent in the respective groups over the two time periods in exception of Time 2 &3 in the Intervention (mean difference = -.880, *SE* = .133, *CI* -1.14, -.620, *p* < .01) and Control (mean difference = -.880, *SE* = .133, *CI* -1.14, -.620, *p* < .01) groups.

### 5.9.5 Evaluating Difference in Adherence: Overall Adherence Score

The overall adherence score among respondent was compared from baseline, month three and month six to determine changes and difference in the Intervention and Control groups. Descriptive outcomes show that most of the respondents were highly adherent at baseline (n =255, 70%) third month (n = 176, 80%) and sixth month (n = 180, 67%). Comparing the group using Chi Square test revealed that no difference occurred in adherence behaviour at baseline $X^2$ = (2, n = 362) = 1.04, $p$ = .59, month three $X^2$ = (2, n = 220) = 2.46, $p$ = .12 and month six $X^2$ = (2, n = 270) = .008, $p$ = .93 among the Intervention and Control groups.

Noting the progressive decline in adherence scores for Visual analogue outcome another computation of overall adherence was done excluding the Visual analogue score then scores were compared. The outcome in Figure 15 reveals the adherence scores in each group and across timelines. Adherence scores declined at Time 3 in the Intervention and Control groups. As shown in Figure 16 excluding the VAS in overall adherence scores revealed increases in adherence outcome in the two groups and overtime compared with Figure 15 outcome. Within group comparison showed difference in Overall adherence outcome for the three timelines in the Intervention ($M$ = 99.2, $SE$ = .059, $CI$ = 99.1, 99.4) and Control ($M$ = 99, $SE$ = .066, $CI$ = 98.9, 99.2) groups. The differences observed was statistically significant $F$ (1, 2547) = 4.24, $p$ = .04. With regards to differences in Overall adherence scores overtime only *Time 2* outcome was statistically significant (mean difference = .579, SE = .172, CI = .241, .916, p < .01).

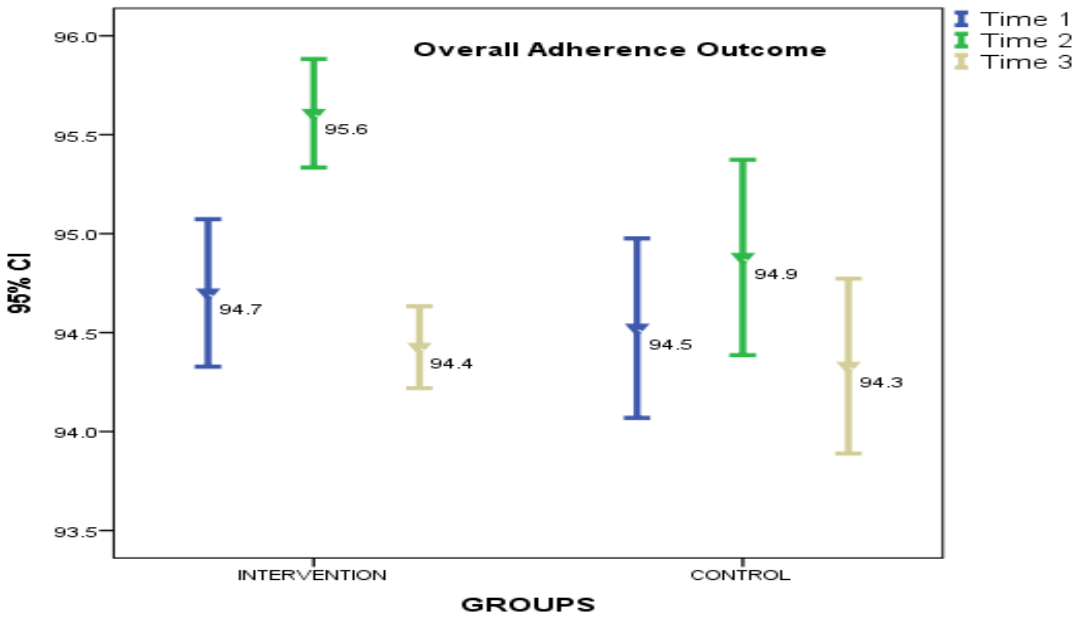



***Figure 15 Overall adherence for baseline, third and sixth months***

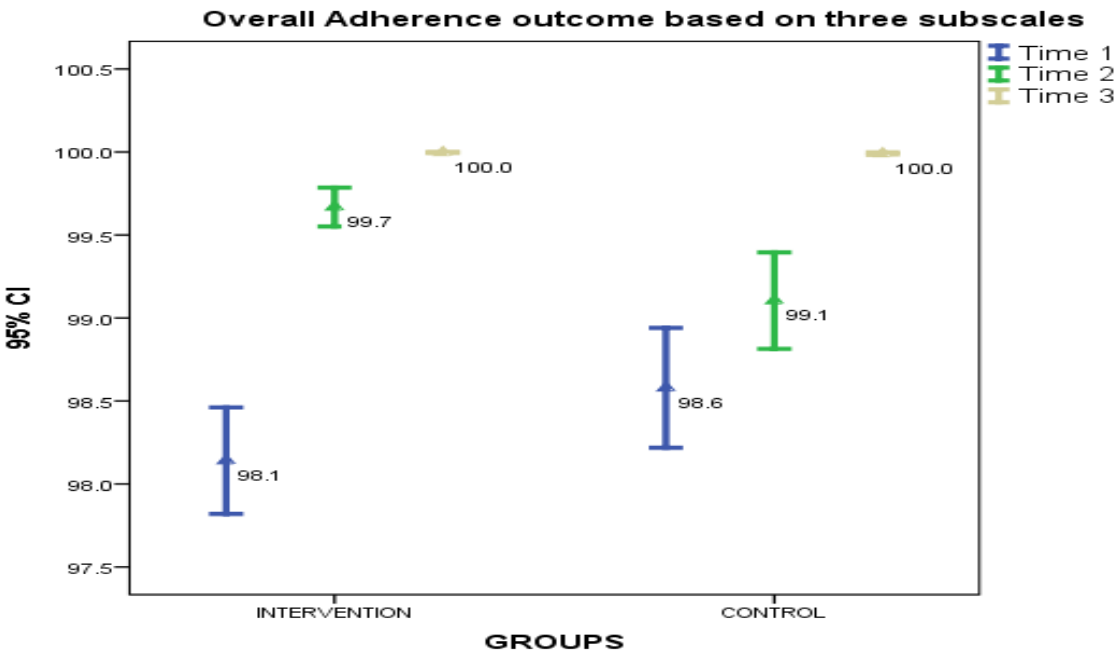



***Figure 16 Overall adherence for baseline, month three and month six without VAS.***

Within subject pairwise comparison overtime and for each group revealed that statistically significant improvement in adherence was observed in the Intervention group at *Time 1 & 2* (*mean difference* = -1.67, *SE* = .143, *CI* = -1.95, -1.39, p < .01) *Time 1 &3* (*mean difference* = -1.95, *SE* = .137, *CI* = -2.21, -1.68, *p* < .01) but *Time 2 & 3* (*mean difference* = -.277, *SE* = .149, *CI* = -.569, -.015, *p*

= .06) outcome was near significant. Control group within subject scores also improved significantly between *Time 1 &2* (mean difference = .579, SE = .172, CI = .241, .916, p < .01) *Time 2 & 3* (mean difference = .579, SE = .172, CI = .241, .916, p < .01) *and Time 1 & 3* (mean difference = .579, SE = .172, CI = .241, .916, p < .01).

## 5.10 PREDICTORS OF ADHERENCE AMONG CLIENTS WITH HIV

The factors influencing adherence behaviour in respondents were explored primarily using the adherence support measure in the multimethod adherence tool. The results which were mainly descriptive were presented in this section. In addition, to determine the predictors of adherence regression, analyses of demographic and clinical covariates were included in the model to test for significance.

### 5.10.1 Factors influencing Adherence



Respondents assessed factors influencing their adherence behaviour at baseline month three and month six. Adherence counselling was considered helpful throughout the three timelines by all the respondents. Following the introduction of mobile phone intervention (alarms, text messaging and voice calls) respondents' rating of these measures improved significantly overtime as shown in Table 31.

The results showed that alarms, SMS and calls were hardly used as adherence support measures. The use of integrated mobile phone intervention improved in the Intervention group at time two and three.

Respondents in the Intervention group (n = 130, 59%) expected to use alarms at time two rated it as helpful (n = 90, 69%) while 10 (7.7%) noted it was absent. Out of the 152 (56%) of respondents, who reported at time three 105 (69%), rated alarms as helpful.

Significant differences were observed in the Intervention and Control group in relation to using alarms as a support measure at time two $X^2$ = (2, n = 220) = 170.9, $p$< .01 and three $X^2$ = (2, n = 270) = 153.7, $p$< .01. The Intervention group had higher ratings compared to the Control group.

Although all respondents in the Intervention group were expected to receive text messages, 65 (50%) reported not receiving the messages, while 6 (7%) of those in the Control group also received text messages and rated these as helpful at time two. At time three, the majority of respondent in Intervention group (n = 110, 72%) rated text messages as not helpful. There were 14 (12%) of respondent in the Control group who rated SMS as a helpful support measure and 4 (3%) as not helpful at time three although they were not expected to receive messages.



Additionally, significant differences occurred in the use of text messaging as support measure in the two groups at time two $X^2$ = (2, n = 220) = 48.1, $p$< .01 and time three $X^2$ = (2, n = 270) = 169.2, $p$< .01. The results reflected significant difference in the use of text message support measures in both groups.

The use of the voice call support measure in the intervention was similarly evident in the outcome reported in Table 31. The majority of respondents in the Intervention group at time three (n = 146, 96%) rated voice calls as a helpful support measure. Some respondents in the Control group (n = 58, 49%) also noted that voice calls were helpful at time three.

***Table 31 : Differences in Mobile phone support measure overtime***

| Variable | Intervention | Outcome Control | Total | Test | *p*-value |
|---|---|---|---|---|---|
| Time 1 Alarm use | | | | | |
| Not helpful | 2(1.1%) | 2(1.1%) | 4(1.1%) | | |
| Absent | 179(98.9%) | 179(98.9%) | 358(98.9%) | | |
| Time 2 Alarm use | | | | | |
| Helpful | 90(69.2%) | 3(3.3%) | 93(42.3%) | $X^2$=170.9 | .01 |
| Not helpful | 30(23.1%) | 0(0%) | 30(13.6%) | | |
| Absent | 10(7.7%) | 87(96.7%) | 97(44.1%) | | |
| Time 3 Alarm use | | | | | |
| Helpful | 105(69.1%) | 9(7.9%) | 114(42.2%) | $X^2$=153 | .01 |
| Not helpful | 22(14.5%) | 0(0%) | 22(8.1%) | | |
| Absent | 25(16.4%) | 109(92.4%) | 134(49.6%) | | |
| Time 1 SMS use | | | | | |
| Helpful | 0(0%) | 1(100%) | 1(0.3%) | | |
| Absent | 181(100%) | 180(99.4%) | 361(99.7%) | | |
| Time 2 SMS use | | | | | |
| Helpful | 27(20.8%) | 6(6.7%) | 33(15%) | $X^2$=48.1 | .01 |
| Not helpful | 38(29.2%) | 0(0%) | 38(17.3%) | | |
| Absent | 65(50%) | 84(93.3%) | 149(67.7%) | | |
| Time 3 SMS use | | | | | |
| Helpful | 29(19.1%) | 14(11.9%) | 43(15.9%) | $X^2$=169 | .01 |
| Not helpful | 110(72.4%) | 4(3.4%) | 114(42.2%) | | |
| Absent | 13(8.6%) | 100(84.7%) | 113(41.9%) | | |
| Time 1 call | | | | | |
| Absent | 181(100%) | 181(100%) | 362(100%) | | |
| Time 2 call | | | | | |
| Helpful | 77(59.2%) | 21(23.3%) | 98(44.5%) | $X^2$=40.6 | .01 |
| Not helpful | 9(6.9%) | 0(0%) | 9(4.1%) | | |
| Absent | 44(33.8%) | 69(76.7%) | 113(51.4%) | | |
| Time 3 call | | | | | |
| Helpful | 146(96.1%) | 58(49.2%) | 204(75.6%) | $X^2$=101 | .01 |
| Not helpful | 6(3.9%) | 0(0%) | 6(2.2%) | | |
| Absent | 0(0%) | 60(50.8% | 60(22.2%) | | |

*Chi Square test*significant at p<.01*

Significant differences were observed at time two $X^2$ = (2, n = 220) = 40.6, $p$< .01 and time three $X^2$ = (2, n = 270) = 101.3, $p$< .01 in both groups.

### 5.10.2 Demographic Factors influencing Adherence

Results from the analysis of covariates adjusted for predictors of adherence as shown in Table 32 indicates that education and time were observed to predict adherence to treatment among respondents.

***Table 32 Demographic predictors of adherence: pill visual analogue/pill count***

| Variables | F | *p* value |
|---|---|---|
| *Visual Analogue scale* | | |
| Age | .469 | .49 |
| Sex | 1.28 | .26 |
| Education | 9.30 | .02** |
| Marital Status | .014 | .91 |
| Employment | .193 | .66 |
| Religion | 2.15 | .14 |
| Time | 30.4 | .01* |
| *Pill count score* | | |
| Age | 2.22 | .14 |
| Sex | .073 | .79 |
| Education | 10.4 | .01* |
| Marital status | .001 | .97 |
| Employed | .372 | .54 |
| Time | 54.7 | .01* |



**significant at p<.001**significant at p<.05*

Visual analogues outcome showed education *F (*400, n = 362) = .9.30, *p* = .02 and time *F (*432, n = 362) = 30.4, *p* <.01 as significant. Similarly, pill count score showed that education *F (*273, n = 362) = 10.4, *p* = .01 and time *F (*299, n = 362) = 54.7, *p* < .01 significantly influenced adherence behaviour. Respondents with higher education scored higher on adherence and similarly adherence scores decline or increase over time depending on the measure applied.

***Table 33 : Demographic factors influencing adherence (self-report, Pill identification test, Overall Adherence)***

| Parameter | Estimate | Std. Error | t | 95% CI | *p*-value |
|---|---|---|---|---|---|
| Self-report | | | | | |
| *Intercept* | 99.8 | .994 | 100 | [97.9, 101] | .01* |
| *Age* | .130 | .113 | 1.15 | [-.091, .352] | .25 |
| *Sex* | -.163 | .245 | -.666 | [-.645, .318] | .51 |
| *Education* | -.388 | .298 | -1.30 | [-.972, .196] | .19 |
| *Relationship status* | .740 | .225 | 3.29 | [.299, 1.18] | .01* |
| *Employment* | -.348 | .196 | -1.76 | [-.732, .037] | .08 |
| *Religion* | .113 | .397 | .285 | [-.665, .891] | .78 |
| *Follow-up visit* | .084 | .142 | .594 | [-.194, .362] | .55 |
| PIT | | | | | |
| *Intercept* | 98.8 | .507 | 194 | [97.8, 99.8] | .01* |
| *Age* | .034 | .057 | .602 | [-.077, .146] | .55 |
| *Education* | -.401 | .149 | -2.68 | [-.694, -.108] | .01* |
| *Relationship* | .061 | .160 | .380 | [-.254, .376] | .70 |
| *Employment* | .185 | .100 | 1.85 | [-.011, .380] | .06 |
| *Religion* | .495 | .203 | 2.44 | [.096, .893] | .02** |
| *Follow-up visit* | .219 | .073 | 3.01 | [.076, .362] | .01* |
| Overall Adherence | | | | | |
| *Intercept* | 99.5 | .387 | 257 | [98.7, 100 ] | .01* |
| *Age* | .060 | .044 | 1.36 | [-.027, .146] | .18 |
| *Sex* | -.069 | .095 | -.721 | [-.256, .118] | .47 |
| *Education* | -.217 | .116 | -1.87 | [-.444, .011] | .06 |
| *Relationship* | .317 | .087 | 3.62 | [.145, .488] | .01* |
| *employment* | -.069 | .076 | -.899 | [-.218, .081] | .37 |
| *Religion* | .253 | .154 | 1.64 | [-.050, .556] | .10 |
| *Follow-up visit* | .074 | .055 | 1.35 | [-.034, .183] | .18 |

**significant at p<.001**significant at p<.05*



Results in Table 33 were obtained as part of the fixed factors included in the linear mixed model. Relationship status was significantly associated with self-report adherence outcome $t$ (2550) = 3.39, $CI$ = .299, 1.18, $p$ < .01. Pill identification test was also associated with education $t$ (2550) = -2.68 $CI$ = -.694, -.108, $p$ < .01, religion $t$ (2.39) = 2.44 $CI$ = .096, .893, $p$ = .02 and the schedule of follow up visit $t$ (2.39) = $CI$ = .076, .362, $p$ < .01. Overall adherence score was associated with relationship status $t$ (2547) = 3.62, $CI$ = .145, .488, $p$ < .01 while

education *t* (2547) = -1.87, *CI* = -.444, .011, *p* = .06 was nearly significant. Although results suggest a relationship between scores and some demographic factors, the magnitude of effect of association was not estimated, more so, the outcome may be due to error.

### 5.10.3 Clinical Variables influencing Adherence

CD4 count and Body Mass Index (BMI) values were secondary outcome variables used to assess adherence outcome. Linear mixed model regression analyses adjusted for covariates were used to determine changes in CD4 and BMI outcome overtime. The assumption was that as adherence improves, CD4 and BMI levels among respondents would increase.

The results as shown in Table 34 revealed that the observed mean CD4 count at time one (*M* = 497.4, *SD* = 22.2), two (*M* = 499.9, *SD* = 95.6), and three (*M* = 510.8, *SD* = 25.9) increased marginally in the Control group.



***Table 34 : Differences in Clinical Variables across Timelines***

| | Intervention | | Control | | | |
|---|---|---|---|---|---|---|
| Variables | *M(SD)* | 95% CI | *M(SD)* | 95% CI | *F* test | *p* value |
| CD4 | | | | | | |
| Time 1 | 542.7(22.2) | [498, 586] | 497(22.2) | [453, 541] | .152 | .15 |
| Time 2 | 566.4(90.1) | [378.5,754.3] | 499.9(95.6) | [300, 699] | .618 | .62 |
| Time 3 | 557.7(23.8) | [510.8, 604.5] | 510.8(25.9) | [459, 562] | .186 | .18 |
| Intervention | | | | | .221 | .80 |
| Control | | | | | .141 | .87 |
| BMI | | | | | | |
| Time 1 | 24.3(.318) | [23.7, 24.9] | 24.7(.320) | [24.1, 25.4] | .724 | .39 |
| Time 2 | 24.5(.350) | [23.9, 25.2] | 24.5(.388) | [23.8, 25.3] | .000 | 1.0 |
| Time 3 | 23.7(.390) | [22.9, 24.5] | 24.4(.429) | [23.6, 25.3] | 1.6 | .21 |
| Intervention | | | | | 3.57 | .03* |
| Control | | | | | .258 | .77 |

*Mixed Model *significant at p<.05*

Mean CD4 count increased at time two (*M* = 566.4, *SD* = 90.1) in the Intervention group and then decreased slightly at time three (*M* = 557.7, *SD* = 23.8) but was still marginally higher than the baseline mean CD4 count (*M* = 542.6, *SD* = 22.2). Nevertheless, no significant differences were present in the Intervention *F (*36, n = 362) = .221, *p* = .80 and Control *F (*35, n = 362) = .141, *p* = .87 groups. CD4 results overtime did not change significantly to predict improvement in adherence to treatment among respondents.

The results displayed in Table 34 reveal changes in mean BMI in the Intervention and Control groups. The Intervention group's mean BMI decreased from 24.5 (*SD* = .350) in time two to 23.7 (*SD* = .390) at time three. Results further showed that changes in the Intervention group were significant *F (*426, n = 362) = 3.57, *p* = .03. Mean BMI decreased (<.5 units) in the Control group from time one to three but no significance was observed *F (*438, n = 362) = .258, *p* = .77. The result does not convincingly suggest predictive characteristics of BMI in adherence to treatment in this study.



## 5.11 SUMMARY OF RESULTS

The assignment of respondents to study groups met the criteria of ensuring a homogenous sample as per requirements for a randomised controlled trial. Attrition rates were high at the second follow-up, but improved at the third follow-up.

The results established that respondents adhere to their treatment at baseline, suboptimal adherence was recorded. Self-report, Visual analogue, Pill identification test, Pill count and Overall adherence outcomes at baseline all

demonstrated respondents were moderately or highly adherent. Visual analogue assessment outcomes were rather low.

Adherence counselling was the most predominant measure rated as a helpful adherence support measure. Respondents further indicated that spousal support was helpful in promoting adherence. A few of the respondents mentioned factors such as sleep, work schedules and fear of being observed by other people when taking their medication influenced their medication schedules.

Respondents were more conversant with using voice calls and hardly used reminders on their mobile phone at baseline. The usage of a phone was associated with education and being employed. Additionally, the baseline assessment revealed that the majority of respondents did not use alarms, text messaging and voice call to support adherence. Respondents in the Intervention group, after training, used alarms, received weekly text messages and monthly voice calls.



The evaluation of the outcome of the mobile phone intervention established that adherence levels measured with self-report, pill count and pill identification showed adherence scores increased overtime and was statistically significant in both groups. Notably, adherence scores decreased with Visual analogue measures however, excluding Visual analogue scores from Overall adherence estimation revealed consistent increases in Overall adherence scores in both groups. Respondents in the Intervention group had adherence outcomes peak at the first follow-up therefore no significant changes were observed between *Time 2 & 3* in adherence outcomes. Integration of a mobile phone as an adherence

support measure was evaluated as helpful but did not statistically predict adherence outcomes.

Exploring the factors influencing adherence levels it was observed that education predicted adherence for most of the measurements that were modelled. Time also significantly predicted adherence in the Intervention and Control groups. In exception of Visual analogue outcomes, adherence improved but was not directly an outcome of mobile phone use alone as the increases were observed in the both the Intervention and Control groups. The majority of respondents in the Intervention group did not find the text messages helpful.

Secondary outcome such as CD4 count and BMI did not conclusively indicate improvement in adherence. Although BMI values changed over time there was a decline instead of an increase. The expected statistical differences were not observed in this study, but on face value adherence improved, with all respondent recording high adherence at time three.



## 5.12 CHAPTER SUMMARY

In this chapter the results of the first phase of the study which consisted of a randomised Control trial is reported. The report focused on answering the following research questions: What is the level of treatment adherence in clients with HIV infection at baseline assessment? What is the level of adherence at third and sixth month? What are the differences in adherence in Intervention and Control groups over the three timelines? What demographic characteristics predict adherence to ART? Which clinical variables predict adherence to ART? What adherence support measures predict adherence? The next chapter present the outcome of the qualitative study which was the second phase of the study.

## CHAPTER 6: PHASE TWO QUALITATIVE EVALUATION RESULTS

To address objective four which was to evaluate experiences of HIV infected clients and perspective of significant others in integrating mobile phone intervention in ART adherence support; a qualitative evaluation of the intervention was conducted. In this chapter, the findings of the qualitative evaluation are presented. The explanatory integrated mixed method which was used required that the qualitative data are obtained subsequent to the quantitative data collection to further inform or confirm the quantitative findings. The questions explored were:

i) What experiences are associated with HIV diagnosis and treatment?

ii) What are the experiences of clients in relation to treatment adherence?

iii) What are the experiences of clients in using integrated mobile phone intervention?

iv) What are the perspectives of clients and professionals in integrating mobile phone intervention?

v) What are the existing policies and guidelines on integrating mobile technology in adherence?



The researcher assumed that the experiences of using the phone are not exclusive of the total illness experience and therefore captured participants' experience with diagnosis and treatment to provide context.

Three approaches were used to obtain data from three different sources namely: interviews with patient participants and professionals, focus group discussions with clients and key document review.

As the researcher was interested in understanding the phenomenon from different perspectives, the data analysis was integrative and is presented as such and not from specific data sources.

This chapter has three sections. Section one captures descriptions of participants' profile and an outline of documents reviewed. Section two presents experiences of participants with diagnosis, treatment and adherence.

**Table 35** *Themes and categories:* ***experiences with diagnosis, treatment and adherence in HIV***

| THEME | CATEGORIES | SUBCATEGORIES |
|---|---|---|
| **Theme 1: Illness history** | 1.1 Diagnosing | *a. Early symptoms*<br>*b. Discovery of status*<br>*c. Reaction to diagnosis*<br>*d. Coping with illness* |
| | 1.2 Treatment | *a. Counselling*<br>*b. Treatment regimen*<br>*c. Effects of treatment* |
| **Theme 2: Adherence behaviour** | 2.1 Adherence | *a. Medication regime*<br>*b. Benefits of adherence*<br>*c. Role of food in adherence*<br>*d. Fear of death*<br>*e. Carry Pills*<br>*f. Transparency* |
| | 2.4.Non-adherence | *a. Forgetfulness*<br>*b. Religious fanaticism*<br>*c. Sleeping*<br>*d. Secrecy*<br>*e. Waiting time at clinic* |
| **Theme 3: Adherence Monitoring** | 3.1 Self-monitoring | *a. Self-consciousness*<br>*b. Use of alarm*<br>*c. Phone as clock* |
| | 3.2 Adherence monitors | *a. Spouse as monitors*<br>*b. Family monitors*<br>*c. Peer monitors*<br>*d. Significant others as monitors* |
| | 3.3 Institutional monitoring | *a. Adherence Counselling*<br>*b. Pill count*<br>*c. Adherence report* |

The third section focuses on the experiences and perspectives of integrating mobile phone intervention in adherence strategies. Additionally, existing information relating to policies and guidelines on adherence to ART were reported. Table 35 presents the summary of themes and categories on experiences with diagnosis, treatment and adherence in HIV.

Table 36 also summarises the themes that emerged from evaluation of experiences and perspective of mobile phone use in adherence strategies.

***Table 36: Evaluation of experiences and perspective of mobile phone use in adherence strategies***

| Theme | Categories | Subcategories |
|---|---|---|
| Theme 4**: Perspectives on Integrated mobile phone intervention** | 4.1.Alarm use | *a. Alarm is personal*<br>*b. Alarm is helpful* |
| | 4.2.Text message: acceptance and scepticism | *a. SMS is good*<br>*b. Messages can expose your status*<br>*c. Consistency in receiving/ reading messages* |
| | 4.3.Voice call | *a. Calls make you feel others care*<br>*b. Voice call for clinic appointment*<br>*c. Automated voice calls preferred* |
| Theme 5**: Readiness for M-health integration in care** | 5.1. Patient readiness | *a. Willingness*<br>*b. Perceived stigma as barrier*<br>*c. Technology & literacy* |
| | 5.2 .Institutional readiness | *a. Willingness and acceptance*<br>*b. Competing demands*<br>*c. Policy review* |

A qualitative thematic analysis approach was used in generating the five themes that emerged from the data with twelve (12) categories and forty-two (42) sub-categories as shown in Table 35 and 36. Atlas Ti7 qualitative data analysis software was used after an initial manual coding of transcripts. The detail analysis of the themes, categories and subcategories are described after presenting the profile of participants and documents used.

The researcher used peer facilitators who were known to the participants during the focus groups and thus created an atmosphere that was relaxing, and participants willingly expressed their ideas without feeling obliged to share their experience. The focus group sessions were intermittently laced with humour, making the discussion informal but informative. Some of the codes, though repetitive, had different meanings under different considerations. Unlike most qualitative data presentations, due to the purpose of the qualitative data, the results are presented without any discussion, and are integrated with the quantitative findings in Chapter Seven.



## 6.1 PARTICIPANTS AND DOCUMENTS REVIEWED

The profile of participants of the qualitative phase included clients, professionals, and the list of documents reviewed.

### 6.1.1 Profile of participants

Table 37 displays the profile of the twenty-eight (28) participants of this phase. *Interviews:* There were twenty-six (26) patient participants and two health professionals. Six individual patient interview participants [P1-P6] were between

25 and 45 years (mean age of 37 years) and consisted of three males and three females. Participants indicated living with HIV for an average of three years and had been on ART for between two and seven years. The two male professionals [P7, P8] (age m=53.3 years), were interviewed to further provide professional direction to the discourse with the patient participants.

*Focus groups*: The first focus group discussion was conducted with six participants [F1, P1-P6] with two males and four females who were all married. Eight (8) participants [F2, P1-P8] participated in the second focus group discussion. More than half of participants in this group had no education.

***Table 37: Profile of Participants***

| | **Individual interviews** *[P1-P6]* | **Focus group1** *[F1,P1-6]* | **Focus group 2** *F2,P1-8]* | **Focus group 3** *[F1,P1-6]* | **Experts** *[P7,P8]* | **Total** |
|---|---|---|---|---|---|---|
| **Age** *Mean (SD)* | 37(7.52) | 41(1.86) | 38(6.85) | 47(5.81) | 53(3.54) | 41(7.28) |
| **Gender** | | | | | | |
| *Male* | 3 | 2 | 6 | 5 | 2 | 14 |
| *Female* | 3 | 4 | 2 | 1 | 0 | 14 |
| **Education** | | | | | | |
| *Tertiary* | 1 | 1 | 0 | 0 | 2 | 4 |
| *Below tertiary* | 4 | 0 | 2 | 2 | 0 | 8 |
| *No education* | 1 | 5 | 6 | 4 | 0 | 16 |
| **Relationship** | | | | | | |
| *Married* | 5 | 6 | 4 | 4 | 2 | 21 |
| *Not married* | 1 | 0 | 4 | 2 | 0 | 7 |
| **Children** | | | | | | |
| *None* | 2 | 0 | 5 | 0 | 0 | 7 |
| *2 or less* | 4 | 5 | 2 | 3 | 2 | |
| *3 or more* | 0 | 1 | 1 | 3 | 0 | 5 |
| **Duration of illness** | | | | | | |
| *Mean(SD)* | 3(1.72) | 4(2.14) | 2(2.27) | 5(2.58) | - | 6(2.58) |
| **Treatment duration** | | | | | | |
| *Mean (SD)* | 2(1.72) | 3(1.86) | 2(1.69) | 4(1.72) | - | 5(1.85) |
| **Total participants** | 6 | 6 | 8 | 6 | 2 | 28 |

The third focus group session was dominated by five males with only one female [F3, P1-P6]. On average, participants in the group had five years' experience in living with HIV and four years of taking ART. The interaction brought to the fore in-depth experiences from the time of diagnosis to the period of participating in the mobile phone intervention programme. An in-depth description of each participant's is profile is seen in Appendix J.

### 6.1.2 Documents reviewed

Additional information was extracted from ART guidelines. The 2014 guideline for ART treatment was received from the Director of the National AIDS Control Programme (NACP) and reviewed along with the WHO consolidated guidelines on the use of antiretroviral drugs for treatment and prevention of HIV infection for 2013/2015.



***Table 38: Documents reviewed***

| Documents | Code | Year | Author | Chapter | Pages |
|---|---|---|---|---|---|
| Consolidated guideline on the use of antiretroviral drugs for treatment and prevention of HIV infection | [D1] | 2015 | WHO | 2 | 11-12 |
| Guidelines for antiretroviral therapy in Ghana | [D2] | 2014 | NACP | 6 | 61-64 |
| Consolidated guideline on the use of antiretroviral drugs for treatment and prevention of HIV infection | [D3] | 2013 | WHO | 9 | 175-179 |

## 6.2 CENTRAL STORYLINE: EXPERIENCES OF USING MOBILE PHONE USE IN IMPROVING ADHERENCE TO ART

The experience of living as an HIV infected client has been widely explored and adherence to treatment is a major concern for addressing the burden of HIV which is now considered a chronic illness. The illness history of HIV infected clients is characterised by their experience with diagnosis and treatment. Client experiences include reports of early symptoms, status discovery, reaction to the diagnosis and coping mechanisms that may be positive or negative. In the midst of dealing with diagnosis, decision making about treatment ensues.

The main treatment for HIV is the use of antiretroviral drugs. Apart from ensuring the physiologic characteristics assessed clinically, the client must demonstrate readiness to adhere to treatment, have an adherence monitor and go through a minimum of three counselling sessions. Once treatment is initiated, the client is required to adjust the schedule to suit daily activities, deal with adverse effects and demonstrate an adherence behaviour that facilitates maximising health outcomes. The simplicity of the medication regimen and dosing enhances adherence. Adherence has also facilitated the benefits of treatment, the fear of dying and an absence of stigma. Ready access to food and keeping some of your medication with you at all times have also been beneficial measures for adherence.

However, non-adherence still occurs in spite of the clients' willingness to take medication; forgetfulness, religious beliefs, sleeping through doses and even time spent at the clinic affect adherence behaviour. Adherence monitoring strategies

such as self-monitoring, use of adherence monitors and monitoring of health personnel are all used.

Additional measures of monitoring adherence through the use of technology based interventions such as mobile phones have been found to facilitate adherence. The mobile phone alarm function, text messaging function and voice calls are interactive ways of reaching clients. Anecdotal information indicates that in Ghana there is a mobile phone in every home. The increased access to mobile phones provides the opportunity for interactive communication with HIV positive clients to support treatment adherence. A mobile phone in the pocket of an HIV infected client is a means, although not an end, to addressing issues of treatment adherence.

In view of this, 181 clients living with HIV were exposed to the use of the mobile phone alarm, weekly text messages and monthly voice calls over a period of six months. The clients were involved in setting adherence goals, identifying adherence needs, planning and implementing adherence interventions and evaluating their outcomes. Participants evaluated the outcomes of the interventions during interviews and focus group discussions. Additional information from professionals and a policy perspective added to the understanding of the experience of using mobile phones in supporting adherence.

Three of the main themes: illness history; adherence behaviour, adherence monitoring, were contextualised within the total illness experience. The other two themes: perspective on integrating mobile phone intervention and readiness for

health integration in care emerged from the use of mobile phones to promote adherence among participants over a six month period.

## 6.3 EXPERIENCES WITH DIAGNOSIS, TREATMENT AND ADHERENCE IN HIV

Table 6.1 summarised the themes that emerged from the experiences within the illness context. Two categories emerged under illness history namely, diagnosis and treatment with seven subcategories. Adherence behaviour also had two categories: adherence and non-adherence, with eleven subcategories which are presented in subsequent sections in details.

The third theme was adherence monitoring with three categories: self-monitoring, adherence monitors and institutional monitoring and ten subcategories. The narratives within the categories captured the total history of the illness.

## 6.4 THEME1. ILLNESS HISTORY



Participants in their narratives recounted their illness history with mixed feelings about the process of having their HIV status diagnosed. They recalled the symptoms that preceded diagnoses and events characterising their status discovery and their reactions. Participants also mentioned the treatment strategy received from pre- and post- test counselling periods until the commencement of medication, the side effects of the treatment and how they coped with the treatment and the illness following diagnosis.

### 6.4.1 Category 1: Diagnosing

Participants narrated how they discovered their HIV status, noting the symptoms that were present, the processes they went through and their reactions. The

general process of diagnosing HIV includes conducting blood test with a standardised test kit. The reagent reacts with the blood to determine a positive or negative result. All participants went through this process, some with their partners. Some of the accounts of the processes of being diagnosed were:

> *I got sick and I went to the hospital for a check-up and it was there that I was told I had HIV (P3)*
>
> *I was also coughing and falling sick very often so the doctor asked that I come here to do this test (F3)*
>
> *I was referred to another hospital and several tests were done (P4).*
>
> *He has tested negative more than four times and on several occasions after I discovered that I have the disease (P2)*
>
> *Series of tests were done including a test for HIV and TB. I was informed I tested positive (P6)*

The narratives around the process of diagnosing were made up of three or sub-categories, namely *early symptoms*, *discovery of status* and *reactions to diagnosis*. The classifications provided a context to the experiences of the participants. The mood of the retrospective narrative as reported in the field diary was sometimes very emotional but in the group sessions some participants used humour to lighten the deep emotions that reflected in their eyes.

#### 6.4.1.1 *Sub-category 1: Early Symptoms*

HIV is one of the infections in which symptoms are not manifested unless the immune system is completely broken down and the body's natural defences are compromised. This results in frequent experience of minor ailments which sometimes do not respond to treatment. Participants' accounts reflected this phenomenon except in two instances where mandatory and voluntary testing

rather than symptoms informed the confirmation of HIV. The participants shared their experiences on their early symptoms in the following narratives:

> *In my case I was coughing and having diarrhoea at the initial stages, it was during this period that they did a number of tests and later confirmed I had the illness. (F3, P2)*
>
> *Initially I was very sick I could not even get out of bed. (F3, P1)*
>
> *I was also coughing and falling sick very often. (F3, P3)*
>
> *I usually get sick most often, I cough sometimes and I noticed some of my clothes became so loose so I knew I had lost weight. Sometimes I vomit after eating and felt dizzy. (P3)*
>
> *I lost appetite and did not eat for a long time. Even when I take tea or soft drinks I will vomit it. Later I started coughing, I could not eat anything not even liquids or porridge. ... I had lost so much weight so my siblings sent me to the hospital and a lot of tests were done but I was still not better, it was later on that they told me it was TB and confirmed my HIV status. (P6)*

The participants reported mainly physical symptoms such as coughing, loss of appetite, vomiting, diarrhoea and loss of weight. Their narratives and field accounts further show that they often reported to the hospital when symptoms were at their worst and stopped them from carrying out routine activities. These were comments from two participants:



> *I was sick for a while and at a point I started seeing blood in my urine so I got scared and went to the hospital. (F3, P5)*
>
> *I was getting sick so frequently with minor illness of which I usually go to the hospital. One day I got seriously sick and I was rushed to the hospital by my brother. (P4)*

This reactive health -seeking behaviour contributed to the manner in which their status was discovered.

#### 6.4.1.2 *Sub-category 2: Discovery of status*

The guideline for the prevention and management of HIV encourages voluntary testing, counselling and prenatal screening. The rationale is to promote early

detection and improve quality of life. Nevertheless, status discovery remains a mystery. The participants discovered their status under three different circumstances, namely: accidental discovery, mandatory procedure and voluntary testing. Participants generally reported discovering their status accidentally while seeking care for frequent symptoms of ill-health. Some of the participants' accounts read:

> *A few years ago I felt sick and was taken to the hospital. Series of tests were done including a test for HIV and TB… they told me it was TB and confirmed my HIV status later. (P6)*
>
> *Three years ago I got sick and I went to the hospital for check-up and it was there that I was told I had HIV. So I was referred to the hospital. (P3)*
>
> *I did not know I had HIV.... One day I got seriously sick and I was rushed to the hospital by my brother who is a teacher. I was referred to another hospital and several tests were done. We went to the doctor... and I narrated everything to him because he had already attended to me and requested the test. I asked about my results…He told me that they have seen the HIV virus in my blood. (P4)*
>
> *I was also coughing and falling sick very often...It was after going through counselling then the doctor in the other small room [referring to counsellor] informed me that they had detected HIV in my blood. (F3, P3)*
>
> *I was sick for a while and at a point I started seeing blood in my urine so I got scared and went to the hospital. I don't know but after narrating everything the doctor asked me to come here and gave me some lab forms. (F3, P5)*

One participant went through voluntary counselling and testing and another was tested within the policy on Prevention of Mother-Child Transmission (PMTCT):

> *I was attached to an international institution during my internship and there was a game and a health screening programme. There was a voluntary screening and testing session. I participated and it was then that I found out I had the virus in my system. (P1)*

> *I was pregnant with my first born child and on my first pre-natal clinical appointment I was informed that it was mandatory for all pregnant women to take the HIV test. I did not know anything of that nature but I complied anyway. (P2)*

Narrating her experience P2 recalled the circumstances around her diagnosis and her frustration at the antenatal clinic prior to her referral. She was relaxed although the tone of her voice went up reflecting the discomfort she felt getting to know her status under such circumstances. She added:

> *During the test there was a queue where some women were told to stand on the left side to wait behind. They were about ten in number and I happened to be one of them. All others were attended to and we were then given referral letters to this hospital. They did not tell us anything, but only asked us to go to the clinic with the letter. I went with the letter and my status was confirmed. (P2)*

Her story was not part of a repetitive trend but it was worth noting how the discovery of a person's HIV status, under unexpected circumstances and shrouded in secrecy, could influence reactions following status disclosure.

#### 6.4.1.3 *Sub-category 3: Reaction to diagnosis*



The nature of HIV and the evidence suggesting that sexual transmission is the most common method of infection makes reaction to the diagnosis reflect explicit and implicit grieving processes. Participants reported different types of reactions that were mainly psychological but with some physical and social issues as well. P2 who reported to an antenatal clinic and was screened for HIV continued her narrative about how she reacted to her referral, without any information or rationale, to another clinic while seeking antenatal services. Then, when subsequent tests revealed her husband was HIV negative, she lamented:

> *...I managed to confront one of the nurses privately and she gave me the details of everything. Indeed, it was a very*

*difficult moment for me to take the news. It was very incredible and I was very confused (P2)*

Another respondent sharing his experience during a focus group session did not want to recall the misery he went through upon discovering he was HIV positive. He said:

*He [the doctor] asked if I knew about HIV so I told him what I knew. Then I was quiet for a while and sweating so he asked if I had any questions. What happened, let us leave that one for now (F3, P3)*

Similarly, other participants indicated their ordeal when their status was disclosed. These are some of the accounts:

*For me I did not take it easy at all because I was thinking how I contracted this illness. People assume that it is men who like chasing women who get this illness and I don't consider myself like that so I was angry and confused but just like the first person said after they talk to you for some time it helps you to get to accept everything and see it as any normal illness. (F3, P2)*

*I was filled with pain; it was difficult and I started remembering the guys I had gone out with trying to figure out which were the naughty and the cool ones. At a point I realised it was not relevant, because who was I going to ask? I thought about a whole lot of nonsense so I had to stop and reassure myself. (P1)*

*It is about ten years now but it is a day that I really wept bitterly so I don't forget. At first I thought I was dreaming but no, it is not. (F3, P5)*

*It affected me emotionally especially the first time they told me. (F3, P5)*

The reactions included confusion, emotional pain, anger, and acceptance. Some reported weeping; one participant mentioned he was sweating. Interestingly, sounding indifferent P6 said he was not scared because he saw HIV as any other illness for which medication is required. He said:

*As for me, when I tested positive I was not really scared, I was not disturbed, because I compared myself with those who had*

*hypertension and diabetes. They take medicine so what is wrong if I am also ill and I am also going to take medication. I am not going to be scared. (P6).*

Recalling their reactions, it was obvious that, despite living with HIV for a minimum of two years and a maximum of eleven years, their feelings were still as fresh as though they were narrating an event that had occurred a few days earlier. Despite the pain, fear and confusion surrounding the discovery of their status, participants found a way of coping with the illness.

#### 6.4.1.4 *Sub-category: Coping strategies*

Discovering being HIV positive was associated with mixed feelings. However, participants reported how they eventually came to accept their status. Some mentioned that they wished it was just a dream state but had to deal with the reality. There were both positive and negative coping strategies adopted by participants. Acceptance of their status and willingness to move on with their lives, irrespective of the circumstances, was helpful in coping with the diagnosis and the treatment. Participants demonstrated instrumental and religious coping strategies as well as self-efficacy in coping with the illness. A participant in reflecting on her HIV status said:



*I thought about a whole lot of nonsense so I had to stop and reassure myself… I think I have accepted the situation and moved on with my life. (P1).*

F3- P1 another participant noted during the discussion that it was important for them to reassure themselves and advocated a religious coping mechanism and self- efficacy as a way of managing the emotional aspect of the illness that they recognised was affecting their physical health. He said:

*You should not be so worried because that could even affect you and your health could get worse. You should reassure*

*yourself that God has taken control of everything and move on. (F3, P1).*

Reiterating the position of F3-P1, F3-P2 recommended instrumental coping also involves emphasising the value of exercise and food. He accepts that he does not have a choice and advises his colleagues in the group to focus their energy on avoiding stress, eating well and exercising to maintain good health, based on his experience of living with HIV and taking ART for three years.

*Whether, you like it or not the illness has come already and there is nothing you can do about it. When you are taking the medicine it is important to eat well, exercise regularly, be free and avoid all forms of stress and tiredness. (F3, P2.)*

Another participant sharing their view on instrumental coping mechanisms had this to say:

*I also take blood tonic which gives me a good appetite for food at all times and makes you look very healthy. (P2).*

*You should take your medicine, eat good food, drink a lot of water and you are ok. (P1).*

F3-P5 advocating for self- efficacy noted:



*You have to be courageous, and face the situation boldly, then commit to take your medication, then everything would be fine. (F3, P5).*

Other participants also had this to say about how they cope with the illness;

*The way they counsel us here, if you adhere you can see that you can live like any normal person. As for me, if I am walking in town nobody can tell I am sick even if they tell you I have such a disease you will not believe it. (P4)*

*Indeed, on my first visit and upon seeing other people I was overwhelmed. I met very rich and popular persons in our social classes which no one would expect them to be here. I took a good look at them and that alone gave me a high level of solace because they were not my class. Together with this experience and that of the counselling, I have been able to cope with the illness. (P2).*

Participant stories revealed that support from spouses, family and significant others as well as the counselling sessions contributed to their adjustment process. These aspects emerged as subcategories of other themes which will be presented later. Additionally, participants also recognised that taking their treatment was the key to living and looking healthy with HIV/AIDS.

### 6.4.2 Category 2: Treatment

ART remains the major landmark in response to HIV. It has contributed to minimising the effects of HIV on the quality of life of infected persons. There are standard HIV treatment guidelines which are followed in managing the patient's status. The individual is expected to go through counselling, laboratory investigations to determine treatment eligibility and other supportive measures relevant to their care. Participants gave accounts of their experiences following their HIV positive diagnosis. Three sub-categories emerged from their stories namely: *counselling, treatment regimen, and the effects of treatment*.



#### 6.4.2.1 *Sub-category 4: Counselling*

Counselling involved preparing clients to go through the HIV test, disclosing the test results and providing information to clients concerning their treatment. Counselling further serves as a supportive measure that promotes the acceptance of one's status and emphasises the need to follow the specified recommended medication regimen. Participants in their stories appreciated and acknowledged the usefulness of counselling in helping them to come to terms with their diagnosis. P2, a 33-year-old trader, whose status was confirmed during antenatal care, shared how the counselling had empowered her:

*The counselling taught me that I do not breastfeed my baby. It was either I breastfeed while I am on the medication till for a period of 5 months and 2 weeks and again at delivery they also gave medication that the baby should be given for a period of 2 weeks at morning and evening. The baby's medication went on concurrently with my medication till 5 months and 2 weeks. Just before the 5 months, or about 4 months I began feeding my baby with food such as SMA or lactogen in bits so that he got used to the food when the breastfeeding stops. I supplemented that with foods like porridge and rice pudding. (P2).*

Other participant also shared how at the counselling sessions he was educated on measures for reducing re-infection with a new strain of virus and how to stay healthy. They said:

*They also told us to protect ourselves before by using condom when having any sexual intercourse; if you have a wife and wants to sleep with her you should protect yourself, we should not go to town to do things haphazardly. So knowing you have such disease then you go to town because you don't want it alone and you spread it to others, as for me I do not have such thoughts no one knows I have such a disease. (P4)*

*At the clinic they really support us through counselling. They educate you about the treatment to make sure you don't get more virus and unnecessary infection. (P1)*

*After narrating everything the doctor asked me to come here and he gave me some lab forms. Before they took my blood sample I was sent to one of the small rooms where they asked me a lot of questions and told me so many things about HIV. (F3, P5).*

*I remember when I was referred to this clinic I went through counselling where they educated us on the medication. (P5).*

The counselling experience revealed there was pre-test and post-test counselling sessions and participants noted they were often encouraged to attend these sessions with their spouses and encouraged to also get them tested. The counselling sessions include education on lifestyle and the treatment regime for ART.

#### 6.4.2.2 *Sub-category 5: Treatment Regimen*

Clients diagnosed with HIV are given antiretroviral drugs subject to meeting eligibility criteria with the state of organs such as the liver and kidneys as a major consideration. The medications also include adjuvant treatment such as vitamins and the management of opportunistic infections. Participants recalled their stories relating to the initiation of treatment with interest. Some were not started on any ART because at the time, the initiation of treatment was limited to individuals with a low CD4 count. P1 was not given ART immediately her diagnosis was confirmed. She said:

> *I was not on drugs because at that time my CD4 counts were very high. Interestingly, after I got to know my status I don't know how the whole thing started but I realised that I was losing weight. I was coughing and had frequent episodes of malaria. (P1*)

Similarly, P5 only started treatment two years after being diagnosed HIV positive after he was referred from another clinic to the current hospital. He mentioned that:



> *The illness started some years ago but I would say it is about 4 years because that is when I started coming to the clinic but was put on treatment about two years ago. At that time I was given about three different medications and asked to take it morning and evening after eating well (P5).*

Other participants, however, noted they were put on treatment subject to education about the medication:

> *The doctor told me that about the sickness in my blood he will teach me what I can do to make the disease go or even if does not go. I then asked him what the sickness in my blood is, he told me that he will write a medication for me but it is not common, but I can get it at other hospitals.*
>
> *I was referred to the hospital and there I was put on medication… I also take blood tonic in addition to my*

*medication, in the afternoon at 12 o clock I take my blood tonic; I do not combine the two medications because it does not work effectively. (P3).*

P2 noted that during her first pregnancy she had a treatment that was different from what she was given in her subsequent pregnancy. Her comment was:

*...my first child, I was told to stop taking the drugs when my pregnancy was 7 months old but in the case of my second born child it was different. During that period there was a drug issued to me which covered while I was pregnant and another drug was given to me to take just before I entered the labour ward. (P2)*

The treatment guideline for HIV is constantly reviewed in line with scientific evidence with the aim of improving the outcomes and the quality of life of individuals affected with HIV/AIDS.

*Every 3 months. Previously it used to be more than 3 months, but due to the recent shortage in the drugs it has been made 3 months and even 2 months on some occasions. (P2).*

*The first time they gave me the drugs I was asked to return every week for one month. Then later they made me reported every month but now I come for treatment every 3 to 4 months and if I am travelling and inform the doctor they give me enough medication. (P5)*



The narratives showed that the regimen were varied but within standard guidelines of treatment. Combination therapy is recommended with three levels of combination therapies available. The facilitator who was a peer volunteer in one of the focus group discussion sessions reminded her peers about the available regimens and encouraged them to adhere to their treatment, no matter the undesirable side effects of the treatment, in order to minimise adherence related drug resistance.

#### 6.4.2.3 *Sub-category 6: Effects of treatment*

Participants also reported events that characterised the initiation of their treatment. Generally, there was improvement in their health after commencing ART; but some participants battled with the side-effects of the treatment initially. Some of them mentioned how they felt:

> *When I take it I feel healthy and strong. I do not have any complaints at all… I am now stronger and healthier than when I was not taking any medication. (P3)*
>
> *I don't have any problem but there is one of them that is yellow, when I take it I feel a little dull but later I feel fine.*

Although the ART was beneficial, with participants confirming their health improved, some participants reported undesired side effects such as nausea, vomiting, weakness and nightmares. The narratives include:

> *I become pale; sometimes I feel nausea and those kinds of things. As you continue, it becomes better. I for instance I grow lean, vomiting, nausea, dizziness, malaria and sometimes for about two to three months then you feel normal again. (P1)*
>
> *I also had problems when I was taking the first drug but after I reported and they changed it, I notice all the problems have stopped (*F3, P4)
>
> *He is right the yellow medicine makes you a little weak after taking it but apart from that there is no other problem. My medicine has not been changed like what P3 and two talked about I did not experience it. (F3, P5).*
>
> *The medication gives me bad dreams. Serious, you have bad dreams that you will not understand. So that if you don't take time you would think it's the witches and wizards that are worrying you, or your house people. Then you will take it to church members and other people, but these are outcomes of the drug. (F2, P8)*
>
> *I have heard some of those I meet at the clinic talk about how the medicine give them bad dreams but it did not happen to me. Just that initially when I started I felt sick and reported I was given some medications and it stopped. (F3, P1).*
>
> *The medicine is very strong, so if you take it without eating you*

*would collapse. (F2, P2)*

F2-P2 recognised the undesired effects of the medication could be prevented by ensuring that medication is taken after meals. The role of food in conjunction with taking medication emerged as one of the sub-categories in adherence behaviour and is presented when discussing adherence behaviour in the next sub-section.

### 6.5 Summary statement: illness history

The account on the illness history revealed that:

- Despite the free access to voluntary testing and counselling, delays in reporting continue to affect the diagnosing of HIV particularly if early symptoms are not severe.
- Communicating difficult diagnoses and managing the aftermath of the disclosure ought to be managed more sensitively and supportively irrespective of how the status was diagnosed.
- Self- efficacy and instrumental support are essential coping strategies in HIV illness disclosure and care in general.
- The side-effects of ART may be present when initiating treatment, but are short-lived, although clients' personal characteristics could influence their response to treatment.



## 6.6 THEME 2: ADHERENCE BEHAVIOUR

ART is a long-term treatment and requires a lifetime of commitment and consistency. Individuals taking ART may either adhere or not adhere to treatment. Participants reported on their motivation for adhering to treatment and the circumstance under which non-adherence occurs and in extreme cases defaulting ensues. Adherence behaviour from the participants' perspective

included the following of advice on diet, substance abuse and meeting follow-up visit schedules. Two main categories that emerged were: *adherence and non-adherence*.

### 6.6.1 Category 1: Adherence

Participants' reports showed that following their medication regimen strictly was not a problem as some of them have been on the treatment for over five years, and taking the medication has become routine. Some participants, because they appreciated the consequences of non-adherence, have challenged themselves to stick to their schedule.

The sub-categories within adherence were: medication regime, benefit of treatment, the role of food, the fear of death, carrying pills and transparency. Some of the comments on adherence to medication were:

> *As for the medicine, when you take it for some time you become used to it such that you do not need anyone to remind you to take it…I have followed exactly as I was taught during the counselling sessions to the extent that I have to run for my drugs when the time passes by a second. I always want to take the drugs on time so that I will be strong at all times. (F2)*.
>
> *During counselling we were informed and cautioned about the need to stick to the medication as prescribed and I have*
>
> *I take my medication religiously because I know how taking it has helped me. (F2, P3).*

P7 who is responsible for monitoring and evaluation of HIV programmes in one of the sectors indicated that there has been a general improvement in adherence over the years.

> *Since we introduced ART the adherence patterns have always been improving. At the last review meeting I think it was over 90%. But the adherence after initiating treatment is good. (P7).*

Other participants acknowledged that they adhered to the medication because of the benefit derived:

> *I have adhered to all the instructions and I can see I am healthy and strong, and the way they told me to take the medication, that is how I take it. (P4).*

They also noted that food played an important role when taking ART, while fear of death motivated them to follow the regimen strictly. Some participants indicated they carried their pills with them so they do not miss or delay taking their medication.

#### 6.6.1.1 *Subcategory 1: Medication Regime*

Although participants were unable to mention the names of their specific medications, they had no problem identifying their medication and how these were to be taken. Most participants took medication once or twice daily, having a pill or two to take in the morning or evening, or both morning and evening. There were no complains of pill burden which could deter them from taking their medication. These were some of the comments on when participants take their medication:

> *The name of the medicine is difficult to mention but I take it morning and evening. (F3, P1).*
>
> *I take my medicine once a day in the evening. (F3, P6).*
>
> *I take my medications early morning. (P4)*
>
> *Mine is also once a day but I take it at 7. (F3, P2).*
>
> *I take my medications in the morning after meals at 9 O' clock and in the evening at 9'0'clock after meals, but I was told that in case I eat early I can eat again before taking my medication. (P3).*

Some of the participant recalled that their dosing scheduled had changed, but did not associate it with any problem, although one noted it changed due to side

effects. However, adhering to treatment was not affected by any modifications of the regimen.

> *Initially, some were twice daily dosing and once daily. Later it was changed again. Currently the medication I have I take 2 in the morning and 1 at night (P1)*
>
> *I used to take it [medication] in the morning and evening and they changed it to give me the one I take only at night. I don't think I have any problems taking it (P6).*

Some participants like P4 who has been on treatment for seven years noted the medication was altered because of the side effects. Field information revealed there were diverse brands of ARV's.

> *When I started I was put on Lamivudine, Zidovudine and Nevirapine, but I realised that I reacted to the drug, and I even got sick, I realised that I could not sleep so I came here to complain and they changed the Lamivudine for me and they gave me another medication to which I have been on up till date. (P4)*

While some of the ARV's are combined into a single dose, others were not and therefore the number of pills and dosing varied. Participants also mentioned that the colour and sometimes the shape and size also changed. No matter the change in medication however, participants were cognisant of the benefits they derived from taking the ARV's and persisted in taking their medication.

#### 6.6.1.2 *Sub-category 2: Benefits of adherence*

Participants were motivated to adhere to their medications considering the beneficial effects of the treatment. Some, in remembering their state at the time of diagnosis and their current state of health remarked the medication was helpful. The medication was described as a source of energy without which there was no power. Some of the narratives on the benefits of adherence were:

*Following the advice and measures has been very helpful. (P2).*

*I have realised that when I was not taking the medication I usually fall sick but since I started taking the medication I realised that I am stronger. I go to town and come back prepare my own meals and do other house chores. I wash my own clothes and do virtually everything. I am now stronger and healthier than when I was not taking any medication. (P3).*

*I have noticed a great change in my health because I know how the medication has restored my energy, if anyone tries fighting me now I would surely beat the person. So it's important for us to try and take the medication. Your medication is your energy, and if you don't take it then you would lose your power. (F1, P2)*

*You cannot doubt the potency of the medicine; it is very good, that is why we need to take it correctly. When you take the medication as prescribed it will help to fight the virus in the blood so you will have energy and look healthy (F2, P2).*

Some participants acknowledged the action of the ARV as being able to fight the activities of the virus thereby improving their general health.

*Just as my colleague mentioned, the medication that we take reduces the activity of the virus and gives us energy. Since I started taking the medication I feel healthier and there is a difference in my energy levels. I feel very strong. I take my medication religiously because I know how taking it has helped me. (F2, P3).*

*I know the medicine cannot cure you completely, but it makes you stronger. (P4).*

Participants recognised that taking the medication consistently was important to maintaining good health while living with HIV. They were determined to be adherent, but were quick to emphasise the importance of eating very well before taking ARVs.

#### 6.6.1.3 *Sub-category 3: Role of food in adherence*

Some participants mentioned that the medication was 'strong' in view of the undesired effects such as weakness and dizziness that they experienced. A

proposed antidote to these side effects was eating very well before taking the ARV. Participants' comments on the role of food included the following:

> *I also think that eating very well before taking the drugs whether in the morning or evening is very important. (F1, P2).*
>
> *The part about eating well before taking the medication is not a joke. The medication needs food. In the evening if you take the drug after eating, then it is able to work well. But if you haven't eaten before taking it, then you will be in serious trouble. You might feel like someone who took alcohol or 'wee' [Marijuana]. (F1, P3).*
>
> *…I realised that when you take the medication early without eating, then you are in for trouble. It is better to make sure you have eaten very well before taking the medication. (F1, P1).*

Additionally, some mentioned that eating a nourishing and well balanced diet also contributed to their general state of health

> *This medication when you are taking it you need to eat well. It is important to take vegetable such as garden eggs, kontomire[spinach] as well as fruits such as banana. As I speak to you now I have some in my house now, sometimes I eat pineapple and water melon. All the time I make sure... I have good appetite so I make sure I eat well before taking the drugs. (P3).*

Some participants noted in a humorous but serious mood that eating very well before taking their medication was very important.

> *I take one in the evening after eating very well. And taking the medication after eating helps me to sleep well...The medicine is very strong so if you take it without eating you would collapse. When you collapse don't even worry yourself to return to the clinic just go home and die. By the time you get to the clinic you might even be gone already. (F2, P2).*
>
> *You have to take your medicine on time and always so that you would feel better. But let me add that you have to eat very well before taking your medication. Otherwise it would weaken you. (F3, P2)*

The availability of food and the knowledge that eating before taking ARVs minimised some side effects encouraged participants to adhere to the treatment.

Some participants also noted that failing to eat before taking the medication worsened side effects of the treatment such as a feeling of weakness.

> *I just make sure I eat very well before taking it, because I noticed that if I don't eat and I take it [medication] I feel a little weak. (F3, P6).*

Adding to this point F2-P2 pointed out that failing to eat before taking the medication could result in death. However, the fear of death was not only related to the medication's side effects but was a motivation for adherence to treatment.

#### 6.6.1.4 *Sub-category 4: Fear of death*

The fear of death served as a motivator for adherence to treatment among some of the participants. Recounting the events characterising their HIV diagnosis, some of the participants appreciated that taking the medication had improved their health. Failing to take their medication was perceived to be a death warrant, and hence made participants strictly adhere to taking their ARVs.

> *I think the way I felt and was seriously sick I was afraid that I will die so it gave me the motivation to be more conscious about my medication.* (P1).
>
> *...if it is time for the medication, and you don't take your medication the disease will recur and if that happens it can kill you…Because you will be there and the illness will come back and if you are not careful you will die and leave your children…(P3)*
>
> *I think that coming to the clinic has helped me so much. I am going through hard times, but I realised that other people have worse situations, and I can tell that they are really suffering, and this disease, if you don't take care it can kill you. This is why it is important to take your medication. (P4)*
>
> *I think you should tell those who come to the clinic to take their medication, if not, they may end up losing their life so they should adhere. (P6).*

P4, comparing himself to other clients, made the point that his situation was better than others. He attributed his good health to his willingness to take the medication in a quest to escape death. Other comments were:

> *I want to make it clear that if you have this illness then you are not part of the living you are as good as dead, but with the medication you have a hope of living and therefore you must take it unless you want to die. (F1, P2)*
>
> *If you do not do that [stop being afraid] you would be worried and end up forgetting to take the medication well. When that happens, you become sick and if you are not careful you end up dying. (F1, P6).*

A participant mentioned, during the group discussion, that HIV seemed like a death sentence but with the medication the hope of survival was increased thus advocating for adherence. Another participant mentioned that anxiety could contribute to poor adherence and the risk of death and therefore encouraged other members to take their medications as prescribed. Apart from adhering to treatment in fear of death, some participants promoted adherence by carrying their pill(s) with them.



#### 6.6.1.5 *Sub-category 5: Carry pills*

The role of carrying pills in encouraging adherence emerged as a third sub-category. As the medication times and schedules of participants varied, the importance of carrying pills emerged. Participants mentioned that carrying pills when travelling or going out was a preferred alternative which facilitated adherence to treatment. The participants said:

> *...when I am travelling I carry the medication with me. (P6)*
>
> *As for me I always have some of the medicine with me so even if I am in church and it is time I come out of the church take my medicine and go back. (F3, P2)*

*I take my medications early morning, so even when I am travelling, I have the drugs on me. If I am in the car I would often check my time so that anytime it is 8:00 then I take the drug. (F1, P1).*

*I always make it a point that it is always on me. Wherever I am going it's in my purse. At least it's either you just cut a piece of it, you wrap it somewhere and put it in your bag so that you take...I think it is working but they should bring something that we don't have to take or carry all the time so you don't forget maybe an injection or something else. (P1).*

*...even if I have to go out I take it [medication] and put it in a rubber then put it in my pocket, when I realise it is 9 I will take it. (P6).*

*The only problem is that sometimes when you go out and you don't take some of the medicine with you, it can delay you in taking the medicine. (F3, P1).*

Participants carrying their pills around with them promoted adherence behaviour among the participants, although P1 would have preferred medication that she did not have to carry with her all the time. F3-P3 identified the possibility of going out without pills and therefore delaying the time that the medication was taken. A participant mentioned taking the medication even on a bus while travelling: an indication of not being bothered by other people noticing that she was taking her medication. Transparency about HIV status and willingness to take medication anywhere at any time also facilitated adherence.



#### 6.6.1.6 *Sub-category 6: Transparency facilitating adherence*

The challenge of being transparent about treatment and the effect on adherence also emerged as a sub-category. Adherence to treatment requires transparency to enable patient to be supported by family and significant others. However, only a few participants mentioned that they could take their medication if others were looking at them.

*I always don't feel anything about where I take my medication. (F3, P4*)

*I don't take my medication in the presence of other people for them to even see what medication I am taking, so it is not such a big issue for me. (F3, P6)*

*...recently I had to inform my younger brother because when I went to his room his wife was pregnant and I saw my drug on the table in their room. I called him aside and cautioned him about the way he had left the drug 'we don't put it like that on a table' because if someone who is taking it sees it he or she would know (referring to knowing HIV status). So he asked me; do you know what it is? I told him that if I did not know I would not say so. I took him to my room and showed my medication to him before he believed me. (P6).*

P6 felt that the brother's wife was careless with her pill bottle. However, her action was because she had opened up and discussed her status with the husband and had his support. The transparency of P6's sister-in-law created the opportunity for him to also open up to disclose his status to his brother. Although this was not the general trend, transparency about the status demonstrated overcoming the stigma barrier and reducing the associated non-adherence behaviour.



### 6.6.2 Category 2: Non-adherence

Although most of the participants indicated they were adhering to treatment, some mentioned instances of non-adherence. Most of the participants reported that they were adhering to their treatment, but a few recognised that occasionally some people could either miss their pills or stop the treatment.

*I came with a lot of people but I have realised that most of them did not make it and I think it is because they did not adhere to the medication. (P4).*

Recognising non-adherence could occur, this was what some of the participants advocated:

*You see if the nurse wants to help and you with the illness and you do not want it what can they do? You people should leave them; the ones who want to be helped are the ones who should be helped. If someone refuses to take the drugs and come back seriously ill, you have to punish the person and teach him a lesson. (P6).*

*You can use people who do not adhere and who are really sick as an example for such people so that they can adhere. (P3)*

*Adherence a major problem affecting people living with chronic illnesses. Adherence affects treatment in different ways. (P8).*

P8 after over 10 years' experience working with clients with HIV noted adherence to treatment was a major problem. A participant's comments implied non-adherence was previously associated with the need to pay upfront for the ARV's. He said:

*At first, even the medicine it was not everyone who gets it. At a point we had to even pay to get the medicine; now if you have health insurance, everything is free. (F3, P6).*

Non-adherence is manifested in situations such as *forgetting pills, religious fanaticism, oversleeping, secrecy and waiting time* at the clinic; these were the sub-categories extracted from the narratives. However, the main concern about non-adherence was the likelihood of missing scheduled appointments because of forgetfulness.



#### 6.6.2.1 *Sub-category 1: Forgetfulness*

Non-adherence to treatment, participants noted, was due to forgetfulness. Some admitted forgetting their appointment schedules while others mentioned occasionally missing their pills. P1 referring to the appointment schedule for refilling their medication commented:

*Most of us forget a lot that is one problem that affects us all the time. (P1).*

P2 also added:

> *I think the doctors themselves know that some people could forget the follow up date. I sometimes miss the date, but once I notice my medication is reducing, I go back to the clinic for refill but the clinic days you have to keep checking and if you don't take care the date would pass before you realize it. If you do not exceed one week then you could still have medications, because they always make sure that you receive medication in excess of your reporting day.*
>
> *(P2).*

Making reference to missing pills some participants said:

> *As for the medicine, I don't forget because even if I am walking I remember because I have programmed it on my phone so I don't usually forget, even if I do forget to take it for a while, after about 30 minutes' time I take it immediately I remember. (P4)*
>
> *It is when you are worried about the illness and see it as a problem that you are likely to forget. (P3)*
>
> *I may forget, so the phone has to be with me always so that I can check the time. (F1, P2)*

Some participants admitted forgetting their clinic follow-up appointments and failing to take their pills occasionally, but F1-P2 mentioned her phone helped her keep track of time so she did not missing taking her pills. While participants were willing to accept measures to improve adherence, they also argued that some persons diagnosed with HIV may default on treatment as a result of religious fanaticism.



#### 6.6.2.2 *Sub-category 2: Religious fanaticism*

Some participants indicated that, although taking their medication was important, sometimes some of the clients may be misled. They gave account of instances in which religious fanaticism influenced non-adherence and resulted in worsening conditions. Some of those who mentioned the issue opined that:

*Sometimes some of them abandoned their medication claiming that their pastors have asked them to come to the prayer camp for fasting… Someone was asked by the pastor to come for fasting and deliverance and she has lost her life through that. (P3).*

*Another bad thing is that most clients listen to their pastors when they visit prayer camps, who advise them not to take the drugs. They therefore expect to be healed from the prayers which eventually make them weaker and weaker after refraining from taking the medications. God is indeed able, but taking the medicine is inexcusable in this regard. (P2).*

*I realised that some people come for the medication and will go and put it down but if you don't take your medication you are worrying yourself, because the medication helps a lot. I know there is God, but if you take your medication in addition to prayers, God will help. (P4.)*

They expressed concerns about seeking religious support without sticking to their prescriptions. P4 and P2 clarified that it was the necessary to take the medication while drawing on faith. They argued that priests who often convinced clients to stop treatment were also contributing to the problem of non-adherence.

#### 6.6.2.3 *Sub-category 3: Secrecy*



Participants mentioned hiding when taking their HIV medication in order to avoid the stigmas associated with the disease. Maintaining secrecy around HIV status can influence adherence behaviour. Some participants mentioned they tried to keep their illness secret:

*… it is the children who do not know that I have HIV but they sometimes see me taking medicine. One of them asked whether I was sick one evening when I was taking it [the mediation] and I just told him I have bodily pain because the work at the shore was hectic.*

*I have poured my medicine in a vitamin bottle so in case I am taking it you would not know which medicine I am taking. (F3, P3).*

*If you are taking medicine every day for people to see you would subject yourself to unnecessary questions. So it is better*

*to keep everything to yourself and hide before taking it. You don't have to expose your medicine anyhow. (F3, P1)*

*There are people with hypertension who take medicine every day, but if you are HIV positive it is as if you have committed a great crime and they start pointing accusing fingers at you so you have to hide and take the medicine to avoid all the criticism.* (F3, P2)

*I have not told anybody except my husband so I would not be taking the medicine anyhow for people to ask whether I am sick. Instead of subjecting myself to unnecessary questions I would rather keep away. (F3, P5)*

Participants did not indicate that hiding when taking medication prevented them from taking the medication. Nevertheless, the way HIV and treatment for it is shrouded in secrecy has the potential to affect adherence behaviour because there could be inadequate social support.

#### 6.6.2.4 *Sub-category 4: Waiting time*

Some of the participants were concerned about the waiting time at the hospital during clinic visits for medication refill. They argued that long waiting hours at the clinic and the pharmacy could discourage them from returning for follow-up appointments. These were some of the comments:

*First when you come for medication there will be so many people and you will be in queue for so long that you will go home in the evening. (P4)*

*My main concern is the time wasting factor at the pharmacy. If you come and you have to go to work you can beg the nurses to help you out, you understand, but you cannot always be doing that. (P6).*

*Previously, we had to leave home very early to join the queue, otherwise you have to give an excuse and cross other people waiting for their turn which does not feel right (P1)*

*Sometimes when you come to the clinic you spend the whole day here waiting. From this place you have to go and wait at the pharmacy as well. (P5)*

Some of the participant admitted they were offered preferential treatment. However, they were uncomfortable because of how other clients might feel each time they jump the queue.

#### 6.6.2.5 *Sub-category 5: Sleeping*

Two of the participants pointed out in their narratives that they sometimes oversleep and as a result miss the exact medication time. However, the use of the alarm later resolved the problem of sleep interrupting treatment schedule:

> *Well, I wasn't taking it religiously because sometimes I oversleep and my time will pass and if that happen it affects me. (P1).*
>
> *Since we were encouraged to use the alarm on the phone I started using it and it was very good for me. Once its time, even when I am sleeping, I will hear the alarm sound and wake up…There are others that, even when the alarm sounds while they are sleeping, are not able to hear (F1, P4)*

Participants in the focus group (F1) agreed with F1-P4 that there were occasions they were sleeping when it was time to take their medication. However, they have since been encouraged to keep their phones close to them so that the alarm would wake them up in case they overslept. This was mainly after going through the orientation for using the alarm during the study.



### 6.6.3 Summary of findings on Adherence behaviour

The narratives from the interviews and focus group discussions revealed that generally participants understood the importance of adherence to treatment. The findings on adherence behaviour revealed that:

- Participants were adherent to treatment and had the motivation to adhere because of the benefits of adherence and the consequences of not adhering.

- Food was an important consideration in adherence.
- Forgetting clinic appointment was a concern to participants.
- Taking ARV is shrouded in secrecy because of the fear of stigmas associated with HIV/AIDS.
- Religious fanaticism contributed to non-adherence.

## 6.7 THEME 3: ADHERENCE MONITORING

Adherence monitoring involves measures used by respondents that enabled them to take their medication according to instruction. These accounts were retrospective narrative of how adherence was monitored prior to the mobile phone intervention for medication adherence. Participants revealed that there was self- monitoring and monitoring from adherence supporters. This was confirmed in the interview with the institutional representatives who were referred to as experts/professionals in this report. Measures were also put in place at the health facilities to monitor ART adherence. The sub-categories discussed under adherence monitoring were: Self-monitoring, adherence monitors and institutional monitoring.



### 6.7.1 Category 1: Self-monitoring

Participants, being aware of the benefits and consequences of not adhering to treatment, primarily self-monitored using the alarm and time functions on their mobile phones:

> *I have made up my mind to take the medicine so I do it without anybody telling me. (F3, P2)*
>
> *I have been taking care of myself since I was sick, although my wife is my monitor. (F3, P3*)
>
> *The medication is for you and you decide to take it. (P6).*

*Self- discipline in taking the medication is very important. (F3, P6).*

*...personal monitoring is part of the adherence monitoring measures. (P7)*

Some participants recognised they had a personal responsibility to take their medication. P7 noted from a professional perspective that personal monitoring was part of the general adherence measures. An important measure, which reflected in the patient narratives, was the need to be conscious about the medication schedules and the discipline needed to stick to it. The sub-categories for self-monitoring were: *awareness, use of alarm clock and phone as clock.*

#### 6.7.1.1 *Sub-category 1: Awareness (conscious)*

Participants reported that they were aware of the need and had the personal determination to take the medication religiously. Participants became attuned to medication time after taking it over a period of time. They encouraged and monitored their personal medication actions and inactions, fully aware of the consequences. P1 did not take her medication regularly prior to being recruited to the study. She admitted that:



*The way I felt and was seriously sick I was afraid that I will die so it gave me the motivation to be more conscious about my medication. Sometimes, although you know you are on medication but unconsciously you may be preoccupied with other thoughts, but since my last experience I have become more conscious and determined to stick to the time… So the consciousness and the seriousness must always be paramount. (P1).*

Some participants mentioned the need for being conscious of the time of day so as to not to forget their medication time:

*I am always conscious about the time and whatever you do once you are conscious about it, you do not forget and you can do it. (P2).*

*…all the time I am alert about taking my medication (P3).*

*I have made up my mind to take the medicine so I do it without anybody telling me. (F3, P2).*

Other participants also mentioned their (self) consciousness emanated from taking the medication overtime:

*As for me I have practice taking the medicine over the years and now I know I am used to it. (P6)*

*But the point is with this medication, once you are on it for one year by the second year if you don't experience any problem it becomes part of you so with or without reminders you would take the medicine. (F3, P5)*

Participants mentioned that the medication has become part of their routine and they are conscious about it. However, there was still the tendency to skip but that would not be an intentional decision. They noted that setting the alarm served as an additional measure that facilitated their ability to monitor their own medication-taking behaviour.

#### 6.7.1.2 *Sub-category 2: Use of alarm*



Alarms served as a means of enabling some of the participants to monitor themselves so they would take their medication. Some reported that setting their phone alarms made it easier for them to know when it their medication time so that they did not miss it:

*I mentioned that sometimes I do oversleep, but since I started using the alarm I am able to wake up once I hear the sound of the alarm. If I feel lazy to wake up, I snooze it, so it rings again so I wake up. (P1).*

*I have set my phone on alarm so even if I am busy it rings and I stop whatever I am doing to take my medication. (P3).*

*I also set my phone alarm at 8:00 to help me take the medications. So anywhere I am, once the phone the alarm beeps I take my medicine. (F1, P)*

*I have set the alarm on the phone so when I hear the sound of the tune for the alarm then I know it is time for the medication.*

*Please, I take the drug at 7:00. I have set an alarm on my phone at 6:58 so when its time my phone blinks until 7:00 then I take the drug. I think the phone is good for us. (F2, P).*

*I sell at the market so at times when I am busy, I am unable to take the drug, so I am prompted by the alarm that was put on the phone for me at around 9:00, then I remember and take the medication (F2,P)*

*The reason why I do so is that, when it is about getting to the time when I take my drugs, the alarm sounds for me to know that time is up for me to take the medication. When I check then I know that I have to take my drugs. (F2, P).*

The use of the alarm by participants to monitor adherence addressed the problem of oversleeping and forgetfulness, as noted by some of the participants. They also used the mobile phone to check the time to enable them to take the medication at the correct time.

#### 6.7.1.3 *Sub-category 3: Phone as clock*

Participants reported checking the time on their phone as a way of self-monitoring. Most mobile phones come with a clock application that is used to tell the time. Participants were aware of the need for to take their medication at regular times and decided that their phone clock was useful for tracking the time in this regard:

*I usually use my time, and the alarm after you taught us how to use it, so even before the alarm blows, I check my mobile phone to find out if it is time. (P3).*

*I usually take my medication 8:00 in the evening. I check the time on my phone regularly when it is 8:00, then I take my medication. (F1, P6)*

*I also use my phone to check the time I take my drugs so that I can take my medication within schedule. (F2, P4)*

*Please, I have time on my phone, so by 7:50 to 8:00, anywhere I am, I take my drug at 8:00 once I confirm the time on the phone.*

*(F2, P6).*

*I use my mobile phone to check if it is time. (P6*)

Checking the time on the phone was a common practice among most of the participants although only a few commented on using the phone to check the time.

### 6.7.2 Category 2: Adherence monitors

Adherence monitors are individuals that have gone through adherence counselling with clients, at the time of diagnosis, and who are tasked to monitor that clients take their medication and return for follow-up visits according to their schedule. The monitors could be spouses, family members or peers:

> *...if you come here they will ask you to bring a monitor or else they will not give you the medication. (P4)*
>
> *We use the adherence monitors who are like a confidant. The monitors are required to go through the counselling sessions with the patient and provide a kind of support and monitor adherence at that level. It is preferred if the monitors live with the person to see the pill box and be sure it is not empty or that the medication was not thrown away as a direct observation of pill taking by the patient. (P8).*

P8 added that in cases where monitors do not live with the patient it is important that the monitors call clients to ensure that they are adhering to the medication schedule. He mentioned that:

> *At least if these monitors are able to call or send messages to be sure what is happening it will be fine, but the concept is to preferably have someone who lives with the patient. (P8).*

Ideally the monitors are expected to live with the patient to promote direct observation of the patient taking the medication. Alternatively, the monitors are

expected to call or send messages to the clients. The monitors mentioned by participants were spouses, family members, peers and significant others.

#### 6.7.2.1 *Sub-category 1: Spouse as monitors*

Some participants noted their spouses were their monitors and they often supported them by reminding them when it was time to take the medication. Some called if they were out of the house to make sure the medication was taken:

> *My husband is my monitor and he always reminds me to take my medication. Sometimes he calls when he gets to work and asks about my medication. (P2)*
>
> *My husband is the only one who knows about my status and he is my monitor. (P3).*
>
> *My husband is ok and encourages me. He is negative but still very supportive. (P1).*
>
> *She is my monitor. I live with her and she is the one who reminds me to take my medication. She makes sure before I get up to take the medication she prepares something for me (to eat). (P4)*
>
> *...My wife has been very supportive since I became ill she is my monitor and she always checks to make sure I am taking it. (F3, P5).*



The monitors, in addition to calling or checking on participants to ensure they take their medication, also provide instrumental support such as food and transport for their partners.

#### 6.7.2.2 *Sub-category 2: Family monitors*

Family members such as mothers, sisters and uncles were mentioned by some participants for helping remind them about their medication times. These family members also supported participants by reminding them about their follow-up

appointments at the clinic. The comments which reflected the support from family members were:

> *My mother also knows about it and she frequently checks to be sure I do not miss my clinic appointments. I sometimes forget my review dates because of my activities in the market. (P2)*
>
> *Sometimes she [sister] may ask if I have taken my medication. And once I read it, then I take the medicine. (F2, P5)*
>
> *I came with my uncle for the counselling and he also calls me to remind me to take the medicine and I think all this is helping me a lot. (P5)*
>
> *My brother is in the university and he told me that at the university he sees lots of these things and as for my sickness he saw it a long time ago but he could not tell me, he advises me not to be afraid because God can do it and that he can help me with my medication so I should not fear. And truthfully my brother helped me a lot I have two brothers and they are the only ones who know about the illness. (P4).*

Monitoring was also carried out by making phone calls or sending text messages as some of the monitors did not live together with the clients. A participant (P4) in his narrative mentioned how the brother suspected his condition prior to the confirmation of the diagnosis and had been supportive throughout the illness.



#### 6.7.2.3 *Sub-category 3: Peer monitors*

A few participants mentioned that they were monitored by individuals who were also clients. Some spouses who were both HIV positive served as peer monitors for each other:

> *He is also positive so we monitor each other in taking the treatment. (P3).*
>
> *I used it [the phone] to call others who have the same problem like me and are taking medication. I call to encourage them and also ask them to take their drugs since it is time. (F1, P3)*
>
> *…when I came here I met a woman and when she was asked to bring a monitor she said I should be the monitor because she does not want any member of her family to know about her*

*status…I constantly call to remind her to take her medication and she sometimes shows me how she takes her medication. (P4).*

There were peer groups that also supported adherence monitoring through education and counselling. While some noted that peer groups were important and supportive, others were ambivalent about being part such groups.

*…belonging to such groups help in the sense that they advise each other by way of counselling and also motivating to be hopeful but with me it's an issue of time constraint and my children are not that grown to take care of themselves. (P2).*

*There are different peer groups but there are some people who don't feel comfortable joining them. I am part of the group 'the heart to heart' and at meetings they educate us on how to take our medication. We learn a lot of things about the illness and how to cope. (P3).*

Peer monitors play significant roles in promoting medication adherence. Observations revealed that some peer volunteers were actively involved in providing services at the clinic. Four of these volunteers were engaged and trained to send messages, call participants, conduct individual interviews and facilitate the focus group sessions. The use of peer monitors also allows for role modelling and mentoring of other persons living with HIV. There were other individuals and significant others who were also involved in monitoring ARV adherence.



#### 6.7.2.4 *Sub-category 4: Significant others as monitors*

Participants were also monitored by other people such as doctors, nurses, counsellors and friends. This was done through psychosocial support, instrumental support and education. Some accompanied the participants during adherence counselling and have continued to monitor them via phone calls.

*At the clinic they really support us through counselling. They educate you about the treatment to make sure you don't get more virus and unnecessary infection. They teach about how to make sure that your partner also doesn't get it. (P1).*

*When we come to the clinic, the nurses counsel us and encourage us to continue taking our medication correctly and not to stop. They advise us to eat before taking our medication. They will ask you about the time that is convenient for you to take your medication so you are the one who will decide when to take your medication. You also came to teach us how to use the phone to help us take the drugs on time. (P3).*

*He [doctor who referred client] calls to check on me, ask about my treatment and sometimes gives me transport. He has been so helpful. (F3, P5)*

A participant mentioned going for counselling with a friend as a monitor:

*It was a friend of mine but he is now dead. I did not tell anybody because I don't want anyone to know my status. (P6)*

Another was willing to ask others what time of day it is in order to ensure adherence to treatment.

*I ask anyone around to know the time so I know if it is time for me to take my medication. (F2, P4)*

Different people help to support and monitor adherence in many ways that may not be the norm. Nevertheless, the ultimate goal is to ensure adherence and participants' stories showed diversity in adherence monitoring.

### 6.7.3 Category 3: Institutional monitoring

The ART treatment guidelines specify institutional adherence monitoring of all clients. The monitoring structures differ from level to level but adherence counselling and pill counts were mentioned by some of the participants. Information from participants' hospital records revealed that self-reporting was obtained on adherence and pill counts and recorded as part of the routine care. The pharmacy department also compiles information on adherence using their

records. The sub-categories discussed are: *adherence counselling, pill count and adherence report.*

#### 6.7.3.1 *Sub-category 1: Adherence Counselling*

Adherence counselling involves providing clients with information on ART, drug regimens, possible side effects and additional instructions. Counselling helps clients to be aware of the tenets and conditions associated with starting ART to enable clients to make choices. All participants went through this process because it was mandatory and a way of ensuring patient readiness.

> *I was asked to bring a monitor so that he or she can remind me when I forget to take the medication. They counsel me three times before they started the medication before, by then my CD4 count was low. (P4).*
>
> *At the clinic they really support us through counselling. They educate you about the treatment to make sure you don't get more virus and unnecessary infection. (P1)*
>
> *It is basically the counselling sessions with the clients which inspire the clients to take the medication. The counselling advocates that failure to take the medication will lead to the breakdown of the body's immune system. (P2)*
>
> *...they emphasised on making sure that the medication is taken correctly and strictly according to the instructions during the counselling. When you follow the education by the doctors and counsellors it is very good. You are not supposed to miss your medication. (F1, P2).*
>
> *The first time I was told they will give me medication I went through counselling and was educated on the medicine so me, I don't have any problem. (P5)*

A general guideline is that before initiating ART we make sure that a patient has had at least two cycles of adherence counselling with a monitor to ensure the patient is ready and willing to undergo the treatment; otherwise it defeats the purpose of prescribing the treatment. We have trained and continue to train

counsellors who have to explain the treatment carefully and in a way that clients could understand. (P8).

The adherence counselling sessions taught participants the need follow the medication regime, recognise the side effects, know the dietary requirements and restrictions and gave the opportunity to give additional instructions. Participants were of the opinion that the adherence counselling was well done and helpful.

#### 6.7.3.2 *Sub-category 2: Pill count*

Although participants presented their pills for counting during each clinic visit, it was not a central point of discussion. However, two participants mentioned that the pills were usually counted at the pharmacy during each visit to the clinic to monitor adherence.

> I always *present the old drugs, as you can see the remaining in my hands. When I present them, they check the record and find the number issued to me and add some to it for me… The pharmacist determines if the drugs are not taken because they record every detail. They normally get annoyed and discipline the fellow and in some instances refer patient for counselling*. (P2)

> *With HIV we have tried pill counts, we tried using pill counters; some of them are quiet expensive, but we have not really succeeded. (P8).*

Field data also confirmed pill counts were done especially during patient initiating treatment, at the pharmacy. In the study this measure was used to estimate adherence behaviour among the participants. The participants presented their pills for counting and this was checked against the prescription date, number of pills dispensed and the follow-up appointment date to estimate the pill possession ratio. The outcome was then reported as percentage adherence.

#### 6.7.3.3 *Sub-category 3: Adherence report*

Adherence reports were used to estimate general adherence among clients infected with HIV who were receiving ART. The reports are usually extracted from patient records, pharmacy records and follow-up data. This point was made by P7 during a face-to-face interview and was further confirmed following a review of the standard guideline of the NACP.

> *The various sectors have their clinical review meetings based on reports from the various district and regional levels. During the review meeting the data is then aggregated to provide estimates on number of new cases, those on treatment, PMTC and all that. As I said NACP collaborates most of the clinical issues so they are actively involved in giving all those estimates but we work with them closely. So we are doing well with our data management system although we could still do better. We have two systems: District health information management system.... I wish we could also have the mandate to know what is happening by just getting into the system at a click of the button. (P7)*

P7, explaining from a professional point of view, noted that there was a system in place to generate adherence at the various levels of service delivery. While interacting with participants and looking through their records it was observed that the clients' records had questions that also assessed adherence based on self -reporting. CD4 count and viral load were monitored between months three and six. The institution had measures in place to collate adherence data in order to generate data and monitor progress.

### 6.7.4 Summary of findings on adherence monitoring

The findings from the theme adherence monitoring revealed that the following factors generally assisted them to monitor their adherence:

- Participant monitored themselves by being conscious about the medication schedule and making use of mobile phones.

- Participant had adherence monitors like spouses, family members, friends, peers and some health professionals who encouraged them to take their medication.
- Adherence monitors served as social support for participants and provided instrumental support.
- There were systems and structures in place for monitoring adherence.
- Adherence counselling was used for empowering clients to be adherent to treatment.
- Pill counts were done at the pharmacy, self- reports were obtained on adherence and a CD4 count test was done as part of the adherence monitoring process.

## 6.8 EVALUATION OF EXPERIENCES AND PERSPECTIVES OF MOBILE PHONE USE IN ADHERENCE STRATEGIES IN THE INTERVENTION



Participants were interviewed to determine their perspectives on using the alarm, receiving text messages and using voice calls during the intervention. Two main themes emerged: 1) perspectives on integrated mobile phone intervention and 2) readiness for M-health integration in care. Two categories emerged from each theme with sub-categories as shown in table 6.2.

In order to address the issues of institutional readiness, three documents [D1, D2, and D3] were reviewed in addition to interviews conducted with two experts.

### 6.8.1 Theme 4: Perspectives on Integrated Mobile Phone Intervention

Patient participants who were from the intervention group were required to give feedback about their experiences with the integrated mobile phone intervention after being part of the study for six months. Participants used the alarm on their phones to monitor their medication, receive weekly motivational messages, and monthly motivational calls. The narratives revealed that generally they found the use of mobile phones helpful, but some were sceptical about using text messages. There were sub-categories described in this section namely: *alarm use, text messaging acceptance & scepticism, and voice call*

### 6.8.2 Category 1: Alarm use

Participants were assessed on their ability to set the alarm, and their training needs were addressed during the intervention stage. Some were assisted to set the alarm based on their medication schedule. Participants' feedback revealed that: *the alarm is helpful and private;* therefore they were comfortable using it to monitor their treatment.

> *I have set my phone on alarm so even if I am busy it rings and I stop whatever I am doing to take my medication. (P3)*
>
> *Yes, we really need it very much. Because at times, when you are asleep even after 6pm when I sleep after work once the alarm alerts me about the time, I wake up and take my medication. (F1, P4).*
>
> *I take the medication at 8:00 and the alarm was set to buzz with a specific music at 8:00 so once hear it I am reminded to take my drugs. (F2, P2)*
>
> *The reason why I do so is that [take medication on time] when it is about getting to the time I take my drugs, the alarm sounds for me to know that time is up for me to take the medication. When I check then I know that I have to take my drug. (F2, P7).*

*I have set the alarm on the phone so when I hear the sound of the tune for the alarm, then I know it is time for the medication. (F2, P6)*

Participants found the phone useful as they were able to set the alarm and check the time on the phone in order to take their medication as scheduled. The alarm was seen as helpful and protective of their privacy.

#### 6.8.2.1 *Subcategory a: Alarm is personal*

The alarm function on the phone enabled participants to programme the medication schedules based on the treatment regimen. The alarm tones were personalised and nobody could tell what the purpose of the alarm was. It was personal and protected the privacy of participants. They said:

*The good thing about the alarm is that you are not worried someone else would know. (P6)*

*The alarm is also ok because it is more personal. (F3, P5)*

*The alarm is convenient for me; I can set it myself without any problems. (P1)*

*I am the only one who knows why the alarm rings and what I do. That is what I like about it. (P5).*

*The application that is personal like the alarm has no cost to it. (P7)*



The use of the alarm assisted participants by reminding them to take their medication. P7 commenting on the use of the alarm from a professional point of view acknowledged that the alarm was personal and that no cost was incurred in using it.

#### 6.8.2.2 *Sub-category 2: Alarm is helpful*

The alarms were set to ring once daily or twice daily depending on the frequency participants took their medication. Some participants noted that their busy

schedule could make them lose track of time, but the alarm was helpful in reminding them to take their medication. The comments were:

> *I sell at market so at times when I am busy, I am unable to take the drug, so I am prompted by the alarm that was put on the phone for me at around 9:00, then I remember and take the medication. (F2, P5)*
>
> *I usually use my time, and the alarm after you taught us how to use it so even before the alarm blows I check my mobile phone to find out if it is time. It has really helped me. (P3).*
>
> *They asked about when I take my medications and then taught me how to use the phone and set the alarm… I was happy…because it has helped me. (P2)*
>
> *I agree with what P1 [in focus group 3] said; I was using the alarm too and it helped. (F3, P2)*
>
> *When I set the phone alarm to my medication time, it made it easy for me to know it is time to take my medication. I did not have to check my watch or anything else. (P4)*
>
> *The alarm is on 8: o'clock and it is helping me so much. (P5)*

The alarm was useful in helping participants integrate their medication routine into their daily activities. Those who did not know how to operate the alarm function on their phone learnt to do so or got help to do it.

### 6.8.3 Category 2: Text message: acceptance and scepticism

Participants received weekly text messages and noted the motivational nature of the messages was good. However, some were also afraid that messages which explicitly mentioned taking medication could subject them to questioning which could make them disclose their status, a risk they were not willing to take. Others also did not read the messages as consistently as expected. The three sub-categories were: *SMS is good; messages can expose your status and consistency in receiving and reading messages*. Some reports are indicated as follows:

*The messages are very encouraging; before I started receiving messages from your team, my sister usually sends me such messages which were not ordinary. (F2, P5).*

*If you ask me to make sure I achieve my goal or God would help me I don't think anybody would have any reason to question you so I think that is ok. (P4).*

*You see this illness; you need to be careful. Do you get me? This monitor or call business sometimes may give you problems. You receive a call at 9 and you are asked to take your medication, may be you are with someone at the time and that person would be curious to know what medicine and why you are taking it. For me I think everybody should just keep to taking their medicine: no phone no monitors. (P6)*

*But the fact that I don't want the sms does not mean it should not be used. (P1)*

*Somebody picks your phone and asks what kind of reminder is this? So we still need to look at how we can make it full proof. Is it by bulk messaging or what? I think we still have to fine- tune it more, but it is a good intervention. (P8)*

The use of text messaging to support adherence was embraced with some ambivalence despite participants appreciating that was helpful. The challenge of the moral and ethical issues associated with using text messaging and protecting privacy were noted as important considerations.



#### 6.8.3.1 *Sub-category 1: SMS is good*

Participants received messages that encouraged them to take their medication consistently. The messages sometimes included coded words such as 'song' to represent medication. They noted that the text messages were good:

*The messages are very encouraging and I don't have any problem with it. (P4).*

*The good thing with the messages you sent is that you did not mention medicine but just encouragement and it was ok. (F3, P1)*

*The men have said it already; the calling and texting is good. (F3, P5).*

*What I feel, if added, would help is when the mobile phone is used to send everyone a message to remind us when the clinic date is due. (F2, P7)*

Recognising that messages were good, participants were willing to allow them to be used it was used to remind them about clinic appointments. Nevertheless, it did not take away the fear of their status being exposed.

#### 6.8.3.2 *Sub-category 2: Messages can expose your status*

Although participants appreciated the messages, they remained sceptical about their use as they were seen as a potential threat to exposing their HIV status:

*As for the text message, I don't believe it can help, because it is not all the people who are having phones, or maybe she is using the same phone with the husband, and also if the text message is sent it's not everyone who can read. Or even if they got somewhere in their education they cannot interpret it well. So as for me, I don't believe the text message will help. (P3)*

*I agree with what they said but I also think that like you arranged with us, we should be given opportunity to decide if you want to receive the message or not. There are some people who do not want anybody to know they are attending the clinic. (F1, P3)*

*The messages and calls were all ok; it makes you know that people care about you. But I have problem with the texting. I say that because some don't use their phone alone. (F3, P1)*

F3-P1 continued his story justifying why he was hesitant about using text messages:

*There was one group some years ago who used to send this text message thing I have forgotten their name. One of my friends that I met at the clinic shared his experience and it was not good. The wife did not know he was on treatment, she then found the messages on the phone and started asking questions and it was very difficult for my friends so he asked the people to stop sending the message. (F3, P1)*

*…you could still send the messages to those who want it, not everybody, because the fear of others reading the message is in our minds. (F3, P2).*

*As for the phone I think it's only one person who is supposed to*

*use it but because you are human you can forget or you may put it on charge and someone will go and take it and look at your messages , and because you don't want people to know you have such sickness and someone takes your phone and reads your message he or she will get to know that you have such a sickness …there was a group that came some time ago who were sending messages every day for people to take their medication and that one I think the way the message was people would know and ask you. (P4)*

Participants were concerned about protecting their status although they appreciated that messages they received were good. However, their narratives also revealed that the messages were sometime not consistent and some participants did not read the message.

#### 6.8.3.3 *Sub-category 3: Consistency in receiving and reading messages*

Some participants mentioned that they did not read their messages very often and others reported not receiving the messages at all. A reason given for not reading the messages was being aware of what the content of the messages would be:



*I did not check on that but the first time we met and spoke with the other nurse she mentioned I would receive the messages. (P4).*

*I was receiving messages every week as they said but sometimes because I know what the message is about I just look at it. (P1)*

*Every month they call me and I receive a text message once every week encouraging me to take my drugs. (F2, P3).*

*I am fine with everything but although you mentioned you would send the message…there were times that I did not get the messages but I still take my medication since I use the alarm. (F3, P2).*

*I was not checking but you said the message would come to me… but sometimes I don't see it. (F3, P4).*

*I was not so keen about the messages so frankly I did not check if it was regular or not. (P1).*

*I don't read messages very often so I did not realise it. (F3, P5).*

Some participants received and read the messages; others did not pay attention to the messages. There were participants who mentioned they did not receive the messages at all.

### 6.8.4 Category 3: Voice call

The monthly voice calls made to the participants were perceived as good and some noted they engendered a sense of belonging. The sub-categories on voice call were: *calls makes you feel others care*, *voice call for clinic appointment* and *automated voice calls preferred*. The participants noted they preferred voice calls that reminded them about their clinic appointments. Some suggested the use of automated voice calls which could have short codes that they could dial to receive information.



*Then for some months now you also encouraged us to use the alarm on the phone to remind us take our medication. Sometimes I received messages and calls as well. I feel that the phone call is good. (F2, P8.).*

*I also receive phone calls from the one I came to the clinic with for counselling, my monitor. He calls me at times to reminds me when it is 8:00 to take my drugs. (F2, P5)*

*There should be good counselling services, better dialogue with clients on the telephone. (P2)*

*I feel that the phone call is good. (F2, P1).*

*The calls are ok. The lady who was calling encouraged me and also checked if I had any problems about the treatment. She also informed me to come to the clinic a few months ago and today. I think I like it. (P4).*

*The way you called us to come to the clinic is the one I like especially when we finish you give us transport that one is very good (P5).*

*It was a good experience although I preferred the calls. (F3, P5).*

Participant were satisfied with receiving voice calls and requested that the service be continued during personal interactions. Some also thought that the calls created the impression of a caring attitude and it gave them encouragement.

#### 6.8.4.1 *Sub-category 1: Calls make you feel others care*

The participants noted that receiving voice calls from the research team and their family members was good for them. Some mentioned that the calls made them feel others cared about them and it gave them a sense of belonging. The voice calls filled a relationship gap among participants who felt that having HIV deprives you from enjoying relationships with other people.

*I think people calling you are like loved ones. If you have loved ones around, somebody can just call you ask Charlie, have you taken your medication? When somebody calls you like that then the person loves you and he wants the best for you so you take your medication but if nobody knows about it then it becomes a problem. But if you tell them too you don't know how they would behave towards you. When you were calling us it was good for me and there should be away to continue. (P1).*

*They should also call to continue teaching us about the medication. I noticed that when you finish the counselling and you are put on treatment they don't counsel you again like it was done the first time. If they can call us once a while to talk to us about the medication it would also be good.*

*The messages and calls were all ok; it makes you know that people care about you. (F3, P1)*

There was generally a preference for voice calls as the calls were made in an indigenous language, had a greater personal and emotional component and were more interactive than text messages.

#### 6.8.4.2 *Sub-category 2: Voice call for clinic appointment*

Some participants noted that the calls they received at month three and month six asking them to turn up for appointments and to be interviewed were useful. They advocated that it be should be included in the care strategy because they had problems remembering appointment dates.

> *I would prefer they call and inform us about our follow up visits. (F1, P2)*
>
> *I really like the calls that coincided with the clinic days because I get to be reminded about my clinic appointment. (F2, P7).*
>
> *If they are planning they should take note of the date you are supposed to return to the clinic and call you. The date is very important. There are some people who do not have a calendar. So if your month is about ending, they should be able to plan and inform you that the month is about ending or that you should come to the hospital on this date. (F1, P1)*
>
> *The messages, well it is good, but I prefer the call; especially the way you called me yesterday to remind me of today's clinic. I welcome it. As a business woman you want to get to the market early to sell your things. You are worried about people you owe and those who owe you. The children, husband, your drugs, and you know women, our responsibilities are not easy. And in the mist of all this you can easily forget the date. So calling to remind us was very good. (F3, P5).*

There was a preference for follow-up calls on appointment days because participants noted their major problem was remembering the various dates. Others suggested an automated voice messaging system that had multiple options that patient would access at any time.

#### 6.8.4.3 *Sub-category 3: Automated voice calls preferred*

Some participants recommended the use of an automated call menu which would allow them to obtain different types of information about HIV/AIDS, not just adherence. Participants wanted an option which allowed them to choose to

receive the automated messages in their language of preference. The comments included:

> *I would prefer they use a short code that, when we dial, our phones would give us the option to select any preferred language to remind us to take our medication and also give us options which can be followed to help us take our medication and education about the treatment. F2, P5).*
>
> *I support what my colleague said, but would add that voice messages rather text messages be sent indicating that it is time for the follow up clinic. Preferably the voice message should be in the indigenous language especially the most commonly used which is Twi, because most people understand it. (F2, P4).*
>
> *Please, as another sister said earlier, if we can get a short code that when dialled can ask your language of preference, and asks if you have any challenges/difficulties with the medications, then you can also register the problems faced. Maybe the time you get at the clinic is not enough, and you may have some problem, so you can get information on any other difficulties we face. (F2, P3)*
>
> *I also want to agree with the use of the automated voice message system because that would allow you get messages in the language that you prefer. Most people cannot read the messages and do not even check their phone to know the messages on it. But as for voice messages, you are just listening so it is very easy. (F2, P6)*



The participants acknowledged the limitations of the text messaging system with regards to language and suggested a more diverse approach to supporting their treatment. They demonstrated their readiness to accept interventions that would make their life better and at the same time protect the privacy of their status.

### 6.8.5 Summary of findings perspectives on mobile phone use

Participants pointed out some key issues for consideration:

- Alarms activated on their phones facilitated adherence behaviour and was preferred because it ensured privacy.

- Text messaging was appreciated for its motivational content, but scepticism existed about the possible exposure of their HIV status.
- Text messages were not read with enthusiasm and were sometimes not received.
- Voice calls were preferred if they were to give reminders about clinic appointment dates.
- There was a unanimous endorsement for the use of an automated voice messaging system with could provide access to multiple levels of HIV/AIDS related information.

### 6.8.6 Theme 5: Readiness for M-health Integration in Care

The integration of mobile phone intervention in the care of clients with HIV depends on the preparedness of clients and the regulating and implementing agencies. The main categories were: *patient readiness* and *institutional readiness*. An analysis of the participants' accounts revealed that although there is a general willingness to accept and use mobile phones, there are some issues that still need to be addressed. These include perceived stigma, difficulties in using the technology and literacy levels among clients. The major challenge for the regulatory and implementing authorities is financial considering that there are competing budgetary demands from other equally important HIV related concerns. There is also the need for a policy review and a study of the legal and ethical implications of integrating mobile phones in adherence monitoring and the care of HIV infected persons.

### 6.8.7 Category 1: Patient readiness

Mobile phone intervention could be integrated if clients are willing, the system adopted addresses stigma related issues and the capacity of clients to use the technology is developed. The sub-categories were: *willingness, perceived stigma as barriers* and *technology and literacy*. A willingness to accept the use of mobile phones to support adherence was reflected in the self- monitoring category described earlier in this chapter. Some respondents within the focus group sessions were explicit in prescribing what they were willing to accept if mobile phones were to be integrated in adherence monitoring.

Responding to a question on what the expectations of using the mobile phones to support adherence were, F2-P3 suggested:

> *... [Referring to automated voice call] Then they can also maybe advise that you come to the clinic the next day, next week, or before your time is due. Or if it can give you any directives to do something, it would help us. (F2, P3).*

> *I think you should focus on calling us more, but you could still send the messages to those who want it, not everybody, because the fear of others reading the message is on our minds. (F3, P1)*

> *Oh, they were all ok for me. It made me keep to taking the medicine and that is fine. (P5).*

> *I don't usually use it but when I start using it, I would tell them to stop texting. You can remind me about the follow-up date but even that… (P6)*

Notably, some respondents were not ready for integrating mobile phone for adherence but one was quick to add:

> *But the fact that I don't want it does not mean it should not be used. (P1).*

The readiness of respondents to use mobile phones is not in doubt, but these were subject to conditions and preference. In spite of the perceived stigma, respondents were willing to try whatever was helpful to support adherence.

#### 6.8.7.1 *Sub-category 1: Willingness*

Participants were willing to use mobile phones if their privacy could be protected. The alarm and voice calls were acceptable to most of the participants, but a few were sceptical about the use of text messages.

> *...you have really helped us, I wish you would come back to continue soon. (P4).*
>
> *Sometime you receive messages like the one you sent to us to encourage us. The phone is very helpful, your family, spouse and friends can also call you and you discuss other issues. (F2, P5).*
>
> *...some months now you also encouraged us to use the alarm on the phone to remind us to take our medication. Sometimes I received messages and calls as well. I feel that the phone call is good. (F2, P8)*

Respondents were willing to use a mobile phone alarm, motivational voice calls and automated voice calls to support adherence. However, they were not keen on receiving text messaging; particularly messages relating to their medical condition or drugs regimen due to the lack of privacy of text messaging and the stigmas associated with HIV.

#### 6.8.7.2 *Sub-category 2: Perceived stigma as barrier*

Perceived stigma associated with HIV diagnosis and the 'pointing of fingers' feared by participants may be an obstacle to implementing integrated mobile phone intervention for adherence.

> *Oh, I think it is very good, it makes you know that people care*

*about you and want you to be healthy. The way the society treats you if they know you have this illness? So because of that you are careful not to get people to know, so it is good. Because the messages did not talk about the medicine, it was ok for me. (P2)*

*Hmm that one, it is some [how difficult] because if the text message comes and you are not around someone may read it. I may come to visit you and my battery is low so in charging someone may like to play with the phone and will end up reading your message, that is why I do not like the text messaging. (P6).*

*There are some people who do not want anybody to know they are attending the clinic. If you do not ask and you send the message or call everybody you can put the person into trouble. Some people treat you badly if they get to know you have such a deadly illness. So my concern is that only those who want to receive messages should be included. (F1, P3).*

The perceived stigmas associated with HIV remains a major barrier for some respondents. They would rather not risk using applications that are intended to help them but which might eventually expose their secrets. Training in the appropriate use of these applications and an enhanced use of passwords and codes could be used to minimise the risks perceived to be associated with using mobile phones. Raising literacy levels is another key element that would facilitate the integration of the mobile phone in adherence support.



#### 6.8.7.3 *Sub-category 3: Technology & literacy*

Participants need to acquire the necessary skills to operate their mobile phones optimally, or where this is not possible; they need to receive assistance from others. Levels of literacy also contributed to the use of mobile phones in supporting adherence:

*When they met us at the first time, they explained to us whatever was going to be done. They asked about when I take my medications and then taught me how to use the phone and set alarm. (P2)*

*You also came to teach us how to use the phone to help us take the drugs on time. (P3)*

*I take mine at 8:00 in the evening every day. My children assisted me to set an alarm on the phone, with a particular music. (F2, P4)*

*I use the alarm, my children helped me to set it on the time, and since then it rings, and wherever I am I know it is time to take my medication.*

*But when they showed me how to use the phone I set the alarm, so anytime the alarm rings, no matter where I am, I go to take the medicine. (P5)*

*I wish all of us had phones; some have the phone but do not know they can use it like the way you explained to us. So, I think that if those who do not have a phone, they could be given a phone; it can help them. (P6)*

*I don't read messages very often so I did not realize it. (F3, P5).*

## 6.9 THEME 5: INSTITUTIONAL READINESS

There are institutions responsible for developing, monitoring and implementing policies and programmes for HIV care and support. The readiness of these institutions to embrace integrating mobile phones in care was explored. Three documents were reviewed, in addition to the interviews, to extract information on ART guidelines and policy on the use of mobile phone intervention.



The extracts and narratives show that mobile phones are already in use in the care and support of people with HIV. There is also a willingness to accept using mobile phones to support adherence, however, budgetary constraints could delay the integration process. The existing policies on adherence would have to be reviewed in order to include guidelines for the integration of mobile phones for adherence support. The sub-categories that emerged from the data were: *willingness and acceptance*, *competing demands* and *policy readiness*:

*I recall not too long ago, I think last year, we had some people even coming in, the UNAIDS, Doctors without Borders, and*

*some other groups but I have forgotten their names. They came to discuss how we can use the same mobile technology in enhancing PMTCT. So they were trying to do some district level data collection, it is like a test of that in, I think, a district in Accra here. We went for meetings and we were trying to see how best we can use it. And I can also tell you that some of our implementing partners like West Africa AIDS Foundation four or three years ago were using mobile phone to call clients to remind them of their schedules for treatment and all that, so some of form of mobile technology is in use. (P7).*

#### 6.9.1.1 *Sub-category 1: Willingness and acceptance*

Discussions revealed that there is general consensus regarding the use of mobile phones to support adherence and that institutions will readily accept the integration of mobile phone intervention in care:

*Indeed, in our environment now, indications are that more and more people have access to mobile phones, about 80% of adults. Sometimes even the children want to have phones and will prefer the phones that are more sophisticated with different kinds of applications. So if we can use that to enhance our health, why not? (P7)*



He added that:

*The commission will readily support any effort to promote adherence. The current UNAIDS and global accepted goal is to ensure 90% of people should know their HIV status, 90% of those who test positive should be on treatment, 90% of those on treatment should have their viral loads improved. Therefore, whatever means we could use in a positive way to enhance this goal would be appropriate. Apart from this issue of using phones to promote adherence, we are actually using the phone for monitoring cases of discrimination and abuse. (P7).*

The WHO has proposed the integration of mobile text messaging in adherence support since 2013. It stated that:

*...individual-level adherence intervention recommendation in this section relates to the use of mobile phone text messages. There have been simple and robust trials to demonstrate its importance as one of many adherence tools. Adherence interventions, such*

*as text messaging, should clearly be provided as part of a total package of several interventions. Many individual level adherence interventions are indicated for reasons in addition to improving adherence to ART (D3).*

P8 recounting some of the interventions in the past noted a willingness to accept whatever would facilitate adherence. He commented that:

*Well if there are interventions that would help support adherence in any way I think it is a step in the right direction. With HIV, we have tried pill counts, we tried using pill counters some of them are quiet expensive but we have not really succeeded so the idea of using mobile phones to support adherence is a good step… I think it is the first time this is being done in Ghana. I mean using the alarm, text messages along with phone calls. I think this research should yield positive results and once it is ok, we wish to put in such interventions. (P8).*

The institutions recognise that technologies such as mobile phones have worked in some settings and clients are willing to embrace this tool. Nevertheless, resource limitations have restricted any commitment to setting timelines or any concrete affirmation. Indications are that support for programmes has been dwindling and that competing demands amidst budgetary constraints might delay.



#### 6.9.1.2 *Sub-category 2: Competing demands*

Despite the willingness to integrate the use of mobile phones in adherence support, there are issues with competing demands. The budgetary allocations may not be able to support this measure in the short-term.

*If we ask that calls should be made, the question of how to pay for the calls or messages would arise. When there was funding some of these issues were easily resolved but now we cannot do that; if you even ask them to call or send messages would they be using their personal phone? Who will provide the phones, especially those with additional application that have upgrades? (P7)*

He further added;

*If the systems are structured and running effectively and equipment is available, the commission will gladly embrace it. The issue now is to raise resources for such a system in the mist of competing demands on the health care budget...The challenge is the logistics for implementing some of these beneficial programmes. Currently, even in some government establishments some of the scheduled officers use their personal phones and credit to make official calls. As a result of resource limitations, we sometimes resort to making only urgent calls with personal resources...the issue is that there are competing demands and you see sometime we have a gap in providing ART. We do experience occasional shortages that require rationing of drugs. (P7).*

The readiness of the institutions to implement integrated mobile phone intervention is subject to resource availability. If the resources could be mobilised then the use of mobile phone intervention would feature in the programmes and policies of the institutions responsible for care and support for persons infected with HIV/AIDS.

#### 6.9.1.3 *Sub-category 3: Policy readiness*

In order to integrate mobile phone intervention to support adherence the existing adherence policies and guidelines needed to be reviewed to include the use of mobile phones. The WHO in their guidelines recommended the following adherence interventions based on moderated quality evidence.

- *peer counsellors*
- *mobile phone text messages*
- *reminder devices*
- *cognitive behavioural therapy*
- *behavioural skills training / medication adherence training*
- *fixed-dose combinations and once-daily regimens(D1)*

*Reminders and communication that engage people in taking ARV drugs could be an important intervention to improve adherence through behavioural change. The use of mobile text messages for supporting adherence and in health care delivery in general has increased as access to phone technology expands...Other patient reminder tools include alarms, phone calls, electronic diaries and calendars and are used to send brief reminders about the timing of ARV drugs, drug dosage and*

> *appointments. The evidence does not demonstrate that these interventions support treatment adherence better than the standard of care. (D3).*

The National AIDS Control Programme in Ghana recognised the barrier of adherence and mentioned in the guideline for ART that:

> *Strategies used to overcome the problem of non-adherence, include use of drug time-tables, reminders by phone, alerts by clocks, adherence monitors, pill boxes and continued adherence counselling. The patient should be reassured about side-effects and an alternate regimen should be discussed if side-effects are intolerable (D2).*

Mobile phone reminders were named as an adherence support measure but with no explicit guidelines. Adherence support using SMS is viewed with sceptically by clients and this ought to be kept in mind. P8 who has worked with clients with HIV over the years noted:

> *The drawback would be whether clients would give you their correct phone numbers and whether clients are comfortable getting text messages because you know your phones can be picked up by anybody. Somebody picks up your phone and asks what kind of reminder this is. So we still need to look at how we can make it full proof. Is it by bulk messaging or what? I think we still have to fine-tune it more but it is a good intervention (P8).*



P8's concerns were further emphasised in participant narratives, some of whom noted that explicit text messages that mention medication and dosages could result in the unintended disclosure of a person's status. In view of the evidence based recommendations in the WHO 2013 guideline they advocated:

> *Using this, [text messaging] however, requires adequate national regulations to protect the privacy of the people receiving text messages. Programmes may explore public-private partnerships to accelerate the scaling up of mobile phone–based interventions. (D3).*

P8 mentioned that there were no explicit policies on using mobile phones to support adherence. He commented:

> *But as to whether we have outlined a policy stating the use of mobile technology, I don't think so. What we do know is that in our 2010 ART guidelines we started talking about adherence. I think that was the first time we introduced that into our document and ever since it has been in there. So we emphasise on adherence alright; and ensure adherence. There are several things that we do but specifically to say that the use mobile technology is the way I don't think it was stated in that document. (P8).*

A review of the national guidelines would have to take into consideration the resource limitations, clients' concerns, public-private partnerships and ethical considerations for using mobile phone intervention in care of patient with HIV.

#### 6.9.1.4 *Summary statement: readiness for M-health integration in care*

Integrating the participants' comments and extracts from the documents reviewed revealed the following:

- Participants were willing to embrace the use of the alarm and voice calls, but were sceptical about the use of text messaging.
- There are technology and literacy gaps which must be filled in the implementation of mobile phone interventions.
- Existing guidelines were not specific about the integration of mobile phone intervention in healthcare.
- Resource limitations could be addressed through public-private partnerships.
- Proposed guidelines for the integration of mobile intervention should be multifaceted so as to manage any possible constraints in its implementation.

### 6.9.2 Summary of qualitative evaluation

Bearing in mind the history of their illness, participants were cognisant of the benefit of ARVs; and were therefore motivated to adhere to their treatment. Instrumental and religious factors facilitated acceptance and motivated their willingness to follow the treatment schedules. Non-adherence behaviour patterns were unintended because they had no problems with the pill burden and dosing but emphasised the importance of eating food when taking the ARVs. Clients also acknowledged that the side effects of treatment were temporary, and they therefore kept their commitment to taking their medication.

The narratives and reviews from the mobile phone intervention context revealed a willingness to accept the alarm and voice call interventions among participating clients. The acceptance of text messaging intervention was subject to the protection of their HIV status. There was preference for automated voice messages that were delivered in indigenous languages. There were technology and literacy gaps which could be addressed with reorientation and the design of the intervention.

Institutions responsible for regulating, planning, implementation and monitoring of HIV/AIDS interventions were willing, in principle, to integrate M-health care strategies to support adherence. However, resources were limited and existing guidelines only mentioned the use of mobile phone reminders but were not explicit about policy, regulations and guidelines.

# CHAPTER 7: DISCUSSION

## 7.1 INTRODUCTION

This chapter presents the discussion of the findings of the study, which sought to evaluate the integration of mobile technology to improve adherence to ART in clients with HIV/AIDS. The study was in three phases: a randomised controlled trial was conducted in the first phase to determine the effectiveness of using mobile phones to promote adherence. A qualitative evaluation of experiences of HIV infected clients and perspectives on integrating mobile phone intervention occurred in the second phase. The third and final phase involved a synthesis of findings and existing evidence in order to make recommendations for integrating mobile phone technology. The specific objectives were to:

1. Assess adherence to treatment among HIV infected clients in Accra, Ghana
2. Identify the demographic characteristics, clinical variables and support measures that predict ART adherence
3. Evaluate the effectiveness of using mobile phone intervention to promote ART adherence among clients with HIV
4. Evaluate the experiences of HIV infected clients and perspectives of significant others on integrating mobile phone intervention in adherence strategies
5. Make recommendations for integrating mobile phone intervention in adherence monitoring strategies

## 7.2 ADHERENCE TO ART AMONG CLIENTS WITH HIV/AIDS PRIOR TO MOBILE PHONE INTERVENTION

### 7.2.1 Overall adherence of study respondents

The findings of the study suggest adherence was good and poor with some factors facilitating or inhibiting adherence behaviour. The assessment of adherence at baseline in this study revealed that the majority of the clients generally adhered to their medication. The adherence scores ranged from 94.6% to 100% depending on the measurement subscale. Amankwah (2015) also reported 100% adherence among respondents with three (3) days pill recall in a study that investigated facilitators and barriers to treatment adherence in HIV/AIDS. The outcome is however, inconsistent with studies that reported adherence of 62% and 91% (Obirikorang et al., 2013b; Ortego et al., 2012).

Good adherence to treatment involves following strictly prescribed regimen and adhering to instructions. This includes taking medication, following advice on diet, avoiding abuse of substances and reporting for follow-up visits (WHO, 2003). With the exception of medication taking behaviour the other aspects of adherence such as diet, substance use and follow-up were not explicitly assessed at baseline. The Pill identification subscale of the Multimethod adherence tool had one item that evaluated knowledge of additional instructions which included issues related to diet and substance use. In view of the limitation in assessing all construct of good adherence, adherence outcome in this study is limited only to the medication taking behaviour. Nevertheless, the adherence measures were varied therefore the outcomes are arguably a reflection of adherence behaviour of respondents at baseline.

Adherence outcomes were observed to differ depending on the tool used for the assessment. The Multimethod tool measured respondents' subjective account of adherence based on the recall of medication behaviour, rating of adherence on a scale (0-10), identifying pills and presenting pills for counting. The Visual analogue scores had the worse adherence outcome in that the rating, compared with other scores, were relatively lower. In effect, including the visual analogue scores in the overall adherence outcome decreased adherence while excluding it from scores increased the scores. The overall adherence score was obtained by summing up the subscale scores. The Multimethod adherence tool developers Steel et al. (2007) in their report indicated correlation between the tool and other measures such as MEMS. Although their sample size was small (n = 30) the outcome seemed convincing. The outcome further suggests a measurement error relating to response bias or lack of understanding of the rating process which is a common phenomenon associated with evaluation tools (Lehmann et al., 2014; Williams et al., 2013).



The qualitative evaluation in the current study revealed that consequences of adherence and nonadherence empowered participants to adhere to treatment. There was such a strong recognition of the importance of adherence that a participant held the view that the clients must take responsibility for adhering to treatment and recommended punishment for nonadherence. The findings support other outcomes that noted that motivation facilitates adherence especially if clients recognise that taking ART is a lifelong commitment (van Loggerenberg et al., 2015)

Notwithstanding, a few cases of suboptimal adherence were observed in the baseline assessment of adherence using the multimethod scale; occasionally

clients missed their pills or appointments. Instances of nonadherence were confirmed in the qualitative reports as some participant mentioned forgetfulness and sleeping through doses as unintended reasons for missing doses and appointments. Suboptimal adherence is a major challenge in clients with HIV however; there have been improvement in ART adherence over the years (Nachega et al., 2014; Pop-Eleches et al., 2011). Previous reports about suboptimal adherence to treatment suggest that some clients intentionally stop treatment due to side effects of the drugs or substance abuse (M. Johnson et al., 2005; Mannheimer & Hirsch-Moverman, 2015). In addition to motivation, nonadherence is inhibited if there are no strategies instituted to support adherence.

### 7.2.1 Adherence support measures at baseline

Good adherence is strongly related to good adherence support measures. At baseline assessment, adherence support measures available to respondents were examined to determine factors that influenced adherence to ART. The support measures assessed included adherence counselling; visits from community health workers; spousal support; family support; support from religious groups, peers and NGO's. The use of medication charts and purses, alarms, receiving text messages and calls to support adherence were also assessed.

Adherence counselling was the most helpful support measure available to the respondents. This is recognition of the value of receiving information on the medication dosing and general lifestyle when taking treatment as a relevant measure. This outcome reflects the effect of implementation of a compulsory adherence counselling policy in all facilities providing ART consistent with the

guideline for ART (NACP, 2014a; WHO, 2013). Counselling prior to initiating treatment provided information about adjusting to life, being aware of the implications of being HIV positive, stigmas associated with HIV and the need for support (NACP, 2014a).

Field observations, interviews with some professionals and a review of existing guidelines revealed that a lot of emphasis is placed on adherence counselling prior to the initiation of treatment. One of the standard eligibility criteria for enrolment into therapy is compulsory adherence counselling sessions with an assigned counsellor. A minimum of two counselling sessions are a mandatory requirement for eligibility for counselling as is the presence of an adherence monitor who is expected to supervise clients following initiation of treatment. Additionally, the institution puts strict measures in place to ensure adherence with an expectation of strict adherence to ART. These measures were explicitly outlined in the guideline for ART treatment (NACP, 2010a, 2014a) and according to professionals interviewed, regular training of counsellors strengthen their capacity to prepare and manage issues of treatment adherence. In other settings there is a shift to nurse-led ART programmes which have been found to improve access and promote adherence when compared with doctor-led ART interventions (Davies, Homfray, & Venables, 2013; Lanktree, Corluka, Cohen, & Larocque, 2014).



Respondents also mentioned support from spouse and family members as helpful measures that encouraged taking medication, adjusting to their new life and keeping clinic appointment. Sometimes spouses and family members doubled as adherence monitors. Consistent with literature, social support is a measure that facilitates adherence to treatment (Portelli et al., 2015; Ruanjahn et

al., 2010; van Loggerenberg et al., 2015) however, stigmas associated with HIV limits the availability of support (Portelli et al., 2015; Starks et al., 2008).

Medication chart, diaries and purses are not measures commonly used in Ghana although they are common in developed countries. The charts and dairies when used ensures tracking adherence while the use of purses improves access to medication. Published reports indicate that these measures have been used to support adherence in other studies (Bärnighausen et al., 2011; Mannheimer & Hirsch-Moverman, 2015). The absence of purses did not prevent clients from carrying their pills with them when needed. Some mentioned putting the medication in polythene bags or in their pocket when they were away from home.

Although there are several NGO's working in the area of HIV, respondents did not receive support from them. The standard guidelines for care and support for clients with HIV indicated home based care as a strategy however; the results do not reflect the implementation of this approach in the health care of clients with HIV because respondent noted that visits from health care providers were absent. Field related communication with respondents revealed they might not even want visits from nurses or health workers so as to avoid unsolicited questions about their health status. The impact of stigma and discrimination remains a challenge to home-based care intervention in HIV/AIDS care. Lee, Moneyham, Kang, and Kim (2015) reported similar concerns from peer supporters who worked in home visit programme.

Prior to the Intervention, respondents were not using alarms to prompt them to take their medication. Text messages and phone calls were also not being used to support adherence. The qualitative findings revealed that although most

participants had mobile phones they did not routinely use them for monitoring their treatment. The most common use of mobile phones that assisted with adherence was the use of the phone as clock to check when it was time to take medication. Some mentioned receiving calls from their treatment supporters but not the health professionals. There are recommendations for countries to explore options of integrating mobile phone use in supporting adherence based on evidence from researches and systematic reviews (Belzer et al., 2015; Kim et al., 2015; WHO, 2013). Nevertheless, there are still issues relating to the effectiveness of these measures such as acceptability, sustainability and resource availability (Chib et al., 2015; Granger & Bosworth, 2011).

### 7.2.2 Challenges in measuring adherence

Adherence was measured with the multimethod tool and evaluated Self-report, Visual analogue, Pill identification and Pill count. Additionally, the scores were summed to determine the overall score. Differences were observed in the adherence scores for each level of measurement (Self-report, Visual analogue, Pill identification test and Pill count) although the overall adherence revealed that 70% of the respondents adhered highly to treatment at baseline assessment. The overall adherence score was obtained by computing transformed scores of the four subscales as indicated earlier on. Findings showed most of the respondents were adherent to treatment. Further analysis of the various subscales however, revealed weak correlation of the subscales. Adherence behaviour is observable but quantifying adherence objectively remains a major challenge (Williams et al., 2013). Despite the limitations in measuring adherence there have been several measures used to estimate adherence in different populations (Agot et al., 2015;

Bärnighausen et al., 2011; Chalker et al., 2010; Ross-Degnan et al., 2010).The expectation was that scores obtained in adherence should be similar, irrespective of the measurement applied. Social desirability or measurement error which is common in research may have accounted for the weak subscale association (Kalichman et al., 2015). In addition, each subscale examined different methods of adherence and this may account for the observed variations (Lehmann et al., 2014). In addressing this problem, weak subscales that significantly contributed to poor outcomes were excluded as was the case with one item in Pill identification test and the entire outcome for Visual analogue. The exclusion of extraneous items and scores in the overall outcome improved the adherence outcomes and demonstrated increases in scores although these were not statistically significant.

#### 7.2.2.1 *Self-report measure*

Participant accounts on the qualitative analysis of the experiences with diagnosis, treatment and adherence revealed that self-reporting was one of the adherence monitoring strategies used to determine if they were taking their medication. The participants' self-consciousness and knowledge of the importance of adherence presumably accounted for the satisfactory self-rating of adherence behaviour. A four-day recall period of taking their medication revealed respondents had no difficulty remembering their treatment; did not miss any doses; and did not stop treatment if they felt better or worse.

Adherence level assessed with the four self-report items, using the Morisky scale, indicated that 75% of respondents demonstrated optimal adherence (≥95%) to treatment. Adherence levels in other studies were high with a maximum of 91%

reported (Obirikorang, Selleh, Abledu, & Fofie, 2013a; Ortego et al., 2012). Arguably, the likelihood of exaggerated adherence level might have occurred due to the tendency to engage in approval responses which is a notable limitation of the self-report scale (Agot et al., 2015; Culig & Leppée, 2014; Stirratt et al., 2015). The bias associated with the tool could be addressed by using approaches to data collection that eliminate face-to-face contact with client (Stirratt et al., 2015).

Another limitation to the outcomes of this assessment is the shorter than normal duration of recall used in this study which could influence the outcome. 30 days pill recall is assumed to be a more sensitive measure of self-report adherence assessment (Stirratt et al., 2015). However, other studies have reported a three-day recall period that effectively estimated adherence (Obirikorang et al., 2013b).

It is worth noting that patient folders were designed in a way that allowed for assessment of adherence at each clinic visit. Observations in the field depicted these assessments were often rushed and clients also gave approval responses. Nevertheless, in this study it was difficult to measure, control and report these effects particularly because interviews were conducted on clinic days.

The remedy for minimising the bias of self-report is to validate outcomes with other measures (Williams et al., 2013) such as MEMS and viral load estimation. However, these measures were not employed but pill count and visual analogue scale data was obtained based on the multiplicity of the tool used in this study.

#### 7.2.2.2 *Visual analogue*

Visual analogue scale outcomes revealed an average adherence of 84% among respondents and it was the least observed results when compared with the other subscales. The respondents were shown a ruler and asked to point to their highest adherence level. Interestingly, respondents' rating of adherence was lower compared with the self-report and pill count score. The Visual analogue score further declined in the month three and month six evaluation. This affected the estimation of overall adherence. This is not consistent with outcomes observed by (Steel et al 2007), when the multimethod tool was developed.

The respondents ostensibly underestimated adherence using the visual analogue assessment. The researcher observed low self-rating by respondents but was unable to measure what accounted for the low self-evaluation. Exploring the socio-cultural context of self-evaluation might clarify the low scores obtained. Visual analogue assessment of adherence is done as part of self-report to obtain numerical ratings but critiqued for social desirability effect. Clients' judgement is assumed accurate (Kalichman et al., 2011) however, none of the themes that emerged from the data put forward the rational for the poor correlation between the visual analogue assessment and other measures such as the pill identification test. The probability of poor administration of the instrument can also not be ruled out. If the concept of rating on a scale of *'0 to 10'* is not understood pointing it out on a ruler could have an influence. There was no measure in place to examine and account for outcomes associated with poor tool administration or performance, but it was assumed that, based on statistical measures employed, errors may be accounted for or declared as a limitation. It is

worth noting that Visual analogue scores were also the lowest adherence scores observed during the validation of the instrument (Dzansi et al., 2015).

#### 7.2.2.3 *Pill identification test*

The Pill identification test outcomes showed 82% of respondents moderately adhere to treatment. The major contributing factor to the low observed scores was the inclusion of the item '*knowing the name of the pills'*, which should have been excluded from the cognate scores. The majority of respondents did not know the name of their pills but could identify the pill, dosage and instruction. The pre-test of the tool also revealed that scoring knowledge of pill name decreased Pill identification test scores. There were no recent studies that established a relationship between knowing medication names and adhering to ART. However, (Trevino, Albright, Wright, and Cigarroa (2005) established no significant relationship existed between knowledge of medication (not just the name but all the drug information) and adherence outcome. On the contrary, (Okuyan, Sancar, and Izzettin (2013) argue that knowledge of the medication improved adherence outcomes. In essence, the respondents in this study, at baseline, could be considered optimally adherent although most of them did not know the name of their ARV. Respondents were able to indicate dosage of drug, timing and instructions to be followed while taking the medication.

Steel et al. (2007) reported PIT measures correlate with MEMS and was a useful compliment in adherence measurement. There was paucity of literature on using Pill identification test as an adherence measure. One article was found to have compared pill identification test measures with self-report and indicated scores were positively correlated (Parienti et al., 2001) but the study was quite outdated.

Paterson, Potoski, and Capitano (2002) also suggested the use of pill identification tests in clinical practice to monitor adherence.

When interacting with participants, it was obvious that they had a way of identifying the medication using the colour, size and shape of the drug. Furthermore, their comments during focus group discussion and interviews revealed their knowledge of regimen dosing and instructions for taking ART but they were unable to name the ART they were taking. A few of the participant who tried guessing the name of the drugs during the focus group discussion only succeeded in amusing their colleagues in the process. It is worth noting that effectiveness of adherence counselling in promoting adherence has been well documented (Chung et al., 2011; Pradier et al., 2015; Wagner et al., 2013). A major focus during the adherence counselling session is educating client on medication (NACP, 2014a). What is unclear is the relationship between counselling the patient to take medication and the ability to identify ARV by name. Observation at the clinical setting revealed that clients were not shown samples of medication during the counselling sessions. Moreover, ART is prescribed after the counselling session with limited post counselling sessions for defaulters and clients with adverse reactions to the drugs even. Nevertheless, pill identification measures are still relevant subjective adherence indicators for assessing adherence (Steel et al., 2007).



#### 7.2.2.4 *Pill count*

Pill count score estimates recorded 99% adherence levels among the respondents which is an indication of optimum adherence. The expected adherence level that limits adherence related drug resistance is estimated at 95%

(Paterson et al., 2002). However, this outcome may not necessarily reflect the real adherence behaviour since the actual act of taking medication was not observed. The pill count measure of adherence has been critiqued for overestimating adherence and the inability to control unseen medication practices such as pill sharing or pill dumping (Agot et al., 2015; Kebaabetswe et al., 2015).

When interacting with respondents they mentioned that quantity of drugs supplied sometimes exceeded the quantity required until the next clinic appointment, because the doctors anticipated that some of them would forget their clinic dates. This was also observed during the intervention period as some outcomes of the pill counts confirmed high drug possession ratios. Some patient admitted still having pills at home from their previous supplies. Field information further revealed pill-hoarding practices in anticipation of pill rationing due to inadequate stocks. Notwithstanding the perceived overestimation of adherence using pill count score, the self-report and other measures also pointed out optimal adherence behaviour among the majority of respondents at baseline. Steel et al. (2007) in their study reported the pill count score correlation with MEMS and self-report. The baseline assessment facilitated the design and implementation of the integrated mobile phone intervention.



## 7.3 EVALUATION OF MOBILE PHONE INTERVENTION FOR IMPROVING ADHERENCE

The evaluation of the integrated mobile phone intervention was situated within a different context. The implementation plan was derived from the transactional goal attainment model that enabled active participation of respondents. The

overall evaluation of the intervention targeted process evaluation, impact of the intervention and the impact of specific the interventions.

### 7.3.1 Process evaluation

The evaluation process was mainly deductive and, as such, no structured outcome indicators were measured. The intervention (alarm scheduled on medication time, weekly motivational text messages and monthly motivational voice calls) were situated within a transactional model of goal attainment (King, 1991). This provided a focused approach to the implementation process. The intervention framework required that the adherence needs of respondent be identified first, in collaboration with the service provider, and then mutual goals agreed upon. Thereafter resources that were needed were identified and the plan was implemented and evaluated. The interaction in the relationship with respondents was face-to-face and via mobile phone. The design of the intervention reflected a one-way feedback oriented system.



Participant accounts suggest satisfaction with the intervention and a desire for the intervention to be extended. Participants also took personal decisions to set and adhere to adherence goals with support from the research team. Harkin et al. (2016) noted that goal attainment interventions are effective ways of ensuring self-regulation and behaviour change in people. The goal attainment model has been utilised as framework for information synthesis (Caceres, 2015; Harkin et al., 2016) but this is the first-time the model was used in a mobile phone intervention for adherence support. A structured evaluation of the process, with specific indicators, would have added to existing evidence on utilisation of transactional goal attainment model in nursing care. Nevertheless, future studies could examine the effectiveness of the transactional goal attainment model. The

absence of an objective measurement of the entire intervention process was substituted with evaluating other aspects such as the usage of mobile phones prior to initiating the intervention.

#### 7.3.1.1 *Low phone usage for adherence prior to intervention*

Respondents included in this study had to have access to mobile phones but it was important to determine the privacy levels they had when using their phones. The findings revealed very few respondents were sharing their phones with only 7% identifying that they share their phones with other people. Hampshire et al. (2015) reported phone sharing occurs among 35% of young people using phones. Other studies also indicate phone sharing practices as a common phenomenon (Aker & Mbiti, 2010; Shet et al., 2010). The sensitive nature of an HIV positive diagnosis, given the associated stigmas, requires the use of strategies that limit the effects of phone sharing practices. This will then enhance acceptance of mobile phone interventions, for adherence, especially in cases where there is limited access to mobile phone.



Studies in Ghana suggest that mobile phone use is increasing with 93% of households owning a mobile phone (Hampshire et al., 2015). Access to phones however, transcends owning a phone. There are other practices besides phone sharing that also endanger phone privacy. The qualitative findings indicated that although sharing mobile phones was not common, some participants, in their narrative during the interview and discussion, reported that they occasionally charged their cell phone in the homes or shops of families and friends if they did not have access to electricity. Notably some participants who were not comfortable with receiving messages mentioned the danger of other people

seeing the messages and asking question in such instances. The perceived risk to privacy was fuelled by the fear of stigma and discrimination following status disclosure. Stigma and discrimination remains a major barrier in the fight against HIV (Brener et al., 2013; Dako-Gyeke et al., 2015; Wekesa & Coast, 2013) and attempts to integrate technology in adherence strategies.

Though studies have suggested that alarms were used to facilitate waking up (Shet et al., 2010) and as reminders to take medication, the majority of the respondents did not use alarms to assist with adherence and less than 40% of the respondents expressed an interest in being trained to use them. Using the alarm facility available on mobile phones was not a common practice although participants in the focus group discussions mentioned that they were aware of these applications but only used them occasionally.

Language of communication was an important consideration that was relevant in planning the next stage of the study. In the WeTel study (Lester et al. (2010) used an indigenous language for text messages but respondents in this study preferred text messages in English and voice call in the indigenous language. The majority of respondents reported using voice calls, which could be because it is simple and required minimal literacy. More so, voice communications were often in the indigenous language and only a few respondents used English.

Only two factors predicted mobile phone usage in this population, namely education and employment, which are often related. This finding is consistent with other studies that reported higher education levels and formal employment influenced the usage of mobile phones (Shet et al., 2010). The evidence from this study suggests that individuals with higher levels of education have appreciable

greater mobile phone literacy skills and are better able to use more complex applications. Formal employment implies having at least a basic education and a consistent income and therefore being able to afford the costs associated with using a mobile phone. Notably SMS applications were found to be associated with younger age groups and levels of education.

### 7.3.2 Impact of Intervention

Adherence was measured between the two groups to determine the effect of Intervention vs. Non Intervention at three time points (baseline, three months and six months). The aim was to determine if the use of the alarm, weekly text messages and monthly motivational voice calls improved adherence over time.

The findings of the baseline assessment, as expected, indicated that no differences existed in adherence levels between the two groups. The groups were homogenous and all other demographic parameters measured. The results demonstrated that the randomisation process yielded the desired outcome. Kahan, Rehal, and Cro (2015) argued selection bias is a major limitation in RCT and could be minimised by using concealment, simple randomisation and stratification of sites or variables. These processes were followed as is reported in the methodology chapter.



#### 7.3.2.1 *Between groups evaluation - impact of intervention vs. receiving no Intervention*

The Integrated mobile phone intervention had no significant effect in this study though differences were observed with different scales between the groups. The adherence score, which was the primary outcome, was slightly higher in the Intervention group but the difference was not statistically significant. Similar and

contrasting findings in other studies have been found ranging from no effect to significant effects of mobile interventions on treatment outcomes (Bärnighausen et al., 2011; Horvath et al., 2012;  Lester et al., 2010).

The self-report evaluation of the outcome revealed a near significant effect ($p$ = .06) for the Intervention group in a univariate analysis while linear mixed modelling showed intervention was significant ($p$ < 01) at month three but at month six adherence peaked at 100% in all groups. Visual analogue assessment revealed the intervention had no effect. The Pill count outcome indicated that although the Intervention group scored higher on adherence the differences were not statistically significant suggesting the intervention had no effect. Similarly observed differences for the pill identification test between the Intervention and Control groups was not statistically significant even though adherence peaked to 100% by month three and month six in the Intervention group. The Overall adherence score had two outcomes; when all the subscale scores were computed, adherence declined however, when visual analogue is excluded from the overall score adherence increased but intervention was not statistically significant. The findings relates to (Shet et al. (2014) who conducted their study in India and demonstrated that mobile phone intervention had no effect after two years of intervention using different study sites.



#### 7.3.2.2 *Impact of time (within group evaluation)*

The results further pointed out changes in the adherence scores of the respondents at the different time points irrespective of whether they were in the Intervention or Control group. Statistically significant increases were observed from month three to month six in both groups except the visual analogue score in

which there was a significant decline. This finding pointed out that adherence levels increased over time. The increases occurred in both groups with the intervention group having slightly higher scores, but these were not statistically significant. The outcome may arguably be associated with the repetitive evaluation of the respondents. The respondents could also have become more familiar with the assessment over time and therefore responses could be pre-emptive. Inference could be adduced that adherence improves with time with repetitive evaluation. The psychosocial effect of the interaction between respondents and research can also not be ruled out.

Additionally, as reported in intervention evaluations there were protocol violations. In spite of the strict monitoring, some events occurred which were beyond control in this study. The decision to link text messaging to a web-based application failed due to technical and technology challenges. In addition, the voice calls made to all participants for follow-up data collection was considered valuable for those in the Control group, which presumably influenced their evaluation. Additionally, the qualitative outcome did not evaluate experiences of the Control group therefore no interpretation could be adduced to the meaning of findings in the Control group.



### 7.3.3 Impact of different components of Intervention

#### 7.3.3.1 *Effect of alarm usage on treatment adherence*

At baseline assessment 76% of the respondents indicated that they did not use the alarm application on their phone. However, when they were asked to indicate if they used it as an adherence support measure 99% admitted not using the alarm at all. Following the introduction of alarm in the Intervention group 69%

reported the alarm was helpful in supporting adherence at month three and month six. The observed differences in alarm usage between the Intervention and Control groups was statistically significant at $p<.01$. The narratives from the qualitative study, which revealed that alarms were preferred because it was personal, supported this outcome. Some noted the alarm was useful in preventing oversleeping and facilitated their ability to take their medication according to schedule. However, the use of alarms did not predict adherence nor result in adherence improvement behaviour which is inconsistent with studies in which the use of alarm and pocket electronic devices improved adherence (Bärnighausen et al., 2011). Chung et al. (2011) found that alarm use did not influence adherence behaviour when alarm usage was compared with counselling in a randomised controlled trial.

Some participants in the qualitative phase mentioned that they set the alarm at medication time but after a while got used to the prompting. The duration of this study limited the evaluation of the long-term effect of alarm usage. The effect of using alarms overtime may wear-off due to the repetitive nature. Conversely the 'Thorndike effect' (Skinner, 2004) is a helpful way of learned behaviour that accustoms individuals to the medication schedule if there is consistency in the regimen.

The use of alarms may, in the short-term, be valuable in facilitating adherence in persons initiating treatment and in cases where the schedule of work or related activities could lead to forgetfulness. Further investigation is required to determine the effects of the long-term use of alarms in supporting treatment adherence and measures to limit the effects of familiarity with the alarm.

#### 7.3.3.2 *Effects of weekly text messaging on treatment adherence*

The initial assessment revealed that 69% of the respondents did not use text messaging applications and that more than half of these were in the Intervention group. Therefore, respondents were trained to use text messages during the intervention implementation process. The training improved usage but had no effect on adherence behaviour. One of the gaps in technology usage and acceptance is the perceive use and ease of use (Georgette et al., 2016) and filling the technology gap enhances the usage.

The multimethod tool used to assess adherence in this study revealed that weekly text messages had no significant effect on adherence scores between the two groups. Nevertheless, a comparison of the usage of the text messages revealed significant improvement in both the Intervention and Control groups at month three and month six $p < .01$. However, the majority (72%) in the Intervention group mentioned the messages were not helpful at the sixth month evaluation.



The interviews and focus group sessions revealed that participants assessed the messages as good since there were was no medication linked content. However, they did not like the messages because of the risk they posed to their status being exposed and the associated perceived stigma and discrimination. The finding confirms stigma as a major barrier in HIV/AIDS responses strategies in general and specifically the use of text messages in improving adherence which has been confirmed by studies recognised the limitation posed by stigma on adherence (Mannheimer & Hirsch-Moverman, 2015; Sanjobo et al., 2008; Wakibi et al., 2011; Wasti et al., 2012).

The text messages used in this study were motivational and had coded communication. This was done to determine if the concerns about privacy that respondents had would change. However, their responses and narratives suggest that, irrespective of the content of the messages, perceived stigma is a barrier to transparency and willingness to embrace measures that pose the slightest risk of status exposure.

Text messages have been used to support adherence in several studies (Horvath et al., 2012; Lester et al., 2010; Lester et al., 2009; Pop-Eleches et al., 2011). Evidence from the literature suggests inconsistent findings, some reports suggesting text messages were effective in some instances but had no effect in other cases (Horvath et al., 2012; Jaiantilal, Gutin, Cummings, Mbofana, & Rose, 2015; Kelly & Giordano, 2011; Kim et al., 2015; Lester et al., 2010; Lester et al., 2009; Pop-Eleches et al., 2011). Horvath et al. (2012) noted that short messages delivered weekly were effective while Finitsis et al. (2014) indicated two way feedback messages that target the specific needs of patient are more effective. One of the concerns related to use of text messaging in adherence support is the risk of status exposure and this affects acceptance of text messaging interventions (Georgette et al., 2016).



Language literacy is another factor that influences the use and effect of text messaging on adherence outcomes. Respondents noted English was their preferred language for text messages but 23% had limitations with language literacy. Language and literacy was identified as a limitation in the use of text messages hence Wolpin et al. (2016) suggested the use of pictorial messages in individuals with low literacy. However, this measure has not been explored as alternative in the current study. Pictorial messages may be useful as an

education strategy but the potential to facilitate adherence in a population that adheres to treatment because of treatment benefits and related psychosocial factors is yet to be determined.

Another observation was the issue of literacy; some respondents indicated their inability to read text messages during the initial assessment. This was confirmed in their narratives as some mentioned their inability to read text messages. Others with no literacy limitations also admitted they did not pay attention to the messages because of being familiar with the essence of the messages. Literacy is a key indicator reported to predict adherence behaviour (Sanjobo et al., 2008; Wasti et al., 2012). The higher the level of education the better the health literacy skills and adherence practices.

There was consensus among respondents in the focus group sessions on their preference for automated voice messages. This suggests that participants would rather listen to information on adherence than read about it. Further investigation into reading culture and its influence on preference for text messages may provide some context to the outcomes on the usage and acceptance of text message applications as adherence support measure.



#### 7.3.3.3 *Effects of monthly voice call on treatment adherence*

The use of voice calls was predominant among the respondents at baseline. Most of them preferred using their indigenous language for their calls. Using voice calls requires less literacy skills and therefore it was easier for respondents to make and receive calls from family and friends. However, 66% of respondents still noted that they required training to use the phone at baseline. Interacting with them, it was observed that they were interested in knowing how to retrieve

missed calls, save numbers to contacts and some other basic functions associated with voice calls.

The voice calls made during the course of this study were meant to encourage respondents and to assist in responding to any issues concerning their medication. Additionally, at month three and month six, calls were made to all respondents (Intervention and Control groups) to remind them of their upcoming clinic appointments.

Adherence scores on all the dependent variables (self-report, visual analogue, pill identification test, pill count, and overall adherence) suggested that voice calls did not make a significant difference in both groups. Therefore, no conclusive attributions could be made that the monthly voice calls improved adherence. Nevertheless, significant difference were observed in the ratings of the use of voice call among the two groups $p<.01$. Out of the 152 respondents turning up at month six, 96% noted that the voice calls were helpful. Some studies and reviews have demonstrated improved adherence to treatment in clients who received voice calls (Cook et al., 2009). There are studies which also noted no significant effects exist between using voice calls for supporting treatment adherence and improvement in adherence outcome (Shet et al., 2014).

The results could not be statistically justified to promote adherence, nevertheless; participants were unanimous in their appreciation of receiving voice calls. The calls were important motivators that made participants experience a sense of belonging. Some participants suggested that the voice calls should focus on reminding them about forthcoming clinic appointments. There are different factors

that may be attributed to treatment adherence behaviour and outcomes that are not necessarily the direct effect of receiving calls.

## 7.4 FACTORS INFLUENCING ADHERENCE TO TREATMENT

In this study factors affecting adherence were assessed using the multimethod tool to statistically compare relationships between variables and in-depth information from participants. Adherence to treatment is a major outcome for determining the health status of individuals infected with HIV/AIDS. There are events, situations or activities that dissuade or precipitate adherence behaviour. Statistical modelling was done to determine the predictability of demographic characteristics and clinical variables in adherence outcomes. The results show that individuals with higher levels of education were more likely to adhere to their treatment. This finding is consistent with other studies that reported adherence scores were associated with educational level in that having higher levels of education improve the likelihood of being more adherent to treatment (Mannheimer & Hirsch-Moverman, 2015; Pellowski & Kalichman, 2015).



Clinical variables measured to determine if there was significant change overtime were CD4 counts and body mass index, which was a secondary indicator of improvement attributable to mobile phone intervention as this would be the long-term goal of adherence. Results showed that the expected significant increases in CD4 count levels for respondents in the Intervention group were not observed. It was beyond the scope of this study to measure CD4 count levels, therefore the results were extracted from patient records. Clinical indicators such as suppression of viral load have been used as measures for determining improvement in health status (Kobin & Sheth, 2011; Lazarus et al., 2016). Initial attempts at obtaining viral load results were unsuccessful because most of the

records had no recent viral load results and there were no reagents. Even with the CD4 count, there was shortage of reagents at a point during the study period, therefore the number of patient with CD4 count results decreased. Moreover, CD4 counts were to be done routinely every six months. This affected the collection and analysis of secondary outcomes that could be used to validate the other measures. Nevertheless, participants reported in the qualitative study that their health improved and they felt better since initiating ART. The evidence from other studies established that clients who initiate treatment showed improvements in viral load and quality of life was enhanced.

Views expressed by the participants in the interviews revealed that motivation for adherence was facilitated by the benefit of treatment and the consequences of no adherence; while religious fanaticism, secrecy and food moderated adherence behaviour. There was also a personal determination to adhere which was further facilitated by the availability of support.



### 7.4.1 Facilitators of adherence to ART

Adherence counselling, spousal support, self-consciousness, use of mobile phones, institutional monitoring and peer support were noted as facilitators of adherence. These emerged from baseline assessments and interviews with participants. Adherence to treatment was not perceived as a problem because from clients' perspective the medication regimen was simple; pill burden was minimal and dosing time was convenient. The findings are consistent with other studies (Langebeek et al., 2014; Mannheimer & Hirsch-Moverman, 2015; Ruanjahn et al., 2010; Wakibi et al., 2011) on factors influencing adherence to treatment.

The benefit of treatment evidenced in the improvement in their health status motivated adherence to treatment as reported by Portelli et al. (2015). The fear of death and carrying their pills with them facilitated adherence. Notably, Starks et al. (2008) mentioned that the will to live facilitated adherence to treatment.

Although mealtime was not a barrier to adherence in this study, the role of food in taking medication was mentioned. Some participants implied eating well prior to taking medication limited the experience of side effects and promoted adherence to treatment. Food is an important aspect of treatment adherence and food insecurity affects treatment adherence (Kalichman et al., 2015). Nutritional support has been used as an adherence intervention and WHO (2013) had recommended it. In this study this was not part of the measures used.

Transparency about HIV status facilitated support from spouses, family and friends. Participants were reminded about their medication time and clinic appointments by spouses, family and peer monitors. Some had instrumental support with transport costs because their status was known. There is evidence that affirms that adherence is facilitated in individuals who disclose their HIV status because they receive support (Portelli et al., 2015; Starks et al., 2008; Wakibi et al., 2011). Sero-concordant partners and co-infected spouses all had support from their partners. Nevertheless, status disclosure to friends was not very common among respondents.

The report from participants showed that using alarms to regulate medication time, receiving text messages and voice calls facilitated adherence. Text messages have been predominantly used for facilitating adherence (Smillie et al.,

2014) but Starks et al. (2008) noted electronic reminders could yield similar outcome.

The results further showed that adherence could not be predicted with clinical indicators such as BMI and CD4 counts although in other studies that measured viral load, improvement was observed. The findings were confounded because of the variations in measurement. The study duration did not allow for comparison of viral load; more so reagents were out of supply. Patient reported paying to have the CD4 count done in other facilities and sometimes the results were delayed. The findings are inconsistent with other studies in which clinical outcomes improved over time(Lester et al., 2010).

Socio-demographic factors influencing adherence were education and time. Higher education and interaction with respondents over time influenced adherence. However, it was observed that while adherence scores declined adherence behaviour nevertheless improved.



### 7.4.2 Barriers to medication adherence in clients with HIV

Factors influencing adherence such as work schedules, pill numbers, pill dosing, forgetfulness, feeling sick, absence of reminders, fear of being seen by other people, mealtimes, sleep and feeling sad were explored at baseline. These factors did not influence respondents' current adherence. Nevertheless, 17% of respondents mentioned fear of being seen by others influenced their medication taking. Some clients indicated the presence of other people; feeling sad and forgetfulness affected treatment adherence. These barriers have been reported in several studies and reviews on adherence to treatment (Mannheimer & Hirsch-Moverman, 2015; Portelli et al., 2015; Ruanjahn et al., 2010; Saberi et al., 2015;

Starks et al., 2008). These barriers were not predominant among the respondents but worth noting since the goal is to ensure optimal adherence.

Forgetfulness was mentioned by participants as a barrier to adherence in the qualitative outcome. Some noted that worrying about the diagnosis could lead to forgetting to take the medication in time. Their main concern however, was forgetting appointment schedules for medication refill. The findings are consistent with other studies that associate emotional factors with adherence behaviour (Andersen et al., 2015; Wekesa & Coast, 2013).

Some respondents noted sleep affected their medication schedule. Although this outcome was not significant it is relevant because it created the possibility of missing or delaying a dose due to sleep. The influence of sleep on delayed medication time was not accurately evaluated but narratives from participants suggest this occurred occasionally. Some participants therefore valued the ability of their alarms to wake them up in order to take their medication at the right time. Other studies have reported sleeping through medication dose as a barrier to adherence (Saberi et al., 2015).



The secrecy shrouding HIV diagnosis was observed as a barrier to adherence in this study. This was reflected in both the quantitative and qualitative studies despite the absence of statistical significance. The fear of being seen by other people was mentioned to account for missing pills or delays in taking medication on time. Others confessed to substituting medication containers or hiding to take medication to avoid interrogations that would expose their HIV status. Van Tam et al. (2011) mentioned that clients sometime disguised medication as a strategy to prevent HIV related stigmas. Similar findings were reported in other studies

that mentioned that stigmas were a barrier to adherence (Portelli et al., 2015; Starks et al., 2008; Wakibi et al., 2011).

Nonadherence was also blamed on religious fanatism in that some clients turn to seek faith-based interventions and stop taking their medication. Consequently, the patient returns to the clinic with deteriorating health. However, this negative outcome sometimes served as lessons for adherence. Mannheimer and Hirsch-Moverman (2015) also noted that seeking alternative treatment was a barrier to adherence in patient on ART. Religious coping is a common coping mechanism reported in other studies (Liamputtong et al., 2012; Wekesa & Coast, 2013); when used positively clients are able to adjust to diagnosis and treatment. A negative instance of religious coping can lead to ambivalence or denial by a patient about their HIV status which, could in turn, result in their withdrawal from treatment programmes. Some participants indicated knowing patient who stopped treatment to seek religious intervention, only to return to the clinic in a worse condition while others died.



The outcome further revealed that waiting times at a clinic affected desire to return to the clinic for medication refills. Admitting that preferential treatment was available some participants were uncomfortable with the arrangement. Waiting times has been cited as one of the factors in the health system limiting adherence to ART in some studies (Sanjobo et al., 2008; Wakibi et al., 2011). In spite of these barriers patient with HIV demonstrated a sense of commitment to treatment adherence.

## 7.5 EXPERIENCES OF HIV INFECTED CLIENTS AND PERSPECTIVES OF SIGNIFICANT OTHERS ON INTEGRATING MOBILE PHONE INTERVENTION IN ADHERENCE STRATEGIES

The evaluation was contextualised within experiences that relate to illness history and those that focused on mobile phone usage. Participants raised issues about the manner in which they responded to the diagnosis, treatment, adherence and their perspectives about using integrated mobile phone interventions.

### 7.5.1 Illness context and adherence behaviour in clients with HIV

Participants recounted their experience of illness with mixed emotions, reflecting on the manner in which they became aware of their HIV. Participants discovered their status while seeking health care for other reasons such as ill-health or antenatal care. The discovery of their status was mainly accidental but for others participants it was either mandatory or voluntary. Similar observations were reported by Wekesa and Coast (2013) where clients mentioned being told their HIV status in the course of seeking health care.



Reaction to their diagnosis revealed most participants experienced the grieving process in different ways. The adjustment influenced their decision to initiate treatment and adherence behaviour. The confusion, pain, anger and weeping in the initial stages changed when, through counselling and support, clients accepted their status with an understanding that treatment was available. Russell and Seeley (2010) made similar observations and noted that the inner drive to initiate changes in lifestyle came from drawing strength from their spirituality to facilitate a return to a normal life following HIV diagnosis. The choice to move on could be derailed by the loss of hope and inadequate support.

Support is a relevant aspect in the adjusting to a positive HIV/AIDS diagnosis. , The battle ‘to tell or not to tell’ creates a dilemma particularly for clients who needed to disclose their status to their spouses who were HIV negative. Clients were required to have an adherence supporter before they could be enrolled on ART, consequently some participants had to choice adherence supporters from other amongst clients (peer adherence supporters). The issue of disclosing HIV status to galvanise support has been negatively affected in settings where there is persistent stigma and discrimination (Portelli et al., 2015; Sanjobo et al., 2008). The moral judgement and labelling of HIV patient further deepens the fear of disclosing an HIV positive status. However, other clients defy the odds to disclose their status, and associate with support groups to enable them to move on positively with their life (Russell & Seeley, 2010).

Instrumental and religious coping mechanisms were used to deal with the diagnosis and treatment of HIV. Participant noted that deciding to receive ART and adhere to the treatment regimen facilitated their return to normal life and daily routines. One participant, who admitted to defaulting on their treatment, noted that it was the negative experience of symptoms that influenced their decision to resume treatment and adhere to the drug regimen. The findings reflect the suggestion by (Russell & Seeley, 2010) that individuals with HIV take action to adjust to their new life subject to their emotional and physical resilience.

The short-term side effects of ART created difficulty for some participants in the initial stages, but over time, following a change of regimen or other measures most of the clients adjusted well to their treatment regimen. Some were willing to tolerate the side effects bearing in mind that the discomfort would be temporary and ultimately beneficial. Other participants observed that the side effects were

brought on by a failure to eat properly and argued the importance of eating properly in minimising the undesired side effects associated with ART. Studies have reported side effects of treatment as a barrier to treatment adherence (Mannheimer & Hirsch-Moverman, 2015; Sanjobo et al., 2008). Continuous monitoring and support as mentioned in the illness history was a measure of addressing non-adherence as patient had opportunity to return to the clinic with problems regarding their medication.

A key facilitator in coping with diagnosis and treatment is adherence to the treatment. ART is a long-term therapy and, once initiated unless contraindicated patient takes the medication for life. Self-efficacy, benefit of treatment and fear were motivators that improved adherence. Nonadherence was not disputed although this was not prevalent. A few of the participants who defaulted on treatment noted that the consequences of their actions were good lessons that improved their adherence behaviour. The support received from spouses, family, peers and the health professional facilitate adherence among participants. Evidence suggests that social support facilitates adherence to ART (Mannheimer & Hirsch-Moverman, 2015; Portelli et al., 2015; Ruanjahn et al., 2010) and reduces stigma and discrimination. Support interventions include adherence counselling, provision of free medication, transport, food, psychological support and the use of mobile phone text messaging (Bärnighausen et al., 2011; Chaiyachati et al., 2014; Moore et al., 2011).



The experiences of participants were observed to have some undefined underlying implications for their decision to accept other strategies that seek to support clients particularly with the focus on supporting adherence. It was clear that addressing the issue of stigma and discrimination, the panacea to secrecy of

HIV status is the major hurdle for technology acceptance for adherence support in HIV/AIDS care.

### 7.5.2 Readiness and acceptability of integrating mobile phone intervention in adherence support

The evaluation from the clients regarding the use of mobile phone technology to support adherence suggests that clients were willing to accept the use of alarms because they were personal. The voice calls were interactive and preferred for motivational support and reminders about clinic schedules. However, there was an ambivalence shown to text messaging. Interestingly, most of the interventions for supporting adherence with mobile phones used text messages and some of these interventions were statistically significant with moderate effects (Bärnighausen et al., 2011; Belzer et al., 2015; Georgette et al., 2016; Horvath et al., 2013).



This study did not demonstrate the expected magnitude of effect but the preferences of participants for automated voice messages needs to be explored further from a cost-benefit point of vide before large scale implementation. The suggested approach requires that there would be designated short-codes which could be dialled for instructions on ART regimen, adherence and general issues relating to HIV. Participants believe that there would be no suspicions about the services since the individual makes the choice. Participants also advocated that some indigenous languages be included in the automated voice facility. There are existing telco-based applications that give access to health information through dialling short-codes or sending messages which could be explored for use in HIV/AIDS care. Evidence on the usage of automated voice calls that were

interactive and enabled response to adherence assessment suggests beneficial outcomes (Bärnighausen et al., 2011; Georgette et al., 2016; Smillie et al., 2014).

Experts interviewed and documents reviewed indicated a consensus on the use of mobile phones to support adherence and there was an enthusiasm to embrace technology given the global trends. Meanwhile, only WHO documents mentioned that text messaging should be used based on moderate evidence from studies and reviews (WHO, 2013, 2015a). The documents of the National AIDS control Programme, Ghana (NACP) was silent on the use of mobile phones. Field information revealed that there was a parallel project which focused on supporting adherence in clients initiating ART. Belzer et al. (2015) reported respondents in their study were willing to recommend the use of mobile phones to support treatment. Willingness and acceptance of technology use are associated with barriers and limits the scaling up of such interventions.

Participants had issues with literacy in using applications requiring technical and cognitive skills. Perceived stigmas were also a barrier considering that privacy when using mobile phones could not be guaranteed due to practices such as charging mobile phone batteries with friends or family members. Some of the experts indicated concerns about privacy may hinder the acceptance of text messaging a view that supported clients' concerns. There is evidence of the acceptance of technology for adherence support among people living with HIV (Georgette et al., 2016; Smillie et al., 2014).

Initial research revealed that there was no mHealth policy framework but while still working on the report an engagement with the officer in-charge of the information, communication and technology directorate within the National Health

Service mentioned there was a final draft guideline on mHealth. A review of the guidelines showed that the aim was to provide guidelines for individuals, agencies and institutions in setting up mHealth programmes. HIV was mentioned as one of the disease conditions in which mobile phones could be used to support retention in care. There was recognition of responsibility in providing infrastructure at the district level and facility levels. No specific recommendations were made in relation to adherence interventions (GHS, 2014). Abbott and Coenen (2008) reported that scaling up of technology integration in developing countries faces the challenge of infrastructure, expertise, lack of context-based programmes and systems, poverty and literacy.

In view of the barriers to the up-take of mobile health interventions and the absence of a cost benefit analysis it is important to adopt strategies that work and are cost effective. While the literature seems to endorse the use of text messaging, the current study does not indicate a preference for text messages. In the short-term, the existing evidence on mobile phone use may be helpful, but further investigation into service preference within the context of perceived use and actual usage of technology from a behavioural and cognitive perspective is recommended. Resource limitation and literacy gaps could be addressed through the use of a task shifting model of integrating mobile phones in health care will facilitate care and support for HIV infected persons. The task shifting model used in the care for HIV/AID and TB co-infection by WHO remains one of the mechanisms of redistributing skills and workload to reflect exigencies of the time.

## 7.6 THEORETICAL CONTEXT OF ADHERENCE TO ART AND MOBILE PHONE USE

Adherence to treatment in clients with HIV was considered a goal that could be achieved through integrating King's transactional model in the intervention process. The transaction process involved implementing mobile phone interventions based on the patient recognising the importance of adhering to treatment. There was no specific strategy to directly assess outcomes of goal setting on adherence behaviour. Nevertheless, patient narratives revealed that the interaction established with clients in this study was considered beneficial.

Synthesis of the intervention and findings reflected two main adherence theory perspectives; behavioural learning and the theory of reasoned behaviour. According to proponents of behavioural learning there are internal and external antecedents explaining adherence behaviour and consequences (WHO, 2003). The findings revealed self-consciousness (internal antecedent) precipitated adherence while the use of the mobile phone and assessment of adherence (external antecedent) moderated behaviour. The consequence of adhering to the treatment was the benefit derived from the treatment.



An elaborate context of describing adherence behaviour of respondents in this study is the application of the theory of reasoned action. The theory postulates that behaviour is controlled by individuals' intention which predicts behaviour (Fishbein & Ajzen, 2011). The intention to adhere depends on behavioural beliefs, perceived norms and control. This is further moderated by individual characteristics, social factors and information.

In this study two behavioural outcomes were explored in the use of mobile phone technology and adherence. Outcomes from assessing mobile phone use revealed the interplay of background factors such as age, education and employment in predicting phone use. The intention to use the phone however, did not accurately predict adherence behaviour. Some studies have reported an association between adherence intentions and actual behaviour but this was not within the context of phone usage (Nelsen et al., 2013).

Participants' attitude towards adherence was informed by the belief that making a personal decision to take the medication was important. Clients acknowledged the benefit of the treatment and acknowledged how it improved their health and were therefore willing to take their medication. Nevertheless, they were cognisant of the possibility of missing pill times and therefore embraced other measures such as alarms, text messages and voice calls. They were willing to adhere to treatment knowing the support and expectation from family, friends and the healthcare professionals they had. Participants also made a commitment to the research team and were willing to work together to achieve their adherence goals. Respondents knew their pills were to be counted during each visit and questions would be asked to be sure the desired behaviour was exhibited. Additionally, the prompting from the alarms, text messages and voice calls were all subjective norms that assisted in meeting the goal of taking medication on time and as prescribed to bring about the expected behaviour. The theory of reasoned action was useful in explaining adherence outcomes in this study based on the constructs within the framework.

## 7.7 CHAPTER SUMMARY

In this chapter the findings of the study were discussed with reference to the literature, theory and practice. The discussions revealed that adherence to treatment was important to the clients hence adherence to treatment was not a problem. However, recognising the influence of other factors which were out of the control of clients, there was willingness to accept measures that will further enhance their behaviour. The next chapter will discuss recommendations for improving adherence to ART with mobile phone technology.

# CHAPTER 8: RECOMMENDATIONS FOR THE INTRODUCTION OF MOBILE PHONE MONITORING OF ADHERENCE

## 8.1 INTRODUCTION

This chapter discusses the recommendations in the form of a proposed algorithm and client information brochure for integrating mobile phone intervention in adherence strategies.

The findings from the mixed methods study showed that adherence to treatment improved over time in the entire group. However, Visual analogue outcomes declined overtime. The outcomes arguably did not show strong evidence for committing resources to implementing the integrated mobile phone intervention across the board. While, the WHO strongly recommended the use of text messages to support adherence in clients on ART, this study found that alarms and voice calls were more acceptable. Concerns about the risk of status exposure, literacy, technological limitations and resource availability were key determinants in recommending the preferred approach to integrating mobile phone in adherence measures, and in view of the resource limitations, institutions may be unable to integrate the necessary support measure.



The narratives of qualitative studies also revealed that clients often used their phone to check the time. The use of the phone as a clock in itself served as a reason for clients to monitor their medication schedules. Enhancing skills in setting their phone clocks correctly would contribute to clients' ability to follow their medication regimens as prescribed. Operating the mobile phone competently is beneficial to clients and significant others including adherence monitors.

The existing counselling system requires the presence of adherence monitors who need to be part of the education process for using mobile phones. This allows adherence monitors, who do not live with the patient, to take on the task of monitoring adherence to treatment by sending messages or calling to motivate the client. The limitation of this measure is that it is not enforceable. The decision to use information obtained is left to the discretion of the client and their adherence supporters or partners. Another difficulty is monitoring the consistency of implementation, because the regularity with which messages are sent and feedback is obtained is not known to service providers and the evaluation of outcome is hence subjective. Service providers have to depend on the accounts of their clients and their monitors regarding the effectiveness of using mobile phones. Nevertheless, until strong evidence is available, resources are adequate, literacy and technological gaps are bridged; creating awareness on how the mobile phone could be used to facilitate adherence is a good start. In view of the limitations, an algorithm expected to assist the care provider to consciously create the awareness and provide tangible support to enable the utilisation of mobile phone adherence support was proposed. The constructs within the algorithm and the recommendations in general were informed by the interplay of the three model (goal attainment, logic model and theory of reasoned action) applied in this study.

In this chapter, a review of the proposed algorithm contextualised within a task shifting strategy of integrating mobile phones in adherence was done. Additionally, a brochure on setting alarms was developed to facilitate easy teaching of willing clients.

## 8.2 PROPOSED PROCESS FOR INTEGRATION OF MOBILE PHONE INTERVENTION

Normally, guidelines are commonly used within the health sector to promote evidence-based practice and improve quality of care. Guidelines consist of principles, recommendations and processes, which might not be necessarily binding. However, in developing guidelines there are recommended processes that ought to be followed. Guidelines may emerge from informal consensus, formal consensus or may be evidence based (Woolf, Schünemann, Eccles, Grimshaw, & Shekelle, 2012). The process also requires that a subject area be identified and refined; constituting a guideline development group; the group identifies and reviews related evidence and translates the evidence into practical guidelines (Eccles, Grimshaw, Shekelle, Schünemann, & Woolf, 2012). The output from the group is then evaluated by external reviewers for validity. Once the guidelines are published they are then updated on a regular basis depending on changing evidence (Eccles et al., 2012; Woolf et al., 2012).



Current guidelines on mobile phone support include the WHO and NACP ART Guidelines for Ghana and framework for mHealth. The WHO (2014) noted that guidelines vary per purpose, scope, duration of intervention, organisation involved and the nature of the evidence. The WHO as an organisation is involved in developing and reviewing of guidelines (Woolf et al., 2012). A review of existing guidelines on ART for the WHO showed moderate evidence for using text messaging to promote adherence (WHO, 2013, 2015c). Nevertheless, it recommended the integration of text messaging in adherence support.

The NACP ART guidelines for Ghana had a section addressing adherence to treatment but there were no specifics on the use of mobile phones (NACP, 2014a).

The use of mobile phones to support adherence falls within the general framework of mHealth. Adherence interventions are not an exclusive mHealth measure but exist alongside other mHealth strategies. MHealth is still penetrating the Ghanaian health sector with most of the interventions being at the pilot stage and are mainly focused on maternal health. A draft seven-page document on guidelines for mHealth implementation in Ghana was reviewed and specific areas in which mHealth was applicable were indicated. mHealth use in HIV was focused on data gathering and maintaining retention in treatment. No specific measures were outlined in terms of structure and resources for integration of mHealth. In view of this, recommendations for including mobile phones to support adherence could be integrated into subsequent guideline updates on ART for Ghana without the need to develop separate practice guidelines.



Additionally, consultation with policy developers and implementers revealed resource limitations in institutionalising mobile phone as an adherence intervention strategy. Meanwhile, clients were observed to be receptive to alarms and voice calls while demonstrating scepticism in using text messages. The outcome of this study is not strong enough to merit developing a guideline; instead an algorithm and a client information leaflet brochure (see appendix) was developed. This is to facilitate access to information for the caregivers and clients in order for them to make informed decision regarding the use of mobile phones to support adherence.

Following the findings of this study and based on available evidence in literature; developing guidelines for integrating mobile phone intervention in ART adherence is not the priority need of clients on ART, the development of an algorithm is instead proposed.

Algorithms, depict the step by step approach to decision making and often requires multiple decision making (Sox & Stewart, 2015). Algorithms used within the health sector are commonly referred to as clinical algorithms. According to Achttien et al. (2015) clinical algorithms facilitate decisions about client care strategies in an organised sequence and are a measure relevant in limiting the differences in patient care.

In view of the resource limitations, literacy and technology gap, the integration of mobile phone strategies in adherence ought to be intentional. There are different steps and the ensuing decision are relative to client choices. These decision matrix needs to be represented in a flowchart to facilitate the decision making process with an understanding of the context of implementation of each process.



## 8.3 ALGORITHM AND BROCHURE FOR INTEGRATING MOBILE PHONE INTERVENTION IN TREATMENT ADHERENCE

### 8.3.1 Introduction

The algorithm was developed to enable flexibility in integrating mobile phone intervention using the existing support system. This approach would ensure protection of clients' autonomy and respect for personal preferences.

### 8.3.2 Aim of Algorithm

To provide adequate information that enables clients and care providers in decision making regarding mobile phone adherence strategies

### 8.3.3 Assumptions

Assumption of what works, with reference to study outcomes and literature evidence, suggest the need to develop an algorithm that fuses the strengths and limitation of clients and adherence supporters in a pragmatic way. The following assumptions underpin the integration of mobile phones as adherence intervention:

- Client have the desire to adhere to their medication; forgetfulness may be unintended therefore they have to be supported
- Clients with access to mobile phones who are willing to use the mobile phone adherence intervention ought to be assisted to bridge technology and literacy gaps
- The autonomy of the client must be respected at all times, therefore clients have the right to information on using mobile phones to support adherence and the choice to accept or reject such interventions
- There are robust adherence counselling interventions in existence within the health sector but specific education about the option to use mobile phones to support adherence is required
- Continuous evaluation of outcome of using mobile phones is required in order to ensure the integrity of the process, identify gaps and improve output

### 8.3.4 Process of development

The method of developing the algorithm was the synthesis of findings, literature evidence, expert opinion, field data and intuitive deduction from personal and professional experiences. During the study period clients, adherence monitors and peer supporters/volunteers were trained to use mobile phones to support adherence. The research team educated and encouraged the usage of mobile phone technology and the transactional goal setting approach that enables collaborative decision making and fluid feedback. The lessons from the intervention process informed the development of the algorithm.

### 8.3.5 Process criteria for Integration of mobile phones intervention in adherence

The following criteria have been proposed for consideration in the short-term until strong evidence is adduced for integration of mobile phones in adherence interventions:



1. Setting adherence goal
2. Determining access to mobile phone
3. Assessing need to use of mobile phone in adherence support
4. Identifying and filling mobile phone literacy gaps
5. Providing continuous education on mobile phone usage in adherence
6. Evaluating mobile phone usage outcome

#### 8.3.5.1 *Setting adherence goal*

The existing adherence counselling system requires providing information and teaching clients about the medication, dosage, possible side effects, additional instruction relating to substance use and diet (NACP, 2010a, 2014a). This serves as a subtle mechanism to identify patient's need for adherence support.

The setting of adherence goals needs to be integrated into the counselling process more explicitly and emphasised during medication refill visits. It is important to discuss with clients specific goals such as taking all prescribed medications on time at least nine times out of every ten occasions. Assessment and goal setting allows providers the opportunity to elicit information on clients' preferences for adherence support while shifting the task of sending messages and making voice calls to monitors and the clients' family. When the client is part of the decision making process it enhances adherence to ART with the client owning all the decisions. Once a patient identifies and personalises adherence goal it may facilitate the acceptance and use of other measures such as alarms, text messages and voice calls but this is subject to the availability of mobile phones.



#### 8.3.5.2 *Determining access to mobile phone*

Mobile phone access refers to the availability of a functional mobile phone owned by a client or adherence monitor, which could be used to set alarms, send and receive messages and make voice calls. Additional Android applications may be useful but not necessary. Where phones are shared it is recommended that clients be asked about the privacy of information received and their willingness to use shared phones in the intervention. Clients who express concerns about

privacy and are afraid of their HIV status being exposed should be educated on measures of ensuring privacy such as turning-off phones when charging the batteries in circumstances that could be a risk to their privacy. It would be appropriate to further explore the regularity of mobile phone usage to assist in scheduling phone support as part of regular routines.

#### 8.3.5.3 *Assessing need for the use of mobile phone in adherence support*

The decision to use or avoid mobile phone based adherence support is a continuous process that is dependent on individual choices. Clients should be questioned as to whether or not they want to use mobile phones to support adherence during the client counselling sessions.

Clients with a high risk for non-adherence duet to cognitive impairment should be encouraged to use mobile phones to support adherence during counselling. Additionally, clients and adherence monitors who agree to use mobile phones should be encouraged to have agreed schedules text messages and voice calls. In instances where mobile phone support is not needed, existing standard adherence support measures are used. Whenever a client chooses to stop or start using the alarms, receive messages or voice calls from adherence monitors, service providers have the responsibility of providing the necessary information and tangible support that is required to enable clients to do so.

#### 8.3.5.4 *Identifying and filling mobile phone literacy gaps*

Mobile phone devices have differing level of sophistication. Clients and adherence monitors need to be assessed as to their ability to operate the

relevant applications which are available for supporting adherence on their specific mobile phones. In cases where neither client nor adherence monitor is able to effectively able to use the applications technical assistance should be provided. In subsequent sessions they should be assessed to see if their phone literacy has improved.

#### 8.3.5.5 *Providing continuous education on mobile phone usage and adherence to treatment*

Adherence to ART is a lifestyle and the aim in the initial stages of therapy is to reinforce behaviour with the understanding that repetition will culminate in learning and habit formation. However, being cognisant of individual factors facilitating or inhibiting adherence, continuous institutional support is required. In view of this, education on the usage of mobile phones to support adherence should be reinforced during follow-up clinic visits. Adherence monitors and family members with technical knowledge on mobile phone use should be encouraged to support patient.



#### 8.3.5.6 *Evaluating mobile phone usage outcome*

Monitoring the outcomes of using mobile phones to support adherence would assist in identifying beneficial aspects and areas that require further improvement. It is important to evaluate outcomes routinely during follow up visits and in surveys. The ongoing technological advancement may lead to the emergence of other mobile applications which may be relevant in supporting not only adherence but other aspects of care.

Evaluation is a continuous process that occurs at every interaction with the client. It is anticipated that clients who do not have mobile phones may later acquire phones and will be willing to use the mobile phone. Other clients may opt out of using the mobile phone at some stage

### 8.3.6 Components of proposed Algorithm for Integration of mobile phones in adherence

As shown in Figure 17, the algorithm illustrates the components of the mobile phone integration in adherence process.

- The client/adherence monitor first makes contact with the healthcare provider.
- Upon contact with client/ adherence monitor, the adherence needs of the patient and the goals are determined collaboratively.
- Access to mobile phones is then evaluated since not all clients are likely to own a mobile phone. In the case of clients with access to a phone additional information is obtained on the ownership of the phone because of concerns about privacy in view of the concerns regarding the risk of status exposure.
- Once measures of privacy are guaranteed, the next component is to determine if clients following information about using mobile phone as adherence measure would be willing to accept the mobile phone intervention.
- The next element is to identify if there are any literacy gaps and provide the requisite training.

- Clients who have no mobile phone or have phones but do not want to use the phone to support adherence are counselled mainly to use alternative adherence support measures.
- Continuous support and evaluation is done intermittently

It is important to inform clients and their adherence supporters that the messages and voice calls, if preferred, would be the responsibility of the adherence monitors.

**Algorithm for integrating mobile phone Intervention in ART treatment adherence**

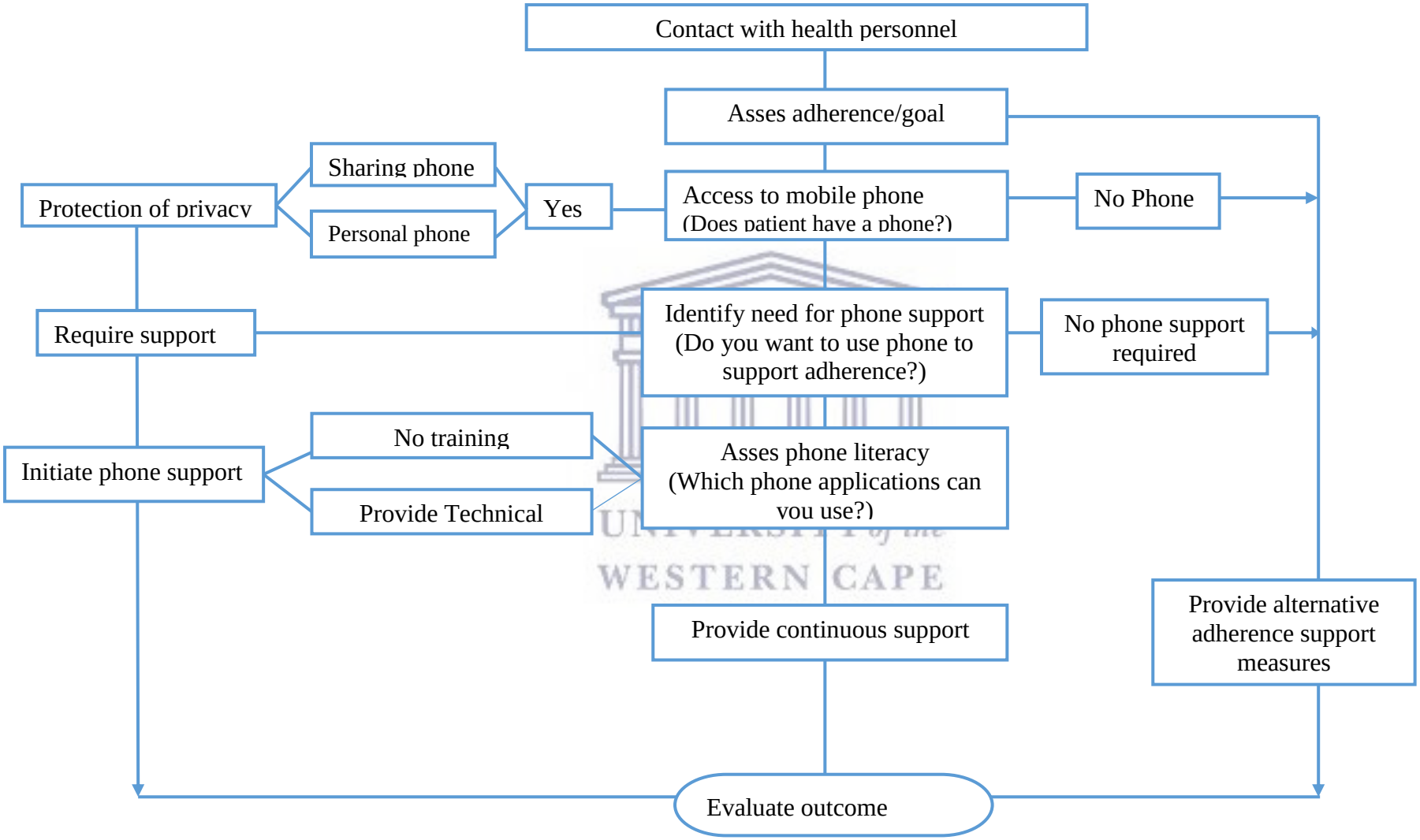



***Figure 17 : Algorithm for integrating mobile phone Intervention in ART treatment adherence***

## 8.4 PATIENT EDUCATION BROCHURE

### 8.4.1 Introduction

The outcome of the study revealed that prior to the study there was low usage of mobile phones in adherence support. The field interactions further showed that the main area where clients required assistance was how to set the alarm function correctly to monitor adherence. The brochure was developed at the intervention stage as part of the training materials. The brochure could be used to bridge aspects of technology gaps particularly in setting up of the alarm. Clients willing to use mobile phones in adherence will be trained using the brochure as learning material.

### 8.4.2 Aim of Brochure

The patient education brochure summarises information on how the time, alarm and voice calls could be used to promote medication adherence with an emphasis on correctly setting the alarm.



### 8.4.3 Principles

The guiding principles in developing the brochure was to have a simple but relevant means of communicating information, on mobile phone intervention in adherence using text and graphics, to a population with diverse educational background.

The brochure was also developed with recourse to the client's values and other specific issues such as resource availability, literacy, technology gap and lack of explicit policy frameworks.

### 8.4.4 Process of development

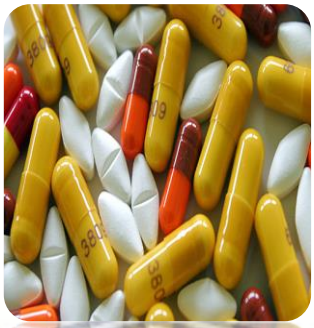
The education material was derived from training sessions aimed at bridging technology gaps at the intervention phase. This included information on using mobile phones to support adherence. Technical support was sought and research assistants were trained to provide support for both clients and adherence monitors who required training. The brochure focused on training clients on how to set the alarm function on their phone. However, the brochure was not piloted since it was intended to be training material and the training was very much ‘hands on’. The acceptability of contents of the brochure was implicitly derived from clients’ feedback, skill sets and usage after the training. In future studies the brochure could be piloted to validate acceptance and readability.

### 8.4.5 Brochure

#### 8.4.5.1 *Taking your medication*

**Taking Your Medication Rightly?**

- Taking your medication at the right ***time*** and right ***dose*** is important in improving your wellbeing.
- You can get support from your adherence monitor to help you remember medications
- You can also use your mobile phone to monitor yourself



- You can set the phone alarm on medication time
- Your adherence monitor can send you text messages
- Your adherence monitor can call to encourage you
- You can set phone reminder on your next clinic appointment day.

**Your mobile phone can help!**

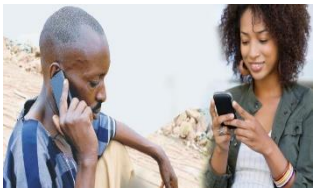
### 8.4.5.2 *Setting the Alarm to your medication time*

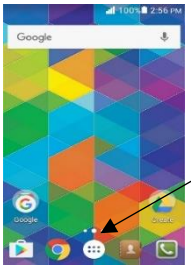
**SETTING THE ALARM TO YOUR MEDICATION TIME**

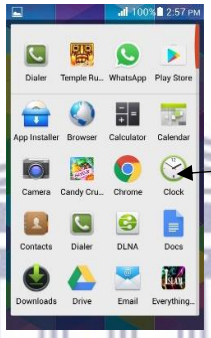
Setting phone alarm varies depending on the type of mobile phone you are using. These guidelines provide the steps for a person using an ordinary GSM phone ("yam") and a smartphone

***GSM Phones***

***Smart Phones***








Ensure phone is on home screen and Press the Menu button

Look for Alarm in menus and select

If Alarm is not in menus select Extras/Applications

Select Alarm Clock

Edit Alarm name to a name you prefer that can't be easily linked to you

Set time to suit medication regimen e.g. 8:00 AM

Set ringtone preference by choosing fom list of tones

Choose all the days so alarm is repeated daily at the set time

Save Alarm

For twice daily medication, set another alarm for the evening medication e.g. 8PM

You can stop or snooze alarm when it rings

## 8.5 CHAPTER SUMMARY

The final phase of this study involved synthesising information to make recommendations for integrating mobile phones in adherence support. In this chapter the proposed algorithm for the integration of mobile phones in adherence support was described. A patient education brochure for creating awareness on using mobile phones in adherence support and on setting the alarm function was also presented.

# CHAPTER 9: SUMMARY, CONCLUSION AND RECOMMENDATIONS

## 9.1 INTRODUCTION

This chapter provides a brief summary of the study, which evaluated an integrated mobile phone to improve adherence to treatment with HIV infected clients. The aim of the study was to evaluate the integration of mobile technology in routine nursing practice to improve and support adherence to ARTs in PLWHIV in Accra, Ghana supported by five (5) objectives to: i) assess treatment adherence among HIV infected clients in Accra, Ghana; ii) identify demographic characteristics, clinical variables and support measures that predict adherence to ART; iii) evaluate the effectiveness of using mobile phone intervention to promote adherence; iv) evaluate the experiences of clients and perspectives of significant others on integrating mobile phone intervention in adherence support; and v) make recommendations for integrating mobile phone intervention in adherence monitoring strategies.



## 9.2 SUMMARY OF STUDY

The study involved developing a protocol that sought to evaluate the effectiveness of integrated mobile phone intervention for monitoring adherence.

The aim of the study was to evaluate the effectiveness of integrated mobile phone intervention for monitoring adherence in clients infected with HIV. This was based on an assumption that an integrated mobile phone intervention comprising alarm set to medication time, weekly motivational text messages and monthly voice calls would improve adherence to ART among clients with HIV. The intervention was informed by research studies that suggested that text messages and use of other electronic devices

improved adherence in different populations and the logic model was applied to evaluate the intervention effectiveness with the assumption that actions implemented will elicit change. In view of this, aim and objectives of the intervention were to improve adherence while the processes consisted of inputs (e.g. phones), activities (alarms, sms etc), outputs (use of phone) and outcomes (improved adherence).

The pragmatic philosophical paradigm informed the choice of research approach which was the sequential explanatory design. There were three phases of the study; Phase 1: a randomised control trial to evaluate the outputs and outcomes; Phase 2: a qualitative evaluation of experiences of using mobile phones; and Phase 3: a synthesis of findings with existing evidence to make recommendations that would inform adherence monitoring strategies.

Phase 1: Adherence was measured at three-time points (baseline, month three and month six) and compared with an Intervention and a Control group using the multimethod adherence tool (Self-report, visual analogue scale, pill identification test and pill count with an estimation of overall adherence scores based on observed mean).

Phase 2: Qualitative evaluation of experiences of the Intervention group on the usage on the mobile phone intervention for adherence through individual interviews and focus group discussions. Additional information was obtained from an expert in policy and another from a professional clinical practitioner both of whom were considered as stakeholders. Selected guidelines were reviewed to provide context to the findings and this facilitated the synthesis process in the final phase of the study.

## 9.3 KEY FINDINGS

The key findings are discussed in relation to treatment adherence and the use of mobile phone intervention.

### 9.3.1 Treatment adherence

#### 9.3.1.1 *Good Adherence to treatment*

Assessment of adherence at baseline and subsequent follow up revealed respondents adhere to treatment, although a few of them demonstrated suboptimal adherence. No significant changes were observed as expected in the adherence scores over the period, but all respondents were adherent at the sixth month of evaluation. Further analysis in the qualitative study brought clarity to the motivation of the patient to adhere is discussed below.

#### 9.3.1.2 *Facilitators of adherence*



The benefit of the medication and improvement in the wellbeing of clients following initiation of treatment increased their motivation to adhere to the treatment. Self-consciousness, fear of death and transparency, also facilitated adherence behaviour. This action is consistent with some theoretical underpinnings of adherence behaviour, notably the theory of reasoned action which postulates that individual actions are intentional. The health belief model argues that benefits and perceived threats can also motivate behaviour resulting in adherence because of the benefit of ART. The interplay of personal and normative values were factors which explained the high adherence outcome observed in this study with for example, education predicting adherence

behaviour enhanced by support from friends and families. Social support from spouses, families and peers moderated positive adherence behaviour.

The data indicated that support measures from individuals, institutions and significant others were relevant in understanding adherence behaviour in this population. Counselling provided extensive education on the HIV infection, ARV and lifestyles that enhanced adherence to ART among clients and though adherence counselling was an adherence support measure that facilitated adherence, clients reported that they expected the pre-treatment counselling to be continual and not limited to the initiation of treatment. Additionally, adherence monitoring strategies such as pill count and adherence monitors were identified as useful strategies for ensuring strict adherence to treatment.

The study identified predictable factors such as education and time moderating adherence levels in this study. Other socio-demographic factors [age, gender, employment and religion] had no predictive effect on adherence levels. The clinical variables [CD4 count, duration of illness and BMI] had no predictive effect on adherence.



#### 9.3.1.3 *Barriers to adherence*

The study also found that barriers such as sleep, work schedules and fear of being observed by other people while taking medication were concerns which affected adherence occasionally. Irrespective of the scale of evidence this ought not to be ignored as these concerns further affirm perceived stigma associated with HIV diagnosis. The resultant secrecy and nondisclosure of HIV status influenced adherence

behaviour and willingness to accept adherence interventions that are perceived as a risk to HIV status exposure.

### 9.3.2 Mobile phone use in adherence intervention

#### 9.3.2.1 *Mobile phone use in clients with HIV*

Mobile phone usage was explored as part of the baseline assessment to determine knowledge and practices on using the phone. Respondents in the study were those who had access to mobile phones. The baseline assessment revealed that the majority of respondents did not use an alarm, text messaging and voice call to support adherence, although the voice call was the most used application. There was also a preference for communication in indigenous languages. Notably, mobile phone usage was associated with age, education and employment. It was worth noting that sharing phones was not a common practice, but compromising phone privacy was possible due to phone battery charging practices. Subsequent to the pre-intervention assessment of mobile phone usage, some of the patient had training to use the alarm, receive messages weekly and voice calls every month for a period of six months.



#### 9.3.2.2 *Effectiveness of integrated mobile phone for monitoring adherence*

Evaluation of mobile phone intervention in improving adherence revealed that there was marginal statistical significance and effectiveness of the intervention on adherence outcome. Despite the measures put in place it was revealed during the interviews that some respondents were not keen on reading the messages. Moreover, the baseline assessment revealed only a few respondents recorded suboptimal adherence. In effect, ensuing assessment and adherence scores revealed marginal improvement. It was

observed that there was a poor association between the different subscale scores of the multimethod adherence measures used for the evaluation. Arguably, it does not mean the intervention was not important considering the qualitative accounts of the clients.

#### 9.3.2.3 *Acceptance and preference for integrated mobile phone intervention for improving adherence*

The evaluation of experiences revealed willingness to accept the use of alarms because this was a personal reminder system. The clients noted that they required mobile phone intervention not necessarily because of adhering to treatment, but because it promoted their sense of worth and left them feeling that others care about them. Voice call interventions were considered to be a demonstration of care and support, but there was ambivalence towards the use of text messaging interventions. The findings further pointed out that the underlying cause of the seeming ambivalence and rejection of text messages is shrouded within the concerns about protecting privacy with regards to HIV status. Maintaining secrecy was used as a strategy to escape stigma and discrimination.



Recommendations from participants show that there was a preference for automated voice messages that were delivered in indigenous languages. The automated voice call, from the clients' perspective, should be structured such that short codes should be provided and when dialled there would be options for selecting preferred languages and information on treatment. Additionally, there was a preference for voice calls that prompted clients about follow-up clinic appointments. Text messages, if used, are

expected to be motivational with no mention of medication or any other clues which would result in interrogation and possibly force them into disclosing their health status.

#### 9.3.2.4 *Readiness for integration of mobile phone in adherence intervention*

Despite the willingness to embrace aspects of mobile phone intervention, technology and literacy challenges were observed among clients, but these are surmountable barriers to mobile technology acceptance, as they were bridged in this study with sufficient training.

Institutions responsible for regulating, planning, implementation and monitoring of HIV/AIDS interventions were willing, in principle, to integrate mHealth care strategy to support adherence. Efforts were being made to create an environment that would facilitate the process by initiating policies and engaging telecommunication agencies to provide support.



Resource limitations and the competing demands of the health sector also pose a barrier to the institutionalisation of mHealth in the national framework. Existing guidelines that mentioned the use of mobile phone reminders were not explicit on the deliverables for the integration of such interventions. More so, there were no in-depth policies on mHealth; the draft guideline for mobile phone intervention in healthcare, which was reviewed, had limited scope and cannot be implemented at the point of service delivery. There was a recognition that the Ghana Health Service and the Ministry of Health need to collaborate with other international and local partners to facilitate a coordinated penetration of mobile phone technology in healthcare.

## 9.4 RECOMMENDATIONS

The findings, notably, have implications for policy makers, health care institutions involved in the care of HIV/AIDS infected persons and healthcare professionals who have roles to play in meeting the aspirations of clients using mobile phones to support treatment. There are also implications for research, education of health professionals and practice.

### 9.4.1 Recommendations for clinical practice

Healthcare professionals working with HIV/AIDS clients need to recognise that clients have high levels of motivation to adhere to treatment. Facilitating the setting of adherence goals is a practical measure that enables clients to own adherence decisions and should be included in adherence counselling.

Adherence counselling is a major facilitator of adherence and therefore must be a continuous process which should be reinforced positively during each follow-up visit depending on the unique circumstances of the clients. Adopting and using the mobile phone integration adherence algorithm as a guide during counselling sessions would provide clients and monitors additional information when making the decision to use a mobile phone in supporting adherence.

Adherence assessment tools provided in the clients' record should be used consistently and thoroughly without seeking to impugn clients' integrity and limit the social desirability effects. The multiple measures of assessing adherence at each visit are commendable, although regular, systematic studies are also important. Measures need to be put in place to minimise pill hoarding practices among patient receiving ART.

There is a need to build the capacity of peer supporters to allow them to continue to serve as adherence monitors. Resources also need to be made available to support their activities.

Collective efforts and strategies should be adopted in addressing the problem of stigma and discrimination. Clients need support and encouragement to allow them to disclose their status, to relevant role players, so that they are able to benefit from the available support systems.

Clients require support to identify personal and institutional barriers that affect adherence behaviour and measures which could assist in addressing them.

There is a need to explore other mechanism that will help reduce clinic waiting time such as appointment scheduling. Appointment scheduling should be for specific dates and times in order to reduce waiting times in the health facilities.



### 9.4.2 Recommendations for education

Adherence to treatment is an area that has been widely explored in literature. Nevertheless, capacity building is necessary to enable an understanding of adherence behaviour.

Continuous education of clients on the importance of adhering to their medication is required and promoted. Existing peer education programmes organised at the various clinics, as observed in the field, need to be maintained.

Technology acceptance and usage barriers affecting mobile phone adherence support measures observed should be addressed by regular training sessions. Peer educators

working as volunteers could be trained to offer support to other clients who are willing to use their mobile phones to set alarms and use other relevant applications.

Education and communication materials could be developed for mobile phone adherence support to enable greater access to information. The brochure developed and used in this study may be a helpful start point.

Health professionals also need to build their own proficiency in using the technology to enable them provide tangible support to clients who decide to adopt mobile phone intervention adherence measures.

Adherence monitors also require training and support to properly use mobile phones. The recommended short-term measures for integrating mobile phones propose that responsibility for this be shifted to clients and their adherence supporters with healthcare provider as the facilitator of the process.



### 9.4.3 Recommendations for Policy and management

The Ghana AIDS Commission, which is the main policy initiator, has authored a number of policy documents that regulates implementation of strategies in the HIV/AIDS response. The gap within these policies is the regulation of mHealth based interventions. The preliminary document of the Ghana Health Service on mHealth is not specific and the legal framework of mHealth is undefined. In view of this, there is a need to scale-up policy on mobile health care in order to provide guiding principles in the use of mobile phones for healthcare. The policy should target issues of privacy and provide the legal and ethical framework to guide implementers.

The availability of such policies would also assist future attempts to engage telecommunication network providers in negotiations to solicit their support in assigning short-codes that would be used to provide the plethora of information that clients with HIV want to have access to.

In the meantime, recommendations made in this study could be integrated in the next review of the National AIDS Control Programme guidelines on antiretroviral treatment in Ghana. The task-shifting approach to the gradual integration of mobile phone intervention in the existing guidelines would set the stage for future work on the integration process.

### 9.4.4 mHealth recommendations

Health institutions should partner with mobile network service providers and government to establish the infrastructure support in all health institutions. The existence of resources will facilitate access. In addition well-structured systems for using mobile phones to support health care, including adherence counselling and support may be helpful.



Peer volunteers should be appropriately integrated in the service structure to enable them take up the task of supporting adherence. It is recommended that in the meantime the task-shifting algorithm be adopted and used until the structures and policies are in place to scale-up mHealth for adherence support.

Subject to regulatory frameworks, network service providers are in a position to offer assistance to the health institutions and clients if the automated voice messages preference is adhered to. Information on adherence, treatment regimens and additional

instruction could be available for individuals to access just by dialling dedicated short-codes.

In the long-term there is a need to explore other sophisticated technology based appointment scheduling systems, which generates automatic messages to remind clients about clinic appointments, as and when resources become available.

### 9.4.5 Recommendations for future research

In this study, Econometrics of adherence interventions inputs could not be determined; in view of this it is recommended that future intervention studies include a cost benefit analysis.

The effect of each mobile intervention and the influence of alarm, text messaging and voice calls was not comparatively analysed to determine the statistical significance. Future investigations should include this.



There is a need to explore the legal implications of mHealth interventions for adherence support to facilitate policy review and regulation.

The socio-cultural context of clients' preference for automated voice messages and the cost implications thereof is an area worth exploring prior to implementation.

## 9.5 UNIQUE CONTRIBUTION

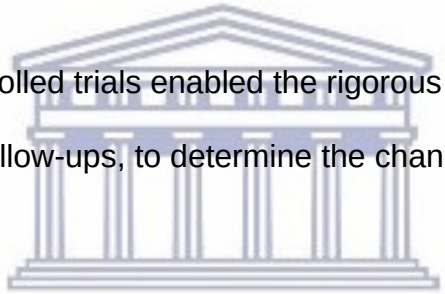
The study has made unique contributions to HIV research, adherence interventions, and the use of mobile phones in adherence intervention application of the mixed method approach in research. This study is one of the many studies done on HIV with

emphasis on adherence behaviour and the use of mobile phone technology. However, this study is the first of its kind in Ghana and makes the following unique contributions.

### 9.5.1 Contextualised and rigorous evaluation of an RCT intervention

The choice of the logic model in the evaluation of the intervention was unique as it enabled a systematic approach to planning and evaluating the goal of the study in relation to the process, inputs, activities, output and outcome which enabled a rich contextualised evaluation. The research problem and questions have previously been explored in different studies and populations. However, the approach, design and context of this study have enriched the evidence on randomised controlled trials.

The use of randomised controlled trials enabled the rigorous comparison of baseline adherence outcomes, with follow-ups, to determine the changes that occurred in each group and individual.





### 9.5.2 Development of an algorithm for mobile phone use in adherence in countries like Ghana

This study has led to the development of an algorithm or protocol that will guide the integration of mobile phones in adherence using a task-shifting model that utilises adherence supporters and peer monitors. A brochure was developed and used to educate the clients on using the mobile phone as an adherence support measure. This brochure could be used for educating other clients and adherence monitors. The study has set the pace for further investigations related to mHealth care in Ghana.

### 9.5.3 Contribution to research

The findings were not new but are nevertheless a relevant addition to existing knowledge and have enriched the evidence on HIV research, adherence, mHealth and nursing knowledge. What makes this study unique is the rich contextual explorations of existing knowledge in order to begin to develop a deeper understanding of the behaviour motivations in this complex field.

### 9.5.4 Contribution to HIV research

This study has contributed to existing literature on the experiences of clients living with HIV. The study affirmed that the illness history of living with HIV/AIDS follows a trajectory of being diagnosed, receiving treatment and adjusting to life with HIV.

HIV/AIDS research is one of the areas in which several studies have been done as part of the response to finding solutions to the burden of disease and improving the quality of life and the well-being of infected persons. The key contributions from this study were:



HIV positive diagnoses were mainly incidental, although some occurred during mandatory testing (screening for HIV during pregnancy screening) or voluntary testing and counselling. Despite free access to HIV counselling and testing, delays in seeking health care are still persistent. Discovering one's HIV status while seeking treatment for other illnesses resulted in emotional responses such as confusion, anger and acceptance consistent with other findings in the literature. Communication of HIV diagnosis and managing reactions requires sensitivity and support from health professionals. Clients use integrative coping mechanisms when facing difficult issues such as being diagnosed with HIV. Instrumental strategies included taking prescribed

treatment, exercising and ensuring adequate nutrition; religious coping mechanisms were prayer and faith in God while others also used self-efficacy to cope with their HIV positive diagnosis.

Treatment initiation was preceded by counselling sessions that involved assessing eligibility, readiness, education on drug regimens and their effects. Consistent with previous studies, clients experienced side-effects from treatment and some had to withdraw from treatment and for others the treatment was changed.

One aspect of adjusting to life with HIV is the experience of stigma and discrimination which has been widely reported in other studies. Protecting the secrecy of their HIV diagnosis was of keen interest to clients, and disclosure of their status to children and friends was not a common phenomenon. The disclosure of one's HIV status, on the other hand, promoted social support from spouses and family. It is worth noting that clients with HIV make decisions around their care depending on how likely it is to affect the protection of their HIV status.



No new findings emerged from this study. However, the findings have contributed to previous studies, particularly from a sub Saharan African perspective. The key interplay in the outcome of this study is the socio-cultural context of decision making about health, openness and secrecy, resource availability and resource limitation which is expected to improve over time.

### 9.5.5 Contribution to literature on adherence

The literature on adherence is quite extensive, but divergent depending on the population studied and measures used in assessing adherence. This study is one of the

few studies that assessed adherence using multiple adherence assessment tools (self-report, visual analogue scale, pill identification test and pill counts) and multilevel repeated measurements (baseline assessment, month three and month six).

Additionally, the use of a mixed method approach generated evidence on adherence that reflects quantitative and qualitative perspective of adherence behaviour. The outcome, which revealed that adherence levels were high, differs from the persistent suboptimal adherence reports that were found in the literature from Ghana. The adherence behaviour was motivated by self-consciousness, self-determination and an awareness of the consequence of nonadherence. These attributes were further facilitated by the simplicity of regimen, benefits of ART, fear of death and transparency about HIV status. The study outcome further confirmed that forgetfulness, religious fanaticism, sleeping habits and secrecy contributed to nonadherence in instances of suboptimal adherence.



This study has also contributed to existing evidence on adherence monitoring strategies. Adherence monitoring involved the clients, significant others and the health institutions. There was self-monitoring, monitoring by spouses, family members and peers (other HIV positive clients) which is consistent with other findings.

The outcome also contributed to evidence on factors facilitating or inhibiting adherence noting that some socio-demographic characteristics influence adherence. Adherence counselling and spousal support were key adherence facilitators while fear of their HIV positive status being noticed by others inhibited adherence. The finding may not

necessarily be unique from a global perspective but is one of the first of its kind conducted in Ghana.

### 9.5.6 Contribution to evidence on intervention research

The mobile phone has been widely used to support adherence in different forms globally. The existing studies applied predominantly text message interventions and assessed adherence with one or two indicators. To the best of the researcher's knowledge this study is unique in terms of the intervention and measures used to evaluate outcomes. The intervention was compared at baseline and two follow-ups to determine the changes occurring in each group and individual.

The implementation of the intervention process was based on a transactional goal model where the mobile phone intervention was considered as a transaction that required interacting with clients to set adherence goals, identify adherence needs take action and make a judgement to promote adherence while ensuring feedback.



### 9.5.7 Contribution to body of knowledge in nursing

Additionally, this is the first study that utilised Imogene King's transactional model in planning and implementing adherence to medication with mobile phone support. Clients had the opportunity to identify their adherence needs, work with the nurses in deciding the action and obtaining feedback. Behavioural and cognitive theories were also utilised in the synthesis of outcomes. This approach allowed for the contextual interpretation of the findings of the study.

## 9.6 LIMITATIONS

Despite the efforts made to protect the integrity of this study there are some limitations that requires cautious generalisations of the findings. The eligibility criteria excluded clients without access to mobile phones therefore their perspectives have not been considered.

The used of randomised control trials required the prevention of biases and protection of data integrity, however; there were limitation with aspects of the intervention which was discussed in details in Chapter four.

The instrument used for data collection had weak psychometric properties, which may have affected the findings. In order to estimate overall scores there were a series of data transformation and reduction, which may have influenced the outcome.

Conducting a narrative review instead of a systematic review affected the quality of literature and broadened the scope of the review without stringent criteria for eligibility of selected studies.



Another limitation of this study is the inability to measure the influence transactional goal setting had on adherence despite using this approach for the implementation. The confounding effects of this variable could therefore not be determined

Although the study required administering an intervention it was not considered an intervention programme therefore the typical processes involved were not strictly applied and this limits the depth of the outcomes. In spite of these limitations, the study made some unique contributions to knowledge.

There were technological and technical difficulties following initial attempts to use web-linked data sources to track intervention delivery. Additionally, protocol registration processes stalled due to challenges associated with the payment of registration costs.

## 9.7 CONCLUSION

Persons living with HIV/AIDS have to take antiretroviral treatment for the rest of their life. Barriers such as forgetfulness and the stigma associated with HIV limit adherence behaviour. Clients, in spite of their own determination to stick to treatment, need support.

Mobile phones are available and could be used to support adherence in HIV infected persons but this requires a collaborative approach.

There are limitations in the availability of resources, despite the willingness and acceptance, demonstrated by clients, policy makers and implementers. Utilising task-shifting approaches will allow adherence monitors and volunteers to take responsibility for monitoring adherence. The nurses' role will be to provide education on adherence and feedback while liaising with other team members to ensure goal attainment.

In the long-term advocacy on policy framework and resource engineering will facilitate the scale-up of using mobile phones to support adherence. Further cost benefit analysis will inform the development of guidelines and strategies on integrating mobile phones in adherence interventions.

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## Appendix A: Participant Information

**Project Title**: Integrated mobile phone intervention for adherence to antiretroviral treatment in clients with HIV infection in Accra, Ghana

**Researcher**: Gladys Dzansi ( PhD Student, School of Nursing, University of the Western Cape)

**Summary of Problem**

Taking medications rightly as prescribed is important. However, sometimes remembering to take medication could be very challenging and others miss follow-up date. This study seeks to find out some interventions that can help in supporting those who take antiretroviral medication to take them as prescribed.

**What benefit will be derived?**

When involved in this study you have the opportunity to answer some questions. The information you share would assist nurses, doctors and other persons to plan better care and support you take your medication well.

**What would it involve?**

When you agree to be part of this study, the researcher would discuss with you when it is convenient for you to meet; the time and place you prefer to meet. You would be expected to answer some questions and given some instructions by a nurse or an assistant on other processes in the study. You are free to choose to answer only questions about things you are ready to share. You would be interviewed at the beginning of this interaction and sixth months later. The information you provide would be written out for academic purposes. You are assured that neither your name nor initials or anything that could be used to trace you would be mentioned to others. You would be required to sign or thumbprint a paper to show your acceptance.

**What would be my reward?**

There is no financial benefit if you participate in this study. However, you would have an opportunity in the course of the study to benefit from some of the interventions that are being tried.

**Is there any harm if I participate?**

Your participation should not be harmful to you in this study, but usually some people may feel uncomfortable and emotionally disturbed if they talk about a sad or bad experience. Should this happen, you would be assisted through counseling and referral

to appropriate counselor specialized in dealing with matters of this nature so that you will be able to effectively deal with such feelings.

**What if I decide to withdraw?**

You are free to withdraw from the study at any time and this would not affect you in any way. All you have to do is to inform any of the researcher, supervisor or any of the contacts given to you at the commencement of the study.

**How would the information provided be used?**

The information and documents would be used for teaching/learning purposes but your identity would not be disclosed. The information would be discussed among nurses and other health professionals to help them provide care and also do other studies.

If you have any questions or concerns please contact any of the following:

Gladys Dzansi
School of Nursing
College of Health Sciences
University of Ghana
Legon
Email: akorfa7@yahoo.com

Tel: 024 30 59 316
Head of Department:
Dean of the Faculty of Community and Health Sciences:
University of the Western Cape
Private Bag X17
Bellville 7535



This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee

**Appendix B: Consent Form**

**Project Title**: Integrated mobile phone intervention for adherence to antiretroviral treatment in clients with HIV infection in Accra, Ghana

**Researcher**: Gladys Dzansi ( PhD Student, School of Nursing, University of the Western Cape)

Please circle (Ọ) the response

| | | |
|---|---|---|
| I understand what the study is about | Yes | No |
| I understand there would be no reward | Yes | No |
| I am aware the study would cause me no harm | Yes | No |
| I know what would be required from me during the study | Yes | No |
| I am convinced that I could withdraw from the study at any time | Yes | No |
| I know I have the opportunity to ask question to clear any doubts | Yes | No |
| I know what would be done with the information provided | Yes | No |
| I accept to be involved in the study | Yes | No |
| I believe the decision to participate in the study was voluntary | Yes | No |



The study was explained to me by

…….

Researcher's Name Signature

Participant's Name Sign/thumbprint Date

……

Witness ……

**Appendix C: Questionnaire**

Research code_____/_____/_____

**Form No:** | | |

Dear respondent

We are collecting information to find out how best clients could be assisted to take their medication. Please listen carefully and answer the question that would be asked. You are free to ask questions about anything you feel uncomfortable about. All the information you provide would be confidential. Thank you.

**Section A: Demographic characteristics**

Please circle or tick or circle the appropriate response where applicable

1) Age in years? | | |

2) Sex 1 Male 2 Female

3) What is your level of education? 1 Tertiary 2 Vocational 3 SHS

4) JHS 5 Primary 6 Middle 7 No education

4) Which of the following best describe your relationship status?

1 Married 2 single 3 divorced 4 separated 5 widowed

5) Which of the following best describes your employment status?

1 Public sector 2 Private formal 3 Informal 4 unemployed

6) What is your religious status?

1 Christian 2 Moslem 3Traditional 4 No religion

Others_____

7) Where do you live?

_____

| | |

8) How many hours does it take to get to the clinic from your current location?

9) Is there another clinic within your locality offering ART services?

1 Yes 0 No

**Section B: Clinical Data (***to be obtained from client's record***)**

10) How long have you known about your condition | | |

11) Have you disclosed your status to any of the following?
   a) Spouse Yes[ ] No [ ]
   b) Family Yes[ ] No [ ]
   c) Children Yes[ ] No [ ]
   d) Friends Yes [ ] No [ ]
   e) Other
      specify_____
      _____

12) What is the current cell count? | | | | |

13) If viral load test has been done | | | | |
    what is the result?

14) What is the stage of infection?
    1Stage I 2 Stage II 3 Stage III 4 Stage IV

15) How often are you required to report for follow-up visit?
   a) Every month
   b) Every two months
   c) Every three months
   d) Every four months
   e) Others
      specify_____
      _____



16) Please indicate the following:

| 1 Weight | | | 2 Height | | | 3 BMI | | | |
|---|---|---|---|---|---|---|---|---|---|

17) Where do you keep your medication most of the time?
   1. In a pill box
   2. In a special purse
   3. In a cupboard
   4. Not specified
   5. Others
      specify_____

**Section C: Mobile phone usage**

18) Do you share your mobile phone with other people? Yes [ ] No [ ]
19) Do you currently use any of the following mobile phone applications? (tick all that apply)

a. Alarm function Yes [ ] No [ ]
b. Reminders Yes [ ] No [ ]
c. Text messaging Yes [ ] No [ ]
d. Voice call Yes [ ] No [ ]

20) Which language(s) do you often use for each of the following? Tick all that apply

| | English | Akan | Ewe | Ga | Others specify |
|---|---|---|---|---|---|
| 1 Voice call | | | | | |
| 2 Text messaging | | | | | |

21) Do you sometime use the mobile phone to help you remember your medication time?

1 Yes 0 No

22) Do you require further training to use the following applications on your phone?

a. Alarm function Yes [ ] No [ ]
b. Reminders Yes [ ] No [ ]
c. Text messaging Yes [ ] No [ ]
d. Voice call Yes [ ] No [ ]

**Appendix D: Adherence Assessment**

**Section A: Multi-Method Adherence Tool**

Research Code___/_____/___

Visit No [ ]

Treatment Group: 1 2



**D1 Self-Reporting**

Please I understand taking medicine can be difficult especially if you have to take a number of them at different times of the day. This is why it is important to understand how you are doing with your medication. Whatever you say just be honest with me because I want to know what is happening and not what you think I expect to hear.

| | *Question* | *Yes* | *No* |
|---|---|---|---|
| 1. | Do you sometimes find it difficult to remember to take your medicine? | | |
| 2. | When you feel better, do you sometimes stop taking your medicine? | | |
| 3. | Thinking back over the past four days, have you missed any of your doses? | | |
| 4. | Sometimes if you feel worse do you stop taking the medication? | | |

**D2 Visual Analogue scale**

5. In the past four days how well would you say you remembered to take your medication at the right time and quantity as required if 0 means you forgot the medicine always and 10 means you always took the pills correctly

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | |

**D3 Pill identification test**

6. If you have your pills please bring them out and tell me the names and how it should be taken or look at the picture shown to you and tell me what medications you have, their name and how to take them

| Name of drug | Knows name | | *Knows pills per dose* | | *knows timing of dose* | | *Knows additional instruction* | | *Accuracy of judgment* |
|---|---|---|---|---|---|---|---|---|---|
| | Yes | No | Yes | No | Yes | No | Yes | No | |
| | Yes | No | Yes | No | Yes | No | Yes | No | |
| | Yes | No | Yes | No | Yes | No | Yes | No | |
| | Yes | No | Yes | No | Yes | No | Yes | No | |
| | Yes | No | Yes | No | Yes | No | Yes | No | |
| | Yes | No | Yes | No | Yes | No | Yes | No | |
| | Yes | No | Yes | No | Yes | No | Yes | No | |
| | Yes | No | Yes | No | Yes | No | Yes | No | |

**D4 Pill count**

7. Now let us see how many pills we have left to help us know how well you are doing in taking the pills.

| Name of drug | Number given | Number left | Score |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

**D5 Section B: Adherence support measure**

8. Please tell us how the following have been helpful in taking your medication as expected

| | | Does not happen | Hardly of any help | Not helpful | Somewhat helpful | Very helpful |
|---|---|---|---|---|---|---|
| | | 0 | 1 | 2 | 3 | 4 |
| | Adherence counseling | 0 | 1 | 2 | 3 | 4 |
| | Visit from community health workers | 0 | 1 | 2 | 3 | 4 |
| | Support from friends | 0 | 1 | 2 | 3 | 4 |
| | Support from family | 0 | 1 | 2 | 3 | 4 |
| | Support from spouse | 0 | 1 | 2 | 3 | 4 |
| | Support from religious group | 0 | 1 | 2 | 3 | 4 |
| | Support from PLWA groups | 0 | 1 | 2 | 3 | 4 |
| | Support from NGO | 0 | 1 | 2 | 3 | 4 |
| | The use of medication purse/wallet | 0 | 1 | 2 | 3 | 4 |
| | Use of medication chart | 0 | 1 | 2 | 3 | 4 |
| | Phone alarms and reminders | 0 | 1 | 2 | 3 | 4 |
| | Text messaging reminders from nurses | 0 | 1 | 2 | 3 | 4 |
| | Phone calls from nurses | 0 | 1 | 2 | 3 | 4 |

9. Taking your medications regularly could sometimes be affected by situations you did not anticipate. How has the following events interfered with your medication routine in the past 1 month.

| | | Not at all | Sometimes | Very often | Always |
|---|---|---|---|---|---|
| 1. | Work schedule | 0 | 1 | 2 | 3 |
| 2. | Number of pills to be taken | 0 | 1 | 2 | 3 |
| 3. | Number of times I have to take the medication | 0 | 1 | 2 | 3 |
| 4. | Forgetfulness | 0 | 1 | 2 | 3 |
| 5. | Feeling better | 0 | 1 | 2 | 3 |
| 6. | Feeling sick after taking medication | 0 | 1 | 2 | 3 |
| 7. | When there are no reminders | 0 | 1 | 2 | 3 |
| 8. | Presence of people who don't know your status | 0 | 1 | 2 | 3 |
| 9. | Fear of being seen by other people | 0 | 1 | 2 | 3 |
| 10 | Changes in meal time | 0 | 1 | 2 | 3 |
| 11 | Sleep | 0 | 1 | 2 | 3 |
| 12 | Feeling sad/unhappy | 0 | 1 | 2 | 3 |

## Appendix D : Interview guide

We had some discussion a few months ago and I informed you we will have a conversation some time later about the taking of your medications. You are free to answer only questions you are comfortable with and I will discontinue the conversation anytime you request. I will record our conversation to enable me remember what we discussed but your name will not be mentioned or written anywhere.

Suggested questions with probes

1. I know we did meet previously but I want to know you more so please tell me about yourself.
    a. I will like to know about you and your family
    b. How long have you been ill?
    c. What work are you doing now
    d. How has the illness affected you
2. One of the important things you are expected to do every day is taking your medication. Tell me more about it.
    a. How were you taking your medication before we met?
    b. What are some of the medication you are taking?
    c. How were you asked to take them?
    d. What are some of the thing you do to help you take your medication as you were told?
    e. What are some of the problems you have taking your medication?
    f. Some people get sick when they start their medication and sometimes the medication has to be changed. Please tell me about your experience.
    g. Who are some of the people who have been of help to you in taking your medicine?
3. Some month ago we started sending you messages and calling you. Please tell me what you think about this experience.
    a. How often were you receiving the calls and messages
    b. What are some of the things about the calling and texting that you are happy about?
    c. Please tell me some of the things you were not happy about that you want addressed.
    d. What do you think about using the alarms?
    e. What are some of the things you want to be done if we have to continue calling you or sending messages?

4. Tell me any other thing you wish to share about your medication taking that we have not talked about.
    a. Some people do not want other people to know they are taking medicine, please what is the case for you?
    b. If you had the opportunity to talk to someone taking the medicine as you are what will you say?

**Appendix E : Focus group discussion guide**

We have been interacting for the past sixth month. Some of you were interviewed individually and we mentioned we would have discussion with other collegues present. Kindly note that, you are not expected to mention your name during our conversation. You are free to ask and respond to the questions or decline from participating.

1. Kindly say something briefly about yourself.
   Probes
   a. *What about you and your family?*
   b. *How long have you been ill?*
   c. *What work are you doing now*
   d. *How has the illness affected you and your family*
2. Who would share some of the important things about taking your medication?
   Probes
   a. *How were you taking your medication before we met?*
   b. *What are some of the medication you are taking?*
   c. *How were you asked to take them?*
   d. *What are some of the thing you do to help you take your medication as you were told?*
   e. *What are some of the problems you have taking your medication?*
   f. *Some people get sick when they start their medication and sometimes the medication has to be changed.*
   g. Who are some of the people who have been of help to you in taking your medicine?
3. Who else has additional experience to share? (same probes)
4. Some month ago we started sending you messages and calling you. Please share your experience with us.
   a. How often were you receiving the calls and messages
   b. What are some of the things about the calling and texting that you are happy about?
   c. What were you not happy about that you want addressed.
   d. What do you think about using the alarms?
   e. What are some of the things you want to be done if we have to continue calling you or sending messages?
5. Share any other experiences or disagreement about the medication taking issues raised.
   a. Some people do not want other people to know they are taking medicine, please what is the case for you?
   b. If you had the opportunity to talk to someone taking the medicine as you are what will you say?

**Appendix F: Stakeholder engagement questions**

1. What are the current policy issues on adherence monitoring?
2. What are some of the strategies being used to monitor adherence?
3. What are some of the challenges associated with adherence monitoring?
4. What considerations if any does the institution have for using mobile phone and related technologies in adherence monitoring?
5. How is the institution partnering with Non Governmental Organisation (NGO's) trying to use text messaging, calls phone alarms and voice calls to improve adherence and follow-up care?
6. What is your opinion on developing a guideline for using mobile phone to promote adherence to treatment

**Appendix G : Document review guide**

1. What are the existing guidelines on antiretroviral therapy?
    a. Regimen
    b. Drugs
    c. Access
2. What is the level of treatment adherence?
3. What adherence monitoring strategies have been proposed?
4. What factors affect adherence to ART?
5. What are the recommendations about mobile phone use in adherence monitoring and support?
6. What policies are guiding the use of mobile phone in health care?

**Appendix H :Scoring multi-method adherence tool**

**1. Self-reporting (Sr)**

There are four questions with Yes/No responses.

| Response | Interpretation | Code | % Score |
|---|---|---|---|
| No to all items | Highly Adherent | 3 | 95 or more |
| Yes to 1 item | Moderately adherent | 2 | 75-94 |
| Yes to 2 or more items | Low adherence | 1 | 75 or less |

**2. Visual Analogue Scale (VAS)**

| Responses | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Score (%) | 0 | 10 | 20 | 30 | 40 | 50 | 60 | 70 | 80 | 90 | 100 |

**3. Pill identification test (PIT)**

| Response | Interpretation | % Score |
|---|---|---|
| Ability to remember dose, time and instruction | Highly Adherent | 95 or more |
| Ability to remember dose and time | Moderately adherent | 75-94 |
| Ability to remember dose only | Low adherence | 75 or less |

**4. Pill Count (PC)**

$$\text{\% Adherence} = \frac{\text{Dispensed} - \text{Returned}}{\text{Expected to be taken}} \times 100$$

**5. Overall Adherence scores (OAS)**

| More than 95 % | 75-95% | Less than 75% |
|---|---|---|
| High | Moderate | Low |

***Note: Guideline adopted from Steel et al (2007) with modification to suit field research since tool primarily is for clinical use***

**Appendix I: Sample of text message content** (coded communication)

| Period | Messages |
|---|---|
| Month 1&2 | Starting anything new could be difficult but I know you can do it. Yes you can |
| | The God who began the great work in you will surely be with you every step of the way remember the 'song' (code for alarm/reminders) always |
| | We agreed to stick together to meet our goal. This is just a reminder of our commitment |
| | Be strong and focused this is just the beginning we all are with you in prayer |
| Month 4&5 | Whenever you hear the 'song' please remember it's time to take another bold step. |
| | Keep up the spirit stay focused on the goal you are indeed a winner |
| | Does the way you feel make you think of giving up? Please don't give up |
| | Congratulation! I guess we are making progress. Don't forget the song is a charge to keep |
| Month 3&6 | We made a promise to work together and sometime talk about our progress. This is a reminder of our commitment. |
| | Ayeekoo! (congratulation) it is good to keep listening and working with the song. Remember we also have to talk about our progress. |
| | God is faithful to his promise. Keep our song and goal in mind. Sharing our progress is also important. |
| | We may be making steady progress listening to the song and keeping the promise. It's time to share our achievements as well. |

## Appendix J: Participants' Profile

### Individual Interview Participants

| Participant | Age | Gender | Education level | Relationship status | Employment | Number of Children | Illness duration (years) | Treatment duration (years) |
|---|---|---|---|---|---|---|---|---|
| P1 | 40 | Female | Tertiary | Married | Government worker | None | 4 | 3 |
| P2 | 33 | Female | Below tertiary | Married | Self employed | 2 | 7 | 7 |
| P3 | 25 | Female | Below tertiary | Married | Self employed | 2 | 3 | 3 |
| P4 | 44 | Male | Below tertiary | Married | unemployed | 2 | 7 | 4 |
| P5 | 45 | Male | No education | Married | Self employed | 2 | 4 | 2 |
| P6 | 36 | Male | Below tertiary | Single | Self employed | None | 4 | 4 |



### Professional/ Expert Interview participants

| Participant | Age | Gender | Education | Marital status | Employment | Position | Employer |
|---|---|---|---|---|---|---|---|
| Professionals | 55 | Male | Tertiary | Married | Government worker | Policy Monitory and Evaluation | Ghana AIDS Commission |
| Professionals | 50 | Male | Tertiary | Married | Government worker | Head of Fever's Unit | Korle Bu Teaching Hospital |

**Focus Group Interview Participants**

| Participant | Age | Gender | Education | Marital status | Employment | Children | Illness duration (years) | Treatment duration (years) |
|---|---|---|---|---|---|---|---|---|
| F1 P1 | 41 | Female | No education | Married | Self employed | 2 | 5 | 3 |
| F1 P2 | 39 | Female | No education | Married | Government worker | 2 | 4 | 4 |
| F1 P3 | 41 | Female | No education | Married | Self employed | 3 | 10 | 8 |
| F1 P4 | 39 | Female | No education | Married | Self employed | 2 | 6 | 5 |
| F1 P5 | 40 | Male | No education | Married | Self employed | 2 | 7 | 7 |
| F1 P6 | 44 | Male | Tertiary | Married | Government worker | 2 | 5 | 5 |
| F2 P1 | 32 | Female | Below tertiary | Single | Government worker | None | 2 | 2 |
| F2 P2 | 37 | Female | No education | Married | Self employed | None | 5 | 5 |
| F2 P3 | 48 | Female | No education | Single | Self employed | 2 | 8 | 6 |
| F2 P4 | 44 | Female | No education | Married | Self employed | 3 | 7 | 6 |
| F2 P5 | 45 | Male | No education | Single | Self employed | 2 | 7 | 6 |
| F2 P6 | 37 | Female | No education | Married | Self employed | None | 4 | 4 |
| F2 P7 | 33 | Male | No education | Single | Unemployed | None | 5 | 5 |
| F2 P8 | 29 | Female | Below tertiary | Married | Private sector | None | 2 | 2 |
| F3 P1 | 56 | Male | Below tertiary | Single | Unemployed | 3 | 11 | 7 |
| F3 P2 | 46 | Male | Below tertiary | Married | Self employed | 2 | 9 | 5 |
| F3 P3 | 46 | Male | No education | Married | Self employed | 2 | 11 | 8 |
| F3 P4 | 38 | Male | No education | Single | Self employed | 2 | 6 | 5 |
| F3 P5 | 46 | Male | No education | Married | Unemployed | 3 | 10 | 8 |
| F3 P6 | 49 | Female | No education | Married | Unemployed | 3 | 5 | 4 |

**Appendix K: Miscellaneous documents**

Added as separate files

- Ethics letter
- Introduction letter
- Certificate of proof reading
- Turnitin results

UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

30 October 2013

**To Whom It May Concern**

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Ms G Dzansi (School of Nursing)

| | |
|---|---|
| Research Project: | Integrated mobile phone intervention for adherence to antiretroviral treatment in clients with HIV infection in Accra, Ghana. |
| Registration no: | 13/9/36 |

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.



The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias*
*Research Ethics Committee Officer*
*University of the Western Cape*

Private Bag X17, Bellville 7535, South Africa
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E: pjosias@uwc.ac.za
www.uwc.ac.za

# ENGLISH LANGUAGE GRAMMAR EDIT

**This is to certify that the attached titled**

Integrated Mobile Phone Interventions for Adherence to Antiretroviral Treatment in Clients with HIV Infection in Accra, Ghana

**prepared and submitted by**

Gladys Dzansi

**has gone through an English language grammar edit carried out by Duncan Harford.**

28/03/2017

**DATE**

**SIGNATURE**

School of Nursing
College of Health
University of Ghana
Legon
25th August 2015

The Director General
Ghana AIDS Commission
Cantonments
Accra

Dear Madam,

**Stakeholder Engagement on Integrated Mobile Phone Intervention for Improving Antiretroviral Treatment Adherence**

I am Miss Gladys Dzansi a lecturer at the School of Nursing, University of Ghana, Legon. I am pursuing a PhD at the University of the Western Cape, Cape Town, South Africa with scholarship from the Brown/Tuft Fogarty International AIDS Training and Research Program (AITRP). My thesis is titled '**Integrated Mobile Phone Interventions for Adherence to Antiretroviral Treatment in Clients with HIV infection in Accra, Ghana'.** The aim of this study was to determine how mobile phones could be used to promote medication adherence among persons living with HIV/AIDS. I collected data from Korle Bu Teaching hospital and Ridge over an 18 months period (February 2014 to July 2015).

I will be grateful if I will be granted opportunity to engage with you or your officers to discuss my preliminary findings and also seek additional information on any policy direction in relation to use of mobile phone in ART adherence strategies.

Counting on your assistance and cooperation.

Thank you

Yours sincerely,

Gladys Dzansi

(Principal Investigator/PhD student)

*email:gladysdzansi@gmail.com Tel: 0243059316*

cc: Officers in-charge

Policy Planning Division

Research Monitoring and Evaluation