

**UNIVERSITY OF GHANA, LEGON**  
**COLLEGE OF HEALTH SCIENCES**

**FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL  
THERAPY AMONG PERSONS LIVING WITH HIV IN ACCRA  
METROPOLIS**

**BY**

**PRISCILLA COBBLAH**

**(10442429)**

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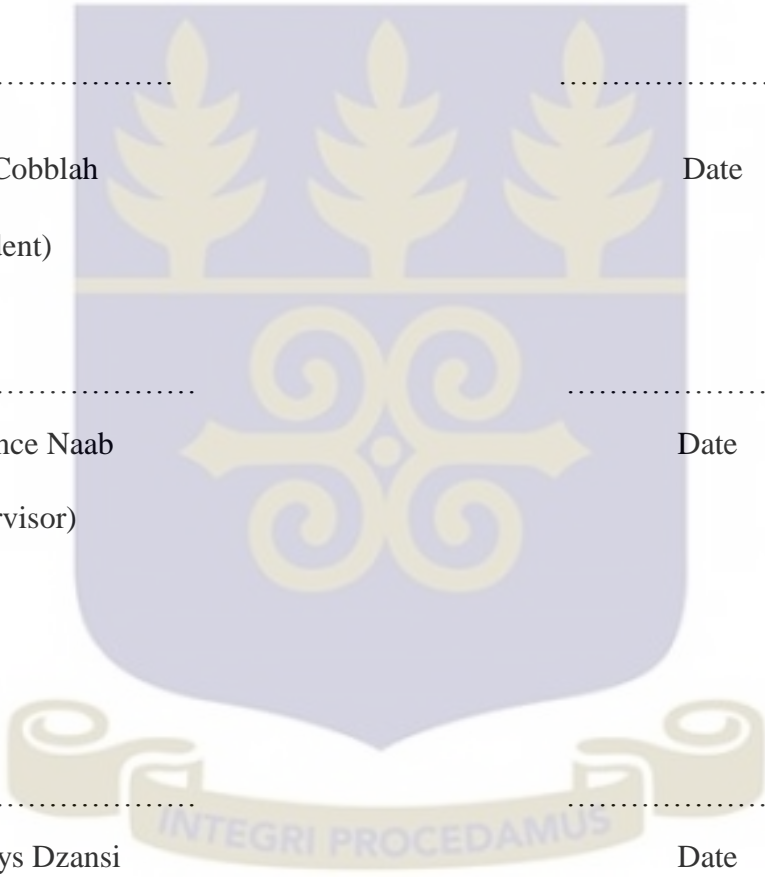
**SCHOOL OF NURSING**

**JANUARY, 2016**

*Factors influencing adherence to ART among PLWHIV*

**DECLARATION**

I hereby declare that except for references to other peoples' work which has been duly acknowledged, this thesis is the outcome of my own original research. None of the materials in this write up has been presented either in whole or in part to any other institution for the award of any degree or certificate.



.....

Priscilla Cobblah Date  
(Student)

.....

Dr. Florence Naab Date  
(Supervisor)

.....

Ms. Gladys Dzansi Date  
(Supervisor)

*Factors influencing adherence to ART among PLWHIV*

**ABSTRACT**

Adherence to antiretroviral therapy (ART) is an essential component in the management of HIV/AIDS. This research explored the factors influencing adherence to ART among persons living with HIV (PLWHIV) in the Accra Metropolis.

An explorative descriptive qualitative design was used to explore the factors influencing adherence to ART among PLWHIV. A total of fourteen (14) participants living with HIV were purposively recruited from the ART clinic in a public Hospital in the Accra Metropolis. In-depth interviews were conducted with each participant lasting about 30-45 minutes. The social cognitive theory by Albert Bandura was used as an organizing framework. The study described the participants' behavioural adherence to ART and identified the cognitive and personal factors influencing such adherence.

The findings revealed that the factors influencing adherence to ART are categorised into behavioural adherence, personal factors, treatment and self-efficacy factors and environmental factors. Consequently, there is the need for continuous education of PLWHIV on the benefits of adherence to ART.

## **DEDICATION**

This work is dedicated to the Almighty God whose goodness and mercies have brought me this far. It is also dedicated to Mr Enock Daniel Essoun and my entire family especially my mother, my children and my siblings for their love and support throughout my course.



*Factors influencing adherence to ART among PLWHIV*

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**TABLE OF CONTENT**

DECLARATION .....	ii
ABSTRACT.....	iii
DEDICATION .....	iv
ACKNOWLEDGEMENT .....	v
TABLE OF CONTENT .....	vi
LIST OF TABLES .....	x
LIST OF FIGURES .....	xi
CHAPTER ONE .....	1
INTRODUCTION .....	1
1.1 Background of the Study.....	1
1.2 Problem Statement .....	4
1.3 Purpose of the Study .....	6
1.4 Specific Objectives.....	6
1.5 Research Questions .....	7
1.6 Significance of Study .....	7
1.7 Operational definition .....	8
1.8 Abbreviation.....	8
CHAPTER TWO .....	9
2.1 THEORETICAL FRAMEWORK AND LITERATURE REVIEW .....	9
2.2 The Social Cognitive Theory .....	9
2.2.1 Behavioural Adherence to ART .....	11
2.2.2 Cognitive and other Personal Factors .....	12
2.2.3 Treatment and self-efficacy factors .....	13
2.2.4 Environmental factors.....	13
2.3 Literature Review .....	14
2.3.1 Behavioural Adherence to ART .....	14
2.3.2 Cognitive and other personal factors.....	17
2.3.3 Treatment and Self-efficacy .....	19
2.3.4 Environmental Influences .....	22
CHAPTER THREE .....	29

*Factors influencing adherence to ART among PLWHIV*

3.1 RESEARCH METHODOLOGY.....	29
3.2 Research Design.....	29
3.3 Research Setting.....	29
3.4 Target Population.....	31
3.4.1 Inclusion criteria.....	31
3.4.2 Exclusion criteria.....	31
3.5 Sample size and Sampling Technique.....	31
3.6 Tool for Data Collection.....	32
3.7 Pretesting of the interview guide.....	32
3.8 Data collection procedure.....	33
3.9 Data management & analysis.....	34
3.10 Ethical Consideration.....	35
3.11 Methodological Rigour.....	36
CHAPTER FOUR.....	39
4.1 RESULTS / FINDINGS.....	39
4.2 Demographic characteristics.....	39
4.3 Organization of Themes.....	40
4.4 Behavioural adherence.....	40
4.4.1 Fear of health outcome.....	41
4.4.2 Avoidance of suspicions.....	44
4.4.3 Avoidance of reprimandment.....	46
4.5 Cognitive and other personal factors.....	48
4.5.1 Depressive factors.....	48
4.5.2 Physical conditions/ Physical function.....	52
4.6 Treatment and self-efficacy.....	54
4.6.1 Treatment efficacy.....	54
4.6.2 Self-efficacy.....	61
4.6.3 Time consciousness.....	63
4.6.4 Confidence in Art.....	66

*Factors influencing adherence to ART among PLWHIV*

4.7 Environmental influences.....	68
4.7.1 Disclosure of status .....	68
4.7.2 Attitude of health personnel towards PLWHIV .....	71
Positive attitude .....	71
Negative attitude.....	73
4.7.3 Hiding and disguising of ART .....	74
4.7.4 Social support.....	75
Spousal support.....	76
Family support.....	78
Support from friends.....	79
Group support .....	80
4.8 Major concerns on adherence.....	82
4.8.1 Adherence and spirituality .....	82
4.8.2 Need for a monitor .....	85
CHAPTER FIVE .....	90
5.1 DISCUSSION OF RESULTS/FINDINGS.....	90
5.2 Demographic Characteristics .....	90
5.3 Behavioural adherence to ART .....	91
5.4 Cognitive and other personal factors.....	92
5.5 Treatment and self-efficacy.....	93
5.6 Environmental influences on adherence .....	96
5.7 Major concerns on adherence.....	99
CHAPTER SIX.....	102
6.1 SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS .....	102
6.2 Summary of the study .....	102
6.3 Implications.....	104
6.3.1 For nursing education.....	104
6.3.2 For nursing practice.....	105
6.3.3 For nursing research .....	105
6.3.4 Policy formulation.....	106

*Factors influencing adherence to ART among PLWHIV*

6.4	Limitations of the study.....	106
6.5	Conclusion.....	106
6.6	Recommendations .....	107
6.6.1	To the Ministry of health (MOH).....	107
6.6.2	To Ghana health services (GHS).....	108
6.6.3	To the ridge hospital.....	108
6.6.4	To the client.....	108
	References.....	110
	Appendices.....	125
	Appendix A: Ethical Clearance (Noguchi Memorial Institute for Medical Research – Institutional Review Board).....	125
	Appendix B: Introductory Letter.....	126
	Appendix C: Information Sheet .....	127
	Appendix D: Consent Form .....	131
	Appendix E: Interview guide .....	135
	Appendix F: Map of greater Accra .....	137
	Appendix G: Budget and Budget Justification.....	138
	Appendix H: Summary of Demographic Characteristics of Participants’ ..	139
	Appendix I: Thematic Codes and Description .....	141



## LIST OF TABLES

Table	Page
4.1 Themes and sub-themes from transcribed data	39
1 Concise Summary of Demographic Characteristics of participants	137
2 Description of Themes and Subthemes	139



**LIST OF FIGURES**

<b>Figure</b>		<b>Page</b>
2.1	Social Cognitive Theory	11



## CHAPTER ONE

### INTRODUCTION

#### 1.1 Background of the Study

Human immunodeficiency virus (HIV) is a lentivirus that is a slowly replicating retrovirus that causes acquired immunodeficiency syndrome (AIDS). This is a condition in humans with progressive failure of the immune system that allows life threatening opportunistic infections and cancer to thrive (Douek, Koup, McFarland, Sullivan, and Luzuriaga, 2000). HIV/AIDS is now a chronic disease similar to other chronic illnesses such as diabetes and hypertension that require daily medications in order to control the associated pathology and optimize health (Volberding & Deeks, 2010).

The 2013 World health organization (WHO) HIV treatment guidelines greatly expanded the number of people eligible for ART. To meet this challenge, UNAIDS in July 2013 joined WHO, the US President's Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, tuberculosis and Malaria and other partners to launch the Treatment 2015 initiative. Treatment 2015 aims to ensure that the world reaches its 2015 HIV treatment target of 15 million as a critical stepping-stone towards universal access to ART. Like all developing countries in Africa, HIV/AIDS is also present in Ghana. The Government of Ghana estimated the number of adults and children living with HIV/AIDS as at 2010 to be 230,000 and the prevalence rate at 1.3% in 2012. The joint United Nations programme on HIV estimated the prevalence rate in adults to be 0.92% at the end of 2012 with an estimated 200,000 people living with HIV/AIDS (W.H.O., 2010).

*Factors influencing adherence to ART among PLWHIV*

The national HIV prevalence in Ghana declined from 3.6% in 2003 to 1.3% in 2013, HIV infection estimates currently show that in 2012, 235,982 persons were living with HIV with 27,734 being children. HIV infection among children has been mainly through mother- to- child transmission (W.H.O., 2010).

With the changing perspectives of the HIV epidemic and the introduction of protease inhibitors to treat HIV disease, the issue of adherence can be said to have gained considerable interest among health care providers (HCP) and other stake holders. Since the introduction of ART and chemoprophylaxis to prevent opportunistic infections, the survival among people with HIV type 1 infection has increased, resulting in a chronic disease condition that can be stabilized with therapy for many years (Riggs, Sethi, Zabarsky, Eckstein, Jump and Donskey, 2007). This shifting paradigm of the HIV-1 illness trajectory requires that HCPs, community based AIDS organizations, legislators, policy makers, and economists, as well as people living with HIV (PLWHIV), seriously reconstruct their understanding of this illness to enhance medication adherence. However there is no agreed upon definition of adherence or compliance.

According to Steiner and Earnest (2000), adherence to (or adherence with) a medication regimen is generally defined as the extent to which patients take medications as prescribed by their HCP. The word “adherence” is preferred by many HCP, because “compliance” suggests that the patient is passively following the doctor's orders and that the treatment plan is not based on a therapeutic alliance or contract established between the patient and the

*Factors influencing adherence to ART among PLWHIV*

HCP. Both terms are imperfect and uninformative descriptions of medication-taking behaviour.

Adherence describes the complement of actions taken to comply with intervention, recommendations and is different from other behavioural change outcome (Boggs, 2007). Prior to studies on ART adherence, other researchers have asserted that if the level of pill taken reached 80%, one could label the patient as adherent. In recent times, there is evidence that an 80% level with ART adherence could be dangerous to a client's health because of the potential to develop ART resistance (Boggs, 2007).

In general, adherence is defined as it is measured, either as self-reports of pills missed, counting of pills, or the recordings from devices of times and dates of opening bottles. Although the term adherence or compliance is often used by HCPs, its interpretation often has different meanings to different people. Jackevicius, Mamdani, and Tu, (2002) define adherence as 'the extent to which a person's behaviour, in terms of taking medications, following diets or executing lifestyle changes coincides with medical advice'.

Laher, O'Malley, O'Brien, O'Hanrahan, and O'Boyle (1981) defined adherence as sufficiently following medical advice to meet a therapeutic goal. According to these definitions, compliance requires that the client bend to the will of a predetermined medical regimen while adherence may imply that the individual is actively involved in his or her health care needs.

Some activities such as the funding of various community-based AIDS service organizations have been thoroughly supported in the treatment of HIV/AIDS over the years. Although the advent of ART has dramatically

*Factors influencing adherence to ART among PLWHIV*

reduced the morbidity and mortality associated with HIV infection. HCP continue to struggle with strategies and innovations that maximize the benefits of treatments for PLWHIV.

According to Shay (2008), factors relating to treatment adherence for persons living with chronic illness include depression, social support and self-efficacy. Given the magnitude and importance of poor adherence to medication regimens, the WHO has published an evidence-based guide for clinicians, health care managers, and policymakers to improve strategies of medication adherence (Sabaté, 2003).

Sabaté, (2003) in his work also indicated that strong social support especially practical support was also related to better treatment outcome. Giannetti, (2005) identified complex dosing regimens, sensory anomalies, age, lack of social support, lack of knowledge, psychiatric diagnosis, and financial problems as key factors that predispose patients to non-adherence to therapeutic regimens. These findings may not apply to the Ghanaian context because of differences in culture. Therefore, the need to explore the factors that affect adherence to ART medication among PLWHIV within the Ghanaian context is important. The study used the social cognitive theory to explore the factors that contribute to ART adherence among PLWHIV in the Accra Metropolis in Ghana.

## **1.2 Problem Statement**

Adherence to ART continues to be of paramount importance in the successful treatment of HIV/AIDS. Adherence to ART treatment regimen involves taking all pills in the correctly prescribed doses at the right time and

*Factors influencing adherence to ART among PLWHIV*

in the right way (Carter, 2005). However, it is increasingly becoming difficult to get full adherence by PLWHIV. Hence, the intended suppression of the HIV infected patients seems to be back firing even though PLWHIV appear to be on ART (Lewis, Colbert, Erlen, & Meyers, 2006). The prevalence of non-adherence to ART has been examined in numerous studies over the years, For example, Machtinger and Bangsberg, (2006), reported that approximately 70% of patients taking ART are non-adherent and adherence to ART is further complicated because it appears to vary depending on the stage of the disease (Powderly, 2004). It is now known that HIV actively replicates from the time of initial infection, and that viral mutation occur randomly and frequently over time, this means that individuals who fail to adhere with treatment regimen may develop resistant viral strains that often cannot be treated by the current spectrum of ART drug (Ruanjahn, Roberts, & Monterosso, 2010). This implies that another level of treatment is required with its accompanying high cost. A 95% adherence level to ART is essential to maintain reduced or undetectable viral loads and prevent the formation of drug resistant viral mutation (Spaulding et al., 2002; Wohl et al.: 2003). This implies that the PLWHIV on ART takes all the drugs as prescribed and at the right time but it is known that the rate of adherence declines over time (Howard, Arnsten, Lo, Vlahov, & Rich, 2002). Therefore it can be concluded that, regardless of the background or the situations of life of the PLWHIV, they may encounter some level of difficulty adhering to ART regime. The consequences of missed doses or non-adherence to ART therapy appears to be more severe with evidence of an increasing viral load after missing only 2 days and the suggestion that mutant viral strains may develop quickly. Currently in Ghana over 138 public

*Factors influencing adherence to ART among PLWHIV*

and private facilities are providing ART in all regions, the number of persons accessing treatment has increased over the years. A survey done in four sites in Greater Accra indicated that there was an increase in access to ART among PLWHIV from 2,017 in December 2004 to 33,745 by the end of 2009 (NACP, 2010).

Anecdotal evidence from fevers unit in Korle-bu Teaching Hospital indicates that clients are not adhering to their ART although it is highly subsidized by the Government of Ghana. Non adherence to the ART has been found to diminish immunological benefits of ART and increased AIDS related morbidity, mortality and hospitalization. Poor adherence to ART may also result in poorer health, more symptoms, and lower physical quality of life (Mannheimer et al., 2005). There is therefore, the need to explore the factors that influence adherence to ART because such studies are vital to ensure that decisions about adherence to ART regime are informed by empirical evidence.

### **1.3 Purpose of the Study**

To explore the factors influencing adherence to ART among PLWHIV in the Accra Metropolis.

### **1.4 Specific Objectives**

The specific objectives of this study are to;

1. Describe the behavioural adherence to ART among PLWHIV.
2. Identify the cognitive and other personal factors that influence adherence to ART.
3. Describe the treatment self-efficacy of PLWHIV on ART.

*Factors influencing adherence to ART among PLWHIV*

4. Identify the environmental factors that influence adherence to ART.

### **1.5 Research Questions**

1. What is the behaviour of PLWHIV towards their ART regimen?
2. What are the cognitive and other personal factors that can influence adherence to ART among PLWHIV?
3. What is the treatment self-efficacy of PLWHIV on ART?
4. What are the environmental factors that influence adherence to ART among PLWHIV?

### **1.6 Significance of Study**

Since evidence from literature on adherence to ART suggests that adherence support programme appears to be acceptable, feasible, and effective in reducing viral load and improving immune function, particularly among PLWHIV who have experienced treatment failure as a result of poor adherence to their ART. The findings of this research therefore may provide in-depth information on the factors influencing adherence to ART among PLWHIV so as to provide tailor made services to address the needs of PLWHIV on ART. The findings of this study will also provide knowledge on adherence programmes that need strengthening to improve adherence among PLWHIV.

The study will also add to nursing knowledge on adherence since most of the other studies were done in different settings. Furthermore, the findings may inform the Ministry of Health and Ghana Health Service on how best to

*Factors influencing adherence to ART among PLWHIV*

integrate adherence programmes to ensure that, PLWHIV adhere with their ART regime.

**1.7 Operational definition**

1. Adherence: number of doses taken, divided by the number of doses prescribed
2. Intervention: health promotion care provided to improve adherence to ART among PLWHIV.
3. Anti-Retroviral Therapy- treatments intended to suppress the HIV virus and stop the progression of HIV disease.
4. Health Care Provider- Persons trained to provide healthcare to HIV patients.
5. Persons Living With HIV (PLWHIV) - Persons at early and middle stages of HIV infection.

**1.8 Abbreviation**

1. PLWHIV: Persons Living With HIV
2. HCP: Health Care Provider
3. ART: Anti-Retroviral Therapy
4. PHA : Peer Health Advisers

## CHAPTER TWO

### 2.1 THEORETICAL FRAMEWORK AND LITERATURE REVIEW

This chapter describes the philosophical underpinnings/ theoretical framework of the study, description of the social cognitive theory (SCT) and relevant literature reviewed.

There are various theories that have attempted to explain the variables associated with adherence. Some focus on the relationship between the HCP and the patient, while others are more patient oriented. All suggest strategies to enhance patient adherence with medical treatment regimens. A useful model to understand the factors that influence adherence to ART among PLWHIV is the SCT. The SCT was used as an organizing framework for this thesis. The theory used enabled the researcher gained meaningful insight to the phenomenon under study and the importance of its occurrence. The SCT was applied to make the research findings meaningful by knitting together all observations and facts. Theories help in predicting the occurrence of a phenomenon (Polit and Beck, 2008).

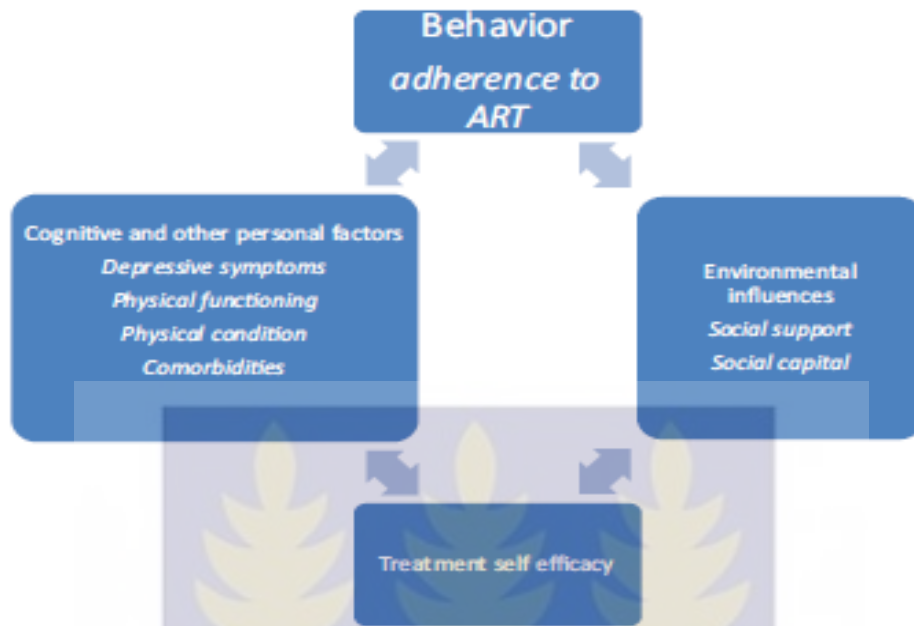
### 2.2 The Social Cognitive Theory

SCT has featured prominently in conceiving adherence among individuals. Albert Bandura, a major proponent of the social cognitive model posited that there is a reciprocal relationship between cognition, behaviour and personal factors, and the environment (Bandura, 1989a). According to this theory, these variables operate interactively to determine behavioural outcomes (Conde, Alonso, Garau, Roca, & Oliver, 2006).

*Factors influencing adherence to ART among PLWHIV*

In the SCT human behaviour is extensively motivated and regulated by the on-going exercise of self-influence. The major self-regulative mechanism operates through three principal sub-functions. These include self-monitoring of one's behaviour, its determinants, and its effects; judgment of one's behaviour in relation to personal standards and environmental circumstances; and affective self-reaction. Self-regulation also encompasses the self-efficacy mechanism, which plays a central role in the exercise of personal agency by its strong impact on thought, affect, motivation, and action. The same self-regulative system is involved in moral conduct, although compared to the achievement domain. In the moral domain, the evaluative standards are more stable, the judgmental factors more varied and complex, and the affective self-reactions more intense. In the interactionist perspective of SCT, social factors affect the operation of the self-regulative system (Bandura, 1991).

According to Bandura (1989b), self-beliefs of efficacy can enhance or impair performance through their effects on cognitive, affective, or motivational intervening processes. This commentary addresses a number of issues concerning the extension of self-efficacy theory to memory functioning. These include the following: the multidimensionality and measurement of perceived memory capabilities; the veridicality of memory self-appraisal; the efficacious exercise of personal control over memory functioning; the psychosocial processes by which people preserve a favourable sense of memory self-efficacy over the life span; and strategies for generalizing the impact of training in memory skills. Details of the constructs of the SCT are shown in Figure 2.1 below:

**Figure 2.1: The Social Cognitive Theory**

Source: (Benight, Ironson, & Durham, 1999).

Figure 2.1 presents a graphical representation of the social cognitive model with three constructs that specify some selected variables and treatments self-efficacy as an antecedent mediator of adherence to ART.

### **2.2.1 Behavioural Adherence to ART**

Adherence research in the behavioural and social sciences are relevant to the nation's health and well-being. Poor adherence to prescription medications and treatments has been labelled a 'worldwide problem of striking magnitude' (WHO, 2003).

Attitudes toward behavioural adherence to ART is a comprehensive approach to health promotion and require changing the practices of social systems that have widespread detrimental effects on health rather than solely changing the habits of individuals. Further progress in this field requires

*Factors influencing adherence to ART among PLWHIV*

building new structures for health promotion, new systems for risk reduction and greater emphasis on health policy initiatives. People's beliefs in their collective efficacy to accomplish social change, therefore, play a key role in the policy and public health approach to health promotion and disease prevention (Bandura, 1998). According to Vitolins, Rand, Rapp, Ribisl, and Sevick, (2000), measuring adherence to medical and behavioural interventions is important to clinicians and researchers since inadequate adherence can reduce the effectiveness of an intervention.

### **2.2.2 Cognitive and other Personal Factors**

This involves cognitive factors and medication adherence to comply with. Medication adherence is increasingly being recognized as a significant issue in treating patients (Ownby, 2006).

Adherence to prescribed medications is a complex phenomenon that depends on an interaction of medical and personal factors. Medical factors that affect adherence include cognitive abilities, as well as overall health status (eg. number of chronic conditions). Medication factors related to adherence include the characteristics of the medication (eg dosing frequency or presence of side effects). Personal factors that affect adherence include: personal beliefs about the condition for which the medication is prescribed (eg. how serious the condition is and how likely the medication is to have a positive effect) (Finucane et al., 2002). However, co-morbidities a concept under cognitive and other personal factors influencing adherence, was not included in this study because it was beyond the scope of the investigation.

*Factors influencing adherence to ART among PLWHIV*

**2.2.3 Treatment and self-efficacy factors**

Self-efficacy is the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations ( Bandura, 1995). According to Conde et al., (2006) self-efficacy appraisals reflect the level of difficulty that individuals believe they can surmount to perform a specific behaviour. In this context, the desired specific behaviour would refer to taking prescribed medications as directed by a healthcare provider. This SCT therefore brings more insight to the possible variables at play in attempting to understand adherence attitudes among PLWHIV.

Findings from a study by Proeschold-Bell et al., (2013) on three types of self-efficacy associated with medication adherence in patients suggested that there are three specific kinds of self-efficacy factors that may benefit medication adherence. These are provider communication, getting support, and mood management.

**2.2.4 Environmental factors**

Environment comprises of the situation, roles, models and relationships as a factor that influences the behaviour of the individual. Environmental setting influences patients' ability to adhere to a medication regimen. According to Bandura, (2001) human health is heavily influenced by lifestyle habits and environmental conditions. Social capital is one of the concepts of environmental influences on adherence which was not investigated in the study.

*Factors influencing adherence to ART among PLWHIV*

## **2.3 Literature Review**

This section of the chapter reviewed literature relevant to factors influencing adherence to ART. The literature was reviewed according to the objectives of the study. Various sources were consulted which included books, published journals and papers. The internet was the main channel used for reviewing this literature. The following search engines were used: PUBMED, Google scholar, Cochrane library, CINAHL and Science Direct. The key words used were behavioural adherence to ART, adherence and compliance, cognitive and personal factors, treatment efficacy, self-efficacy, depressive moods, physical functions, social support and environmental influences. The literature reviewed was organized under the following headings:

- Behavioural adherence to ART
- Cognitive and other personal factors
- Treatment and self-efficacy factors
- Environmental influences on ART

### **2.3.1 Behavioural Adherence to ART**

Adherence to ART can be influenced by a number of factors, including the patient's social situation and clinical condition, the prescribed regimen, and the patient-provider relationship (Boggs, 2007). It is critical that each PLWHIV receives and understands information about HIV disease including the goals of therapy, achieving and maintaining viral suppression, decreasing HIV-associated morbidity and mortality and preventing sexual transmission of HIV, the prescribed regimen (including dosing schedule and potential side effects), the importance of strict adherence to ART, and the potential for the

*Factors influencing adherence to ART among PLWHIV*

development of drug resistance as a consequence of suboptimal adherence (Lieber et al., 2005). However, information alone is not sufficient to assure high levels of adherence. Patients must be positively motivated to initiate and maintain therapy. Fear of health outcome may make PLWHIV adhere to their ART. They however, may resort to doing anything possible to avoid suspicion. Beer, Fagan, Valverde, and Bertolli, (2009) also reported that patients adhered to their ART because they needed to avoid suspicion.

Further qualitative study carried out on secrecy and fear of disclosure of status among Sub-Saharan African migrant women living with HIV/AIDS concluded that fears and emotions are the outcomes of patients' adherence to ART (Arrey, Bilsen, Lacor, & Deschepper, 2015). Preliminary evidence suggests that most individuals on ART therapy are not 100% compliant (Finzi et al., 1997). In fact, data from pilot studies suggest that in the preceding 2 to 3 days, as many as 30% of patients report missing at least one dose (Hill & Kavookjian, 2012).

Studies report that hypertensive patients may be adherent to their medications at the 50% level and that adherence to medications for other diseases as well as HIV generally ranges from 20% to 80% (Small, Wood, Betteridge, Montaner, and Kerr, 2009). This work shows that providing simpler dosing regimens with fewer side effects will not necessarily result in increased adherence. Rates of adherence to HIV medications by PLWHIV also vary widely. Nolan et al., (2011) also reported low rates of adherence to ART among a community cohort of drug users and suggested the reinforcement of the importance of adherence as the key determinants of successful virological response to ART.

*Factors influencing adherence to ART among PLWHIV*

Kenya, Chida, Symes, and Shor-Posner, (2011) also reported that 67% of their patients were compliant at the 80% level. They also reported that there was a significant correlation ( $p < 0.007$ ) between self-reported missed ART doses and increasing viral load. These patients (N=16) reported the following reasons for missing a dose: 43% forgetfulness, 36% fallen asleep, 32% being away from home, 27% changed routine, 22% being too busy, 11% were too sick, and 9% were too depressed. These reasons were also enumerated by other studies (Johnson, Heckman, Hansen, Kochman, & Sikkema, 2009; Hill and Kavookjian, 2012). The consequences of missed doses or non-adherence to ART therapy appears to be more severe or unforgiving, with evidence of an increasing viral load after missing only 2 days and the suggestion that mutant viral strains may develop quickly (Berger, 1996). As a result, PLWHIV are struggling with challenges of being 100% adherent to ART.

Nel and Kagee (2011), reported that as many as 50% of the patients in a retrospective chart audit who were highly pre-treated were experiencing increasing viral loads. Treatment breakthrough is typically defined as a rising viral load, usually accompanied by a falling CD4 count. Initially, these changes in values may or may not be related to clinical deterioration, although that is the assumed future end point without any intervention. Treatment breakthrough is thought to be due to several factors including, drug potency, absorption, and adherence. Poor absorption may be due to the poor bioavailability or metabolism of medication(s), excretion of the medication, or ineffectiveness due to the development of viral resistant strain. Poor adherence may be due to forgetfulness, lack of information, symptom side effects, treatment fatigue and lack of social support (Nel and Kagee, 2011).

*Factors influencing adherence to ART among PLWHIV*

In summary the literature reports behavioural adherence to ART among PLWHIV as an important factor that influences adherence.

**2.3.2 Cognitive and other personal factors**

Cognitive and other personal factors of adherence may include perceived stigma, uncertainty of illness and poor access to care can affect patient's ability to adhere to a complicated medication and treatment regimens (Johnson, Heckman, Hansen, Kochman, and Sikkema, 2009) Horberg, Silverberg, Hurley, and Quesenberry (2008) studied relational messages between nurses and terminally ill patients. Some of whom were diagnosed with AIDS, and found that control was a major theme, as evidenced by different situations in which nurses or patients exerted control in their care. The least behaviour observed among patients is the one willingness to relinquish control of care to the nurse. Schönnesson et al. (2008) also examined perceptions of control over health in HIV positive women. The authors found that the women had high scores for both internal and external locus of control. They concluded that this finding reflected the paradoxical nature of living with HIV disease or possibly the conflicting forces in their everyday lives. It was also noted that the relationship between the women and a patriarchal health care system made many demands upon them, often conflicting with other responsibilities.

Subsequently, a study by Victoria, Julia, Vicente, & Juan, (1999) assessed the degree of compliance with antiretroviral therapy in HIV-infected patients, and identified which sociodemographical and psychological factors influencing it in order to develop strategies to improve adherence. It however

*Factors influencing adherence to ART among PLWHIV*

concluded that sociodemographic and psychological factors influenced the degree of adherence to antiretroviral therapy.

In a study by DiMatteo, Lepper and Croghan, (2000), a positive relationship between depression and HIV medication adherence was established. As a result, the desire for PLWHIV to end their lives when they noticed they have a chronic disease such as HIV has been reported by Dunear-Jacob, Erlen, Schlenk, Ryan, and Sereika (2000). The participants in the study, however also attributed physical support to family-based support, treatment availability, access and quality and HIV stigma and discrimination as some of the reasons they wanted to end their lives. Meanwhile Nyamathi, Stein, and Swanson, (2000) also reported that patients who perceived the risks of progressing to AIDS devise coping styles and strategies. Consequently, HIV-infected adults with significant neurocognitive compromise are at risk for poor medication adherence, particularly if they have been prescribed a complex dosing regimen. As such, a simpler dosing schedule for more cognitively impaired patients might improve adherence.( Hinkin et al., 2002b),

Internal conflicts and social stress also affect the ability of PLWHIV to adhere to a prescribed regimen. The internal conflicts a patient may be dealing with, include concern over HIV transmission, protection from infection, guilt over previous lifestyle, and concerns about personal relationships (Nel and Kagee, 2011). Social stressors may include fear of disclosure and exposure, stigma, employment and insurance, social support limitations, and family concerns.

*Factors influencing adherence to ART among PLWHIV*

With the introduction of ART, PLWHIV have seen improvement in physical condition and functions. For instance a study by Luszczynska, Sarkar, & Knoll, (2007) investigated whether received social support, self-efficacy, and finding benefits in disease are related to physical functioning and ART among men and women infected with HIV. They however concluded that besides personal and social resources, benefit finding was related to better adherence to antiretroviral medication. Identifying patients receiving low social support, with weak general self-efficacy and finding no benefits in being diagnosed with HIV may help to elicit those people who are at risk for poorer adherence and physical functioning. Moyle, Daar, Gertner, and Kotler, (2004) in their study also discovered an overwhelming increase in weight and body functions in ART treated HIV infected subjects.

In summary, the literature suggests that the cognitive and other personal factors contribute significantly to adherence or non-adherence to ART regimen.

### **2.3.3 Treatment and Self-efficacy**

Treatment and self-efficacy involves the willingness of the individual to continue to adhere to the medication regimen while self-efficacy is the extent or strength of one's own ability to complete a task or reach goals. Treatment and self-efficacy deals with how long an individual will stick to a prescribed regimen or writes it off as an impossible task (Reynolds et al., 2004). Prescribed medications and treatments, with the requisite instructions on their proper use, can either positively or negatively affect the ability of the PLWHIV to be adherent to the regimen. The more complex the regimen, the

*Factors influencing adherence to ART among PLWHIV*

less likely the patient is to follow the treatment plan, regardless of age and educational level (Wasti, Simkhada, Randall, Freeman, and Van Teijlingen, 2012). Nel and Kagee (2011) found out that the major reasons PLWHIV cited for non-adherence were forgetting the dose or the inconvenience of dosing schedule, that is, waking up in the middle of the night to take the medicine and having to self-inject a drug.

Loirello et al., (2009) revealed that PLWHIV experience improved health outcome as evident by negligible viral load with the use of ART, which results non-adherence to the ART. A study by Kesteren, Hospers, Kok, & Empelen, (2005) also affirmed that HIV-positive men who have sex with men always adhered but they ended their ART when they observed that treatment is effective and there is improvement in their health.

Numerous other factors that can also affect adherence with HIV-related drug regimen have also been identified. Horberg et al., (2008) conducted a study to examine Zidovudine adherence in persons with HIV infection and found four factors related to adherence: (a) problems taking and scepticism about Zidovudine, (b) their degree of concern about HIV disease, (c) their perceived severity of HIV illness, and (d) barriers to taking the medication. They also identified that scepticism about the efficacy of the medication prescribed and ethnicity were significant independent predictors of variance in adherence. PLWHIV are more likely to be noncompliant when they believe that the medications were of little value, have less faith in the traditional medical system, are less educated, and are more likely to use alternative therapies. (Nel and Kagee, 2011)

*Factors influencing adherence to ART among PLWHIV*

Reback, Larkins, and Shoptaw, (2003) reported that many participants in their study were very conscious about the time they were supposed to take their ART and this made it possible for them to adhere to their ART regimen. Numerous relationships between good dieting and ART have also been established (Wanke et al., 2000). This however was consistent with the finding that emerged when patients were told to eat very well and take their ART on time. A study by Cunningham et al., 2005 revealed the awareness of HCP of infected HIV patients that poor dieting lead to weight loss and does not enhance adherence to ART. Good nutrition is a major potential obstacle to ART adherence. Access to adequate nutrition is a major determinant to long term adherence to ART (Au et al., 2006). Most PLWHIV learn from the advice, experiences and observations of other people who are living with the disease and this makes them stronger as they adhered to their ART (Oursler et al., 2011). Other persons can also influence adherence to ART among PLWHIV such as pastors and other family members. Family members and friends can act as monitors who can enhance adherence to ART (Gale et al., 2013). Meanwhile a relationship has been established between spirituality and adherence to ART (McDonnell-Holstad, Pace, De, & Ura, 2006). According to Dalmida, (2006) there are pastors who inspire PLWHIV to discontinue taking their ART and rather resort to prayer and fasting.

Side effects of the ART may also influence adherence to ART. For instance Ammassari et al., (2001) reported that in addition to patient characteristics, medication-related variables and reasons for non-adherence. Most patients complained about symptoms of HIV and ART side effects as significantly associated with their adherence to ART.

*Factors influencing adherence to ART among PLWHIV*

In summary, the reviewed literature suggests that the factors that lead to the ability of PLWHIV to adhere to a prescribed medication regimen and therapies are diverse. Therefore treatment and self-efficacy factors may or may not contribute significantly to adherence to ART among PLWHIV.

**2.3.4 Environmental Influences**

Cultural factors are relevant environmental factors that play a very important role in the decision-making process for medications and treatments of clients (Vranceanu et al., 2008). Often because of culturally insensitive delivery of health care, no effort is made by the health care professional to effectively interact with the client. The motivation of some cultural groups to please authority, or to distrust authority, may establish barriers to developing the relationships necessary to ensure medication and treatment adherence (Sherr et al., 2008). Environmental setting influenced the individual's ability to successfully complete a behaviour that is by making the environmental condition conducive for improved self-efficacy. Providing appropriate support and materials may improve adherence (Giles-Corti & Donovan, 2002). The importance of understanding and respecting the cultural background of the client and family has been frequently cited in the literature (Conde et al., 2006). The research cited by these authors give clear examples of how making an effort to understand a client's cultural beliefs can go a long way to foster a therapeutic relationship, which could then result in better disease management.

A study by Bikaako-Kajura et al., (2006) established numerous reasons for patients non-disclosure of their HIV positive status. To ensure adherence to life-extending ART, there is the need for providers to support caregivers of

*Factors influencing adherence to ART among PLWHIV*

children to disclose, provide on-going support and maintain open communication with HIV-infected patients.

Locus of control is another issue that may affect care management. Studies have shown that ethnic people of colour, persons of lower socioeconomic groups and older individuals are often found to have an external locus of control (Conde et al., 2006).

Non-adherence as seen among PLWHIV can often stem from negative experiences in the past. The nurse-patient relationship can be a very powerful tool that can greatly affect adherence. The nature of this relationship can go far in enhancing a client's willingness to make an effort to make changes in his or her behaviour. A study by Wu et al., (2002) laid more emphasis on the positive relationship between patients and nurses during hospital reviews. However, this relationship could also be the reason a client is completely lost to follow-up when the client is offended by the nurse's behaviour or attitude.

The key element of the nurse-client relationship is the establishment of trust. Riggs et al. (2007) indicated the importance of building trust in the nurse-client relationship. Strategies to build a trusting relationship include (a) establishing credibility; (b) using an empathetic non-judgmental approach; (c) respecting the client's privacy; (d) expecting testing supervised programme from the client; and (e) learning to trust the client (Riggs et al., 2007). When PLWHIV were asked what were the most important nurse caring behaviours they wanted to see, the highest ranking themes were acceptance, respect, treatment of the person as an individual, and non-judgmental attitudes of the nurse toward the patient (Riggs et al., 2007). According to Genberg et al.

*Factors influencing adherence to ART among PLWHIV*

(2009), negative attitudes of some of the health personnel tend to cause many problems for patients.

Lazo et al. (2007) categorized behaviours and attitudes of HCP's approaches to client care as either an 'I can' or 'I can't' position. In the 'I can' position, the HCP is more likely to be able to deal with clients creatively and effectively in order to achieve the desired outcomes. In the 'I can't' position, the ability to work successfully with a client is defeated from the start. It is important to note that no HCP is locked in a position and therefore has the ability to change. Equally important is the fact that many HCPs may, from time to time, have some attributes from both positions. However, recognizing those positions is the first step toward change.

The primary purpose of patient education is to assist the client with decision making regarding health promotion and treatment decisions (Riggs et al., 2007). It is important to note that after information is provided to a client, some may decide to follow all the advice, some may select portions of the advice, and yet others will reject all the information. The ultimate decision belongs to the client and in no way implies failure on the part of the HCP. The education process should include goals that are flexible, short term, and realistic for the client's life situation (Chen, Kuo, Chou, and Chen, 2007). All education should take into account that failures and relapse may occur and the client should be prepared by the HCP to handle these situations. Perhaps the most used method of attempting to enhance adherence, employed by HCPs, is patient education employing face-to-face teaching, counselling and the use of printed materials. Printed materials such as pamphlets and self-care guides are

*Factors influencing adherence to ART among PLWHIV*

a means of extending the patient teaching process outside the hospital, clinic, and office setting.

Combining patient education with another incentive has also been successful in improving adherence to ART. Patient reminders have also been used to improve adherence with medical visits and medications. Boggs (2007) describes the use of timers and recorders on medication bottles that will remind patients of the scheduled dose by beeping and then register when the bottle is opened. For patients with HIV disease on multiple medications with multiple doses per day, however, the cacophony of beeps could be quite distressing.

Santos et al. (2006) performed a small scale study to replicate the findings of other studies on usual care and the use of postcard reminders and telephone calls to clients to improve adherence with clinic visits. Their findings showed no significant difference between usual care and telephone call intervention or postcard reminders. However, it was felt that the telephonic intervention was preferred because it allowed those clients who wished to reschedule an appointment the opportunity to do so at that time, and it added a personal touch.

Another tool often used in the nurse-patient process to increase patient adherence is the patient contract. It is negotiated between the nurse and the client and, ideally, contains the goals to which they have mutually agreed. Nokes et al. (2012) described their success with the use of a patient contract in the treatment of chronic non-malignant pain and a resulting retention and adherence rate of 79% over a 3-year period. This supervised programme is an

*Factors influencing adherence to ART among PLWHIV*

example of the success that can be achieved with a detailed protocol and the staff commitment to support it. Outreach has been a very successful tool in improving the participation of clients in their health care. The use of peer health advisers (PHA) to improve adherence with homeless populations to improve outcomes of TB treatment has been reported by Santos et al., (2006). Santos et al., (2006) compared clients receiving usual care with a client being assigned to a PHA or given money incentive in the form of payment to visit the clinic. When compared to usual care, both of the intervention groups significantly improved adherence. In this same supervised programme, Colbert, Sereika, and Erlen, (2013) concluded that community-based projects work best if they involve the target population, in this case, using PHAs who are homeless themselves.

Social support is also an important component in ensuring adherence to ART among PLWHIV. In a study by Gonzalez et al.,(2004), findings from the study revealed that greater social support relates to better adherence whereas lack of support relates to non-adherence. The lack of social support for PLWHIV may stem from the fact that PLWHIV do not want to disclose their positive status to family and friends because of fear of stigmatization. In a study by Wyatt, Tugenberg, and Ware, (2006), it was reported that lack of disclosure and disguising of medication by participants are some of the efforts made by PLWHIV to progress in their career and also to be able to associate themselves with social groups and organizations.

Other studies have established relationships between serostatus disclosure and adherence to medication regime. In a study by Stirratt et al.

*Factors influencing adherence to ART among PLWHIV*

(2006) on the role of serostatus disclosure in ART medication adherence. Overall, 19% of the sample (N=215) reported missing medication doses in the last two months due to concerns regarding serostatus disclosure. Participants who reported greater serostatus disclosure to others demonstrated higher rates of adherence, and this relationship remained after controlling for other explanatory variables. The findings of that study revealed that interventions to improve ART adherence should address the role of serostatus disclosure by providing patients with skills to maintain adherence in contexts of non-disclosure and to make informed choices regarding selective disclosure.

In summary, issues affecting adherence to ART are numerous and multifaceted for PLWHIV. Many of these factors coexist and their levels of importance vary from person to person. Several factors have been implicated as having influence on adherence to ART among PLWHIV which are the behavioural adherence to ART, treatment and self-efficacy, cognitive and other personal factors and environmental factors on ART adherence. Behavioural adherence to ART is an important factor which influences adherence to ART regime.

Cognitive and other personal factors may affect adherence to ART, with issues of depression and physical functions or physical condition having an important role to play in influencing adherence to ART among PLWHIV. Treatment and self-efficacy as a factor can either improve adherence to ART or may result in non-adherence among PLWHIV.

Environmental factors influencing adherence include the provision of support and the use of appropriate strategies and tools to improve adherence

*Factors influencing adherence to ART among PLWHIV*

among PLWHIV. Relationships with Health care providers (HCP) as well as attitude of HCP may either result in adherence or non-adherence to ART regimen.



## CHAPTER THREE

### 3.1 RESEARCH METHODOLOGY

This chapter presents the methodology used for the study. The chapter commences with a description of the research design, the setting where the research was conducted, sampling technique, data collection and analysis and concludes with ethical considerations.

#### 3.2 Research Design

A qualitative research design using exploratory descriptive approach was used for the study. This method used enabled the researcher to describe the process relative to its context rather than outcomes (Morse, Barrett, Mayan, Olson, & Spiers, 2008). The purpose of an explorative design is to gain a deeper understanding of the phenomenon under study.

For the researcher to understand the behavioural adherence to ART, the cognitive and other personal factors influencing adherence to ART, the treatment and self-efficacy as well as the environmental influences on adherence to ART, requires that a qualitative approach be used to better understand the lived experiences of participants.

#### 3.3 Research Setting

The Greater Accra Region is the urban hub of Ghana that is located in the south most part of the country. It is bordered by the gulf of Guinea in the south, the Eastern region to the north, to the Central region to the west and finally the Volta region to the east. It is the smallest of the regions in terms of land mark occupying an area of 3,245 square kilometers or 1.4 per cent of the

*Factors influencing adherence to ART among PLWHIV*

total land area of Ghana. Accra is the capital city of Ghana which is second most populated Region after the Ashanti Region. Out of a total population of 24,658,823, the population of Accra is 4,010,054 forming 16.5% of the general population. Ghana Statistic service (2010) indicated that females form 51.2% of the general population whereas the rest (48.8%) are males in Greater Accra.

The study was conducted in Ridge Regional Hospital. It is located along the castle road. It occupies a total land area of about 15.65 acres and falls within the Osu Clottey sub metro of the Greater Accra Region.(see appendix F) The hospital includes Adabraka Polyclinic (which became part of Ridge Hospital in 2012). It is a Ghana Health Service level ‘A’ facility and serves as a referral point for all district hospitals in the Greater Accra region. It has 240 beds and its immediate catchments area includes Nima, Maamobi, Kanda, Accra New Town, Kotobabi, Osu, La, Adabraka, Achimota and Central Accra. The hospital has 479 nurses with qualifications in different specialties. They provide a whole range of general and specialist services to people within and beyond its catchment area. The hospital provides both out and in-patient services however majority of the out-patient cases are seen at the Adabraka Polyclinic which is currently part of Ridge Regional Hospital. It has a Computed Tomography (CT) Scan machine and other basic equipment necessary for providing care for all patients. An average of about 600 cases is seen every day at the Out Patient Department (OPD) in the hospital. Out of these, some clients are admitted to the ward. The hospital also has a Medical ward, Surgical ward, Paediatric ward, Female ward, Postnatal ward, Maternity ward, Neonatal Intensive Care Unit, Physiotherapy unit, Public Health unit,

*Factors influencing adherence to ART among PLWHIV*

Blood Bank, Laboratory unit and ART unit. There are about twenty (20) specialists providing various specialist services in the hospital.

### **3.4 Target Population**

The target population for the study was PLWHIV who are receiving ART in Ghana.

#### **3.4.1 Inclusion criteria**

Any PLWHIV including both men and women receiving ART at the Ridge Regional Hospital for a period of 12 months. PLWHIV who were able to speak English, Twi or Ga and were voluntarily willing to be part of the study. PLWHIV who were 18 years or older, physically and mentally fit to participate were included in the study.

#### **3.4.2 Exclusion criteria**

Clients who were not receiving ART, clients receiving treatment for comorbidities, seriously ill patients, and client with speech or hearing impairment were excluded.

### **3.5 Sample size and Sampling Technique**

Purposive sampling was done based on the ability of the participants to provide the needed information. The study used purposive sampling because it sought to explore and describe the lived experiences of PLWHIV. Data was collected until the researcher reached the saturation point which was estimated to be on the fourteenth participant. Saturation is when the researcher senses closure because there is no new information emerging (Polit and Hungler, 1999). The fourteen participants were engaged in an in- depth interview.

### **3.6 Tool for Data Collection**

The tool for data collection was a semi structured interview guide. This method of data collection was used because it is not rigid in nature and it provides a sequence for data collections, it also allows probing into specific areas of interest to the researcher during an interview (Mason, 2004). The researcher developed the interview guide, guided by the constructs of the theory used and the objectives of the study. The interview guide had two sections. Section A featured the demographic data of participants while the section B consists of open ended questions with their attached probes. The interview guide contained only open ended questions typed in English since that was the only language the researcher wrote. However it was translated in the Ga and Twi languages by the researcher for participants who sought clarification in those languages.

### **3.7 Pretesting of the interview guide**

Pretesting or piloting of the interview guide is the process of interviewing a few participants who shared similar characteristics as participants in the study setting to ensure appropriateness of the interview guide (Hennink, Hutter, and Bailey, 2011). The instrument was piloted or pretested among two participants who had similar characteristics with the study participants in Korle bu Teaching Hospital. Questions that were not clear were restructured. Thus, analysis of the responses obtained improved upon the interview guide where necessary. Data gathered from the piloting was not included in the main study.

*Factors influencing adherence to ART among PLWHIV*

### **3.8 Data collection procedure**

Ethical clearance was sought from institutional Review Board of the Noguchi Memorial institute for Medical research, (IRB-NMIMR) (see Appendix A). An introductory letter was taken from the School of Nursing, University of Ghana and was addressed to the Deputy Director of Nursing Service and the Nursing Administration seeking for permission to recruit clients on ART in the facility for a study (see Appendix B). After permission was granted, the ART unit was visited to explain the process, purpose and objectives of the study to the in charge of the ART unit. A discussion was held with the in charge on the best way to recruit participants. A day was fixed at the convenience of the participants to brief them about the study. During the briefing session volunteers were informed of the objectives and purpose of the study, how data would be collected from them; that was face-to-face interview between the researcher and the participant which would be recorded on an audio tape. Potential participants were assured of confidentiality and how data would be managed to promote privacy and avoid any trace. They were also informed of their right to withdraw at any point in time they wish during the study and the incentive package they stand to benefit. They were also given the opportunity to ask questions.

Participants willing to be part of the study received an information sheet (see Appendix C) and were given consent forms (see Appendix D) which were further explained to them. Those who gave their consent by signing the consent form kept a copy of the form and the researcher also kept a copy. An appropriate and convenient date, time and place of choice by the participant were fixed to commence the interview.

*Factors influencing adherence to ART among PLWHIV*

During the actual data collection, a participant was purposively selected and interviewed in a private room. Permission was sought from the participant for the interview to be audiotaped. The interview took a conversational mode using open ended question for the participants to freely express their views and opinions. An in-depth interview guide was used (see appendix E) because, it is the most appropriate to be used since the lived experiences of the participants was to be explored. This enabled the researcher to explore and probe further to enhance clarity.

The time allotted for participants to be interviewed was between 30 to 45 minutes. During the interview, leading questions were avoided. The help of a psychologist was not needed because participants answered questions with less emotion.

### **3.9 Data management & analysis**

The main purpose of data management in a qualitative study is to store data for maximal efficiency in retrieval and analysis (Padgett, 1998). The researcher kept a field note and diary in which she wrote the date, time and place where the interview was conducted. Each participant was given a number (P1 to P14) and pseudonyms such as Nana, Adez, Ayerki, Eben and Jay. A written file was separately kept for each individual for easy retrieval. All audio tapes, transcribed data, field notes and diaries as well as all documented information were kept in a safe which was accessible to only the researcher and her supervisors.

After each interview the recordings on the digital recorder was transcribed verbatim before the next interview. The simultaneous collection of

*Factors influencing adherence to ART among PLWHIV*

data and transcription made it possible for the researcher to improve on the next interview and also take note of emerging codes. The researcher looked for accuracy of the manual transcripts by reading the transcripts while listening to the audio-taped interviews.

Thematic content analysis was used. Thematic analysis of qualitative data is a type of analysis which is directed by preconceived themes based on the theory, concepts or models that guides the study (Graneheim & Lundman, 2004). During the analysis of data, the researcher compared statements made by each interviewee and identified the similarities of the statements. Commonalities in each of the transcribed data were put together to form categories. This was achieved by looking for relationships between categories. The codes were then copied into a separately labeled word file on a computer with their subsequent quotes. Similar codes that were related were put together or categorized to form the themes based on the constructs of the SCT by Albert Bandura (Bandura, 2001). Different colours were used to mark similar codes as well as codes that can be linked to each other to form the themes. The themes identified were given names differentiating them from each other. The common themes were grouped from which sub-themes were identified. These themes were further analysed.

### **3.10 Ethical Consideration**

According to Creswell, (2009), the issue of ethics is about morality and deals with issues of right and wrong among a group or society. It is therefore important that researchers do not take for granted the ethical aspects of their studies (Babbie, 1995). The researcher made every effort to ensure that sound

*Factors influencing adherence to ART among PLWHIV*

ethical principles were used in this study. Creswell (2009), identified ethical issues for consideration in research as; respondents being fully informed about the aims, methods and benefits of the research, granting voluntary consent and maintaining the right of withdrawal. This was carried out by the researcher.

Ethical approval was sought out from Noguchi Memorial Institute for Medical Research, University of Ghana. The researcher identified and introduced herself to the authorities of the Ridge hospital. The tapes and the transcripts were available only to the researcher and her supervisors. The tapes and the hard copies of the transcripts were kept under lock and key. Soft copies of the tapes were kept in a computer that has a password known to only the researcher and her supervisors. Participants' privacy was assured through anonymity by replacing their real name with pseudonym to avoid any traces. Again participation in the study was voluntarily. Participants were only interviewed upon reading and understanding the content of the information sheet and the consent form. They were allowed to seek clarification before signing the consent form.

### **3.11 Methodological Rigour**

The following techniques were suggested by Lincoln and Guba, (1985b) as the best ways to ensure that all the attributes needed for rigour in qualitative research are met. These are credibility, dependability, transferability and confirmability.

Credibility is essential in qualitative study to ensure accuracy of the research work. Credibility focuses on the truth and value relating to the findings of the study and the representation of these truth and values (Topping,

*Factors influencing adherence to ART among PLWHIV*

2006). In this study, the researcher ensured credibility through prolonged interaction and member checking of ambiguous responses and persistent observation by the researcher. The researcher also recruited respondents who met the inclusion criteria in order to provide in-depth information. Member checks were used to verify responses on their adherence to ART. The researcher also supported emerging themes with direct quotes of the respondents. Debriefing sessions between the researcher and supervisor also ensured credibility.

Dependability refers to the stability of data over condition and time (Polit & Hungler, 1999). Dependability was ensured by the researcher through external audit of the study by the researcher's internal supervisors. A detailed research design was used for the research work as well as the procedure for data collection. The methodology was also described in detail. An audit trail was kept.

Transferability in a qualitative research can be met when the outcome or findings of study can fit into a different context other than the original setting of the study (Krefting, 1991) and it depends on the extent to which the two context under consideration are similar (Lincoln & Guba, 1985a). To achieve transferability the researcher gave a detailed description of the primary context in which the study was carried out. The sample for the study and the methodology used to arrive at findings was fully described. Participants from this study were allowed to express their views and opinion freely and were assured of anonymity and confidentiality.

*Factors influencing adherence to ART among PLWHIV*

Confirmability refers to the extent to which a research finding reflects the experiences explained by participants and is devoid of researcher biases (Lincoln & Guba, 1985a). To achieve this there must be a likelihood of another researcher arriving at the same result should he be given the data used by the previous researcher (Krefting, 1991). In order to achieve confirmability this research sought real in-depth information on the factors that influence adherence to ART from the participants. The researcher sought clarification of any unclear information from the participants. Data was collected until it was saturated; audio recorders as well as field diary kept for audit trail.



## CHAPTER FOUR

### 4.1 RESULTS / FINDINGS

This chapter presents the findings of the study. Based on the model used four main themes emerged which are behavioural adherence to ART, cognitive and other personal factors, treatment and self-efficacy and environmental influences with their emerging sub themes. Major concerns on adherence emerged as a theme through content analysis, which was not related to the theory. The demographic characteristics of the participants are presented first followed by the themes.

### 4.2 Demographic characteristics

Fourteen (14) participants aged between twenty five (25) and forty-seven (47) years were recruited for the study. Participants were all persons living with HIV residing in the Accra metropolis and at different suburbs in the Accra metropolitan area; the duration of illness of the participants ranges from between one to ten years. Out of the fourteen participants ten constituting majority of the participants were females. Ten of the participants spoke Twi while three spoke Ga and only one spoke English language. All participants had some form of formal education with one being a graduate. Almost all the participants were self-employed with only one working with a private firm. Eight of the participants were married; two were co-habituating, one divorced and three not married. Majority of the participants had children whose status is all negative with two looking for a child. The participants were Christians from different denominations with one Muslim. The data was transcribed verbatim.

*Factors influencing adherence to ART among PLWHIV***4.3 Organization of Themes**

Based on the constructs of the theory, four themes and fourteen sub-themes emerged. One other theme which was not related to the theory emerged from content analysis. Details of all the themes and the sub themes are presents in table 4.1

**Table 4.1: Themes and sub-themes from transcribed data**

<b>THEMES</b>	<b>SUB-THEMES</b>
Behavioural adherence	<ul style="list-style-type: none"> <li>• Fear of health outcome</li> <li>• Avoidance of suspicions</li> <li>• Avoidance of reprimandment</li> </ul>
Cognitive and other personal factors	<ul style="list-style-type: none"> <li>• Depressive mood</li> <li>• Physical function/ physical condition</li> </ul>
Treatment and self-efficacy of ART	<ul style="list-style-type: none"> <li>• Treatment efficacy</li> <li>• Self-efficacy</li> <li>• Time consciousness</li> <li>• Confidence in ART</li> </ul>
Environmental Influences on adherence to ART	<ul style="list-style-type: none"> <li>• Status Disclosure</li> <li>• Attitude of health personnel towards PLWHIV</li> <li>• Hiding and disguising of ART</li> <li>• Social support</li> </ul>
Major adherence concerns	<ul style="list-style-type: none"> <li>• Adherence and spirituality</li> <li>• Need for a monitor</li> </ul>

**4.4 Behavioural adherence**

Behavioural adherence is the response the individual receives after performing behaviour. Participants explained the factors which led to their adherence and non-adherence in three categories which are: fear of health outcome, avoidance of suspicion and avoidance of reprimandment.

*Factors influencing adherence to ART among PLWHIV*

**4.4.1 Fear of health outcome**

The fear of health outcome of non-adherence was the major reason why some of the participants adhered to the ART; they were able to recollect what happened to them before treatment was commenced, and what is happening during treatment. The participants described this in terms of their physical appearance, well-being and their state of health. Some of the participants talked about what they experienced when they defaulted for some time and why they had to come back. A male participant who is forty seven years and had defaulted for about a year had this to say;

*“It did not ever come to my mind that the infection will be very serious at that time and put me down. It did not come into my mind at all: The headache is the problem as at now I am having severe headache and my ribs is paining me. I fear I will be weak.” (Eben)*

With the above in mind, many of them are of the opinion that once they stopped taking their ART they will not look fit and strong anymore and hence will not like it to happen to them. However there were others who were of the view that some of them perceived that once they start looking healthy and strong then they stopped taking their ART. Nii, a tailor had this to say when he was asked why people do not adhere to their ART regime;

*“There are some people, who whenever they take their ART and end up feeling healthy, perceive that they are well and cured. However, discontinuing the ART will result in*

*Factors influencing adherence to ART among PLWHIV*

*increasing the number of virus, which in turn will make you very sick.” (Nii)*

The fear of dying was an issue that featured prominently among participants and this was how one young lady in her forties put it;

*“The thing that makes me take my ART is the fear of dying. Though, I know that there is no cure for the disease. Sometimes I don’t think about but when I am alone, then suddenly it frightens me, which makes me say to myself ‘eiii’! Have I taken my ART? So each morning at 8 o’clock, I ensure that I take my ART irrespective of where I am”. (Cece)*

Most participants have been educated on the result of non-adherence and are aware of the implications and the consequences of non-adherence, the fear of dying from HIV/ AIDS is one thing that scares them and makes them take their ART. Adez a lady in her early forties described her fear in this manner;

*“I do feel that if I do not take the ART, I will soon die and leave my children alone, I do not know who will take care of them. I do not want to die so I need to take the ART to live”*  
**(Adez)**

Jay a thirty year old man also describes his fear of outcome on health, if ART is not adhered to in this manner:

*“My fear is that if I do not take the ART I will not be physically fit to do my job and may eventually die. (Jay)*

*Factors influencing adherence to ART among PLWHIV*

Other participants also talked about what they see happening to other PLWHIV who do not adhere to their ART regimen. They stated this, as the reason why they take their ART. The participants said some people suffer from so much pain and misery that they may end up losing their lives. The participants were also of the view that if they do not adhere, this misfortune will befall them. Therefore to avoid that they will take the ART as prescribed and abide by all the activities and instructions related with the ART regimen. In order not to go through similar situation, Ayerki described her fear in this manner;

*“When I initially came here I saw some people who had stopped taking their ART, and the way they look made me scared. I fear that if I don’t take my ART like them, I will progress to such a deteriorating stage, and I will be ill”.*

**(Ayerki)**

The outcome of non-adherence is most of the time evident in various forms ranging from minor illnesses to major ones with the patient ending up losing their lives. Most participants have either experienced the consequences of non-adherence while others have seen other people going through problems as a result of non-adherence. With this many of the participants, fear the negative health outcome of non-adherence and therefore feel obliged to take their ART as prescribed. The fear of poor health outcome therefore serves as a deterrent to other PLWHIV to be adherent to their ART. They claim that it is difficult to be put on medication for the rest of one's lives, because sometimes you may get tired and the zeal may go down which will affect adherence. The

*Factors influencing adherence to ART among PLWHIV*

participants claim that they are aware of the consequences of non-adherence and will do their best to continue taking the ART. Most of them said they compare themselves with other categories of people with chronic illnesses such as diabetes and hypertension that require the intake of daily drugs for life. This is how Nii described it;

*“As for me when I tested positive I was not really scared, I was not disturbed because I compare myself to those who have hypertension and diabetes because they are on antihypertensive and anti-diabetic drug respectively for the rest of their lives, so if I am also going to take ART for life. I am not going to be scared”.* (Nii)

Jay also confirmed this assertion by saying this;

*“For me I see HIV to be more like having any other disease, such as chronic diabetes which requires the intake of daily anti diabetic drugs.”* (Jay)

#### **4.4.2 Avoidance of suspicions**

Avoidance of suspicion stems from the fact that most participants are aware that their physical health has improved significantly with ART. Therefore by not adhering to their ART regime may result in them becoming sick and unwell again. The participants said when this happens people will be suspicious about them. One significant sign that tends to disturb the participants is the severe weight loss associated with HIV/AIDS. Cece explains what happened to her when she did not adhere to the ART judiciously:

*Factors influencing adherence to ART among PLWHIV*

*“I became very slim and pale and you could see my eye holes with a whole lot of things happening to me. People were suspicious and began asking me what the problem was, so I said to myself let me come to where I was diagnosed.”(Cece)*

The avoidance of suspicion by most participants was one of the reasons why they adhere to their ART. The participants claim that people talk a lot and will be wondering why they have gone down so drastically. People then become suspicious about their health, and will begin wondering what is happening. The participants claim they are afraid that if people get to know their status, they will shun their company. To avoid people becoming so suspicious about their status means that they have to adhere to the ART. Again the participants claimed that they are aware of the negative repercussion of non-adherence and will not like people to know their status. This is what Araba had to say:

*“I am aware of what would happen if I do not adhere, so because I do not want people to be suspicious about me I would take the ART.” (Araba)*

Yaa also had this to report

*“The ART will make you strong and healthy and if you do not take them you will be sick, people will be asking what is wrong with you, for me I do not want that so I have to take it.” (Yaa)*

Most of the participants said they are very careful not to give people the slightest indication of what is really happening to them, and that is why they

*Factors influencing adherence to ART among PLWHIV*

think it is important to adhere to the ART in order to be healthy all the time.

This is what Felicia said to confirm this:

*“I have to take the ART to avoid people becoming suspicious of me; I know the stigma attached to the disease.” (Felicia)*

#### **4.4.3 Avoidance of reprimandment**

Most participants stated that they do not want to be reprimanded by health personnel and therefore they take their ART as prescribed. The participants indicated that before the drugs are dispensed to them the pharmacist will check the date of the last visit, compare with the number of ART in the bottle, and if it does not tally then you will be questioned and reprimanded as narrated by Araba:

*“I always present the old drugs, as you can see the remaining in my hands. When I present them, they check the records and find the number issued to me, they then calculate it, and add some to it for me, if it does not tally then you will be reprimanded” (Araba)*

So in order to avoid being reprimanded they had to take their ART. Ayerki reiterated the above statement in this manner:

*“I will take my ART because if I don't take and I come to the clinic they will reprimand me, so I have to take my ART.”*

**(Ayerki)**

Some participants claimed that they are adults and if drugs have been dispensed to them they need to take it in order not to be reprimanded. The

*Factors influencing adherence to ART among PLWHIV*

participants indicated that it is embarrassing to be talked to in such a manner. Most of the participants acknowledged that the health personnels are usually right to reprimand those who do not take their ART religiously. Jay had this to say:

*“I am an adult and once I have been given a drug to take. I have to take it, in any case why should I come for it, if I will not take it. They are right to reprimand us if we do not take it.”*

**(Jay)**

Nii was also of the view that they should be reprimanded and sent home to come back later. This is how he expresses this assertion:

*“Oh yes we should be reprimanded, if the nurse wants to help you and you with the disease do not want that help. What can the nurse do for you? I think the health personnel should leave them alone to teach them a lesson as for me, I do not want to be reprimanded like a child.”* **(Nii)**

Contrary to the above statement, other participants were also of the view that instead of reprimanding the defaulters, a little pampering with a little bit of encouragement will help PLWHIV adhere to their ART regime. This is how Nana described how to deal with people who do not adhere to ART:

*“if somebody is on ART and does not come for a while and the situation worsens, when he or she comes a little encouragement and a bit of pampering will help them come back. Some of them before they come they are so down and therefore they cannot control themselves so when they come and you do not have*

*Factors influencing adherence to ART among PLWHIV*

*patience then it becomes a problem. I always say if you come here and you do not abide by the instruction and education truthfully it will worry you.” (Nana)*

#### **4.5 Cognitive and other personal factors**

This aspect deals with the interaction of personal and medical factors that influence adherence to ART. Medical factors that affect adherence include cognitive abilities, as well as overall health status of the individual. Personal factors which may influence adherence to ART regime include: personal beliefs about the condition for which the ART has been prescribed. These personal factors also include the seriousness of the condition, as well as likelihood of the ART having a positive effect on the PLWHIV. Cognitive and other personal factors were evident in two distinct ways, which are depression and physical functioning/physical condition.

##### **4.5.1 Depressive factors**

Depression is a feeling of sadness and rejection. Most of the participants reported having gone through some form of depression one way or the other during the course of treatment. Depression stems from the fact that the participants claim that HIV is deadly and that there is no cure for it. This is how Ayerki expressed her sadness;

*“When I was told I have HIV. I asked the nurses to give me a drug that will kill me; they however assured me that being HIV positive is not a death sentence. Many other people talked to me in fact, I was really depressed.” (Ayerki)*

*Factors influencing adherence to ART among PLWHIV*

There were some sort of suicidal tendencies when most of the participants were informed about being HIV positive. The participants said they felt sad and dejected, most of them claimed they were confused and did not know who to talk to. They reported that they were so scared that they felt like ending their lives. Some of the participants mentioned that they considered drinking poison to end their lives. A young lady in her mid-thirties described her reaction in this manner;

*“Yes I was very worried. Had it not been the encouragement from nurses, I would have drunk poison to end my life” (Yaa)*

Women who were diagnosed during ante-natal care were very scared of infecting their unborn babies; this became a source of worry for them. The participants claimed that they were depressed over the issue of either terminating or to proceed with the pregnancy. To some extent some of the participants thought about and even asked for abortion services. This is how Alima a thirty five year old lady recounted her depression about infecting her unborn baby:

*“I wanted to terminate my pregnancy because I tested positive. This was because I was afraid that my child will also be infected, it was indeed a depressing time for me” (Alima)*

Mr Kay a male in his mid-thirties had this to say about how depressed he was when her lady who is also positive had to abort their unborn child:

*“Hmmm when the pregnancy comes then she aborts it. Recently she got pregnant but we were told that before you impregnate*

*Factors influencing adherence to ART among PLWHIV*

*someone, you have to come so that they will check on you and educate you on how you can give birth safely without infecting your baby, so again she got pregnant but aborted it, I was so sad and depressed. Since then I would love to have a child but the pregnancy is not coming” (Mr. Kay)*

Depressive moods tend to make most PLWHIV sad and disorganized, they feel saddened with the fact that they are saddled with the burden of being diagnosed with this deadly disease, which requires that they take ART for life. This is how Felicia a forty year old lady narrated her plight;

*“I was initially so discouraged and sad so I did not take my ART well at all and i became so skinny and sick”. (Felicia)*

Some of the participants were so depressed due to the fact that their husbands were HIV negative and they were positive. The participants claimed that they wondered what society will think about them. Some of the participants said they requested for the same test to be done twice or three times before they accepted they were HIV positive. The participants reported that they simply did not understand why their husbands were negative and they were positive. This was how Adez whose husband is negative described her depressive feelings;

*“I had to do the test three times before I accepted the truth, my husband was negative and I positive, in fact, I was very confused and so depressed, I asked myself “eiiii” what will people say about me “hmmmm” which did somehow affected the way I take the ART. (Adez)*

*Factors influencing adherence to ART among PLWHIV*

Some of the participants have been neglected by their spouses because of their HIV positive status resulting in a feeling of loneliness and depression. The participants claimed that sometimes these depressive moods affect the way they take their ART. Felicia came home from the hospital to realize that her husband who tested negative had abandoned her. She narrated her ordeal in this manner;

*“Three months after birth, I once came home from the hospital to realize that my husband has packed his belongings. He told my mother, who was then staying with us that he was going somewhere. Where are you going and is your wife aware that you are travelling? My mother asked. No, my husband replied. Why and how will she know since you have not told her where you are going? My mother asked. Nothing, he replied. He did not leave me any money behind. We waited for his return and it’s been 9 years now since he left me. Indeed he has been gone for almost 10 years now in the next 4 months. I was so sad and depressed and those sad moments affected the way I adhered to the ART.”(Felicia)*

Some of the participants also claimed that they get depressed due to the fact that they have to come to the clinic regularly for their ART. This is how Cece describes this:

*“I wish that when I am coming to the hospital, I am coming for something like i have grown fat and my doctor says I should lose weight or I am coming to check the weight of my child or I*

*Factors influencing adherence to ART among PLWHIV*

*am coming for ante-natal services, but coming to the clinic because of this deadly disease, really weighs me down a lot.”(Cece)*

Jay also reported:

*“The thought of going to the clinic every two months depresses me a little bit sometimes” (Jay)*

#### **4.5.2 Physical conditions/ Physical function**

Most participants indicated that they are much stronger physically with ART than when they were not on ART. They can currently say with confidence that there has been some level of improvement, in one way or the other with regards to their physical conditions and physical functioning. The participants stated that their physical functioning and physical condition has become better. Maame Adwoa had this to say;

*“I have realized that when I was not taking the ART I frequently fell sick but since I started the ART I realized that I am much stronger. I could go to town, prepare my own meals, wash my own clothes and do virtually everything. I am now stronger and healthier physically than when I was not taking ART.” (Maame Adwoa)*

Another participant also had this to say about how he feels about his physical condition;

*Factors influencing adherence to ART among PLWHIV*

*“I have adhered to all the instructions and I can see I am healthy and strong. I followed well the dosage of the ART. I came with a lot of people and have realized that most of them did not make it because they did not adhere to the ART. As for it is very hard to be identified as an infected person I can say that my physical condition has improved”.* (Mr. Kay)

This is how Ayerki simply put it:

*“I am healthy physically and I don’t have any complain about my health and that is why I take my ART simple”.* (Ayerki)

It is evident that most participants have seen tremendous improvement in their physical conditions over the course of their treatment and that has made it possible for them to continue taking their ART. Participants attested to the fact that non-adherence may lead to a deterioration in physical conditions as well as other illnesses and diseases associated with HIV. On the other hand there are some who because there was an improvement in their physical conditions and functioning may also have some negative repercussion such that they may stop their ART regimen. A lady’s husband has stopped the ART. This is because he believes he is not sick and that his physical condition and functioning has improved. This is how she expressed her frustration:

*“I don’t know what is wrong with him. He always says he is not sick, and that his physical condition has improved, hence he will not come for his ART or reviews. Initially I used to come for it on his behalf but he refuses to take it so I have stopped.”*

(Lamiley)

*Factors influencing adherence to ART among PLWHIV*

This may imply that once some of the PLWHIV see a considerable improvement in their physical condition and functioning then they may not continue to adhere to the ART. Again sometimes when the viral load is negligible they may feel the disease is gone and therefore may end up defaulting or not adhering to their ART as prescribed. Nii explained why some people do not adhere to ART:

*“They do not adhere to the ART because they are looking fine and healthy. They are enjoying but they don’t know that the viral load is increasing and can cause harm to them. By the time they come back to the clinic it will be too late.” (Nii)*

#### **4.6 Treatment and self-efficacy**

Treatment and self-efficacy describes the willingness of the PLWHIV to continue to adhere to the ART regimen. Most participants generally acknowledge that ART is effective when adhere to as prescribed. Treatment and self-efficacy was evident in four distinct ways these are treatment efficacy, self-efficacy, time consciousness, and confidence in ART.

##### **4.6.1 Treatment efficacy**

Most of the participants acknowledged that the treatment was indeed working for them. They have seen a lot of improvement in their health; they indicated that when ART is adhered to, it is very effective. They expressed their willingness to continue taking their ART,

Maame Adwoa who has been on ART for two years explained the effectiveness of the ART this way:

*Factors influencing adherence to ART among PLWHIV*

*“Yes the ART is working because I have realized that when I was not taking the ART, I usually fall sick and could not do a lot for myself. But since I started taking ART I have realized that I am stronger. I go to town and come back prepare my own meals and do other things. I wash my own clothes and do virtually everything. I am now stronger and healthier than when I was not taking ART, I believe the drug is effective”.*

**(Maame Adwoa)**

Adez who has also been on ART for seven years said this:

*“Yes the ART is working, as for me there is absolutely nothing I cannot do I am fit and sometimes I think I am healthier than those who think they are negative, I know the drug is effective”.*

**(Adez)**

From all indication the ART is working for them and the participants think that the ART is effective. Most of the participants expressed their willingness to continue taking the ART because their health has improved dramatically. Some of the participants recounted the numerous bad experiences they went through when they were not on ART. The participants indicated that they were weak and suffered from various kinds of illnesses such as diarrhoea, malaria, cough and other ailments. Nana who has been on ART for six years explains why he thinks the ART is working in this manner:

*“Looking at when I was not on ART and the way my body was I can say, the ART is working and effective. There have been a lot of changes in my body. I realize that when I was not on ART*

*Factors influencing adherence to ART among PLWHIV*

*when I move from one place to the other I easily get tired, Most often I am sick but when I started the ART I don't fall sick but then, if I will get sick then it may be minor sickness. All the education I was given at the clinic, I abide by them and I have realized that the ART is effective". (Nana)*

Nii who has also been on ART for five years recounted his experience when he was not on ART, and put it this way:

*"I usually fell sick and was even diagnosed with TB but since I started ART I don't have such problems anymore." (Nii)*

All the participants could tell the differences in their physical strength and health which they stated as positive. From all indication it was evident that there was some sort of improvement in their state of health from the time they commenced treatment. The participants claim that because of the effectiveness of the ART, they are willing to continue taking it so as to remain fit. In some instances, the improvement in health was not only evident on the participants only but they could see changes in other PLWHIV who come to the clinic. This is how Alima who has been on ART for six years explained this:

*"Hmmm the people who are brought here, sometimes you will see that they cannot do anything for themselves. Sometimes they will be in wheel chairs but when they start the ART within two to three weeks you will realize that they are ok. They can now get up and do things for themselves so you realized that there is a change." (Alima)*

*Factors influencing adherence to ART among PLWHIV*

Some of the participants even indicated that they experienced side effects during treatment but despite the side effects of the ART, they are willing to overlook those problems and continue taking their ART. The participants' mentioned having experienced nausea, paleness, numbness, insomnia, rashes and itching as some of the side effects of the ART. Some of the participants said they experienced minor side effects. Lamiley who has been on ART for six year recounted what happened to her when she was put on ART:

*“Initially as it started I was experiencing severe itchy body. I sometimes thought it was worms but the itching never stopped when I dewormed”.* (Lamiley)

Another participant also recounted his experience when he started the ART as follows:

*“Initially when I started treatment when I sleep I become numb and I started having bad dreams. I do feel dizzy too but I did not stop taking them”.* (Nii)

This was how Cece who has been on ART since 2011, typified the side effects she has during the course of treatment.

*“I for instance always get the reactions after taking the ART. I become pale; sometimes I feel nauseated and those kinds of things but I realize that as you continue taking the ART, it becomes better even I heard it affects some people mentally. For me I grow lean, I vomit, I feel nauseated and dizzy. Sometimes I will have the side effect for about two or three*

*Factors influencing adherence to ART among PLWHIV*

*months then i feel better again but I continue taking it despite the side effects” (Cece)*

It was clear that they were informed about the side effects of the ART. The participants claimed that because they were pre informed about these side effects it has helped them to deal with the situation. But some of the participants said they were uncomfortable with the side effects. Again the participants claimed they were educated on what to do when those problems occur, and this made them gain confidence to continue their ART. This according to the participants has made it possible for most of them to adhere to the ART regime. Some of the participants also talked about how the number of ART’s did not deter them from taking the medicine, Mr Kay who has been on ART for seven years explained the treatment efficacy this way:

*“At times when I come in for my ART I realize it is a lot, at first I come for three month medication when I receive it. I will ask myself am I going to take all these medication. But I have seen a change in my life because of the ART. Knowing I have such a disease I have to take medication I will not be deterred from taking my ART despite the number because it is indeed working for me”. (Mr. Kay)*

Some of the participants also indicated that the daily dosing helped them to better adhere to the ART regime than the twice and thrice dosing, Yaa who has been on ART for four years reported that:

*Factors influencing adherence to ART among PLWHIV*

*“the once a day dosing one is good for me, because sometimes when I wake up in the morning I do not feel like eating because the twice daily one that I was initially on you have to make sure that you have eaten before you take it and I don’t usually feel like eating in the morning”.* (Yaa)

Almost all the participants also talked about the need to eat well before taking their medicine because they claimed that ART works very well with food. And because they are eating well they look well and healthy. The participants also talked about the need to add multivitamin and other drugs such as septrin to the ART. Some participants explained that sometimes because of non-availability of the drugs at the pharmacy at the ART clinic the drugs delay a bit. Lamiley and Nana reported this respectively:

*“They also add blood tonic to the ART, so that I can get appetite for food and eat very well, this has made me strong and healthy”.* (Lamiley)

*“I was told to add septrin to the ART, so sometimes people react to the septrin but as for me septrin is good for me, but when i do not get some to buy at the clinic, they write it for me to go and buy outside the hospital facility. Sometimes it delays a bit because it is a bit expensive; one is sold at 80 pesewas.”*

(Nana)

Ayerki and Araba also had this to say respectively:

*Factors influencing adherence to ART among PLWHIV*

*“I was taking well woman but now I have stopped because it is expensive and I cannot afford anymore.” (Ayerki)*

*“The vitafol did not make me eat very much even though other people complained that it made them very fat. I did not experience any of that but it made me looked very nice and fresh.” Araba*

Again the need to eat was a source of worry for some of the participants. Some of the participants indicated that they do not like eating very early and others also stated their crippled financial status as a result of the sickness. This is how Mr Kay described his plight:

*“Sometimes the food to eat before taking the ART becomes a bit difficult for me. I was once a carpenter but when I got the disease initially I was sick so I could not work well”. (Mr Kay)*

Yaa also had this to say:

*“Sometimes when I get up in the morning I do not feel like eating but I am obliged to do so because, this drug goes with food.” (Yaa)*

Most of the participants are aware of the instructions when on ART. They claim they do their best to adhere to all the instructions so that the ART will work effectively. This is how Maame Adwoa explained the instructions given to her when she comes to the clinic:

*“they advise us to eat before taking the ART, again I was also advised that any time i take my ART, it is important to take*

*Factors influencing adherence to ART among PLWHIV*

*vegetable such as garden egg, kontomire 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 these things around, after meals I make sure I eat a little bit of oranges, and that is how come my drug is working.”*

**(Maame Adwoa)**

Nana also explained the instruction given to him in this manner:

*“they made us understood that this medicine, when you are taking it do not take in too much sugar so sometimes when I go to buy porridge I do not buy sugar, as well as alcohol should be avoided so now for me even taking a bottle of malt has become a bit difficult for me.”* **(Nana)**

#### **4.6.2 Self-efficacy**

Most participants indicated their willingness to adhere to ART despite all odds. Participants claim that sometimes they get tired with the ART but then what motivates them most often is that although the disease is a deadly one they know that the solution is adherence to the instructions on ART. This is how Ayerki reported about her source of motivation to adhere:

*“One thing that gives me the strength to adhere is the fact that, there is a solution to the problem and that is when you adhere to ART the virus will reduce”.* **(Ayerki)**

*Factors influencing adherence to ART among PLWHIV*

Most of the participants indicated that what motivates them to gather all their energy to take the ART is the effectiveness of the medicine. The other factor that makes them take the ART is the need to be healthy.

This is how Felicia explains her source of motivation:

*“The one thing that encourages me to continue taking my ART is the need to stay healthy to take care of my kids, since I have no one”.* **(Felicia)**

Another participant explains what inspires him to take the ART:

*“I have children to take care of and if I get sick who will do that for me, I am the breadwinner of the family and therefore my children look up to me what will they do if I am not there”.* **(Jay)**

Nana also explains his source of motivation as:

*“The thing that motivates me to take my ART is that if you are sick, and you have a medication that will help and you take it well it will give you long life.”* **(Nana)**

Some participants indicated that by comparing themselves with the people they come in contact with. And the ability of the people who are also positive to be healthy, is their source of inspiration to adhere to the ART. This is how Araba confirmed this;

*“Fortunately for me I met a lot of people who are also positive at the clinic; big people in the society and that gave me the strength to adhere to the ART because if they can stay healthy*

*Factors influencing adherence to ART among PLWHIV*

*then I can also do it that is what gives me my strength to adhere.” Araba.*

Most of the participants claimed that they got their source of motivation from the counselling session. They claimed that they were made aware of the problems they may face during ART regime, and were equipped with the knowledge and skills to enable them deal with problems that may occur during the course of the treatment. The participants indicated that it has improved their self-efficacy, which in turn has made it possible for them to adhere to ART. Araba who was diagnosed during Antenatal services had this to say:

*“The counselling session taught me how to take my ART regularly, and also to avoid leaving gaps in between the intake of my drugs. 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. That is my source of motivation”. (Araba)*

#### **4.6.3 Time consciousness**

Time consciousness was another sub theme amongst the participants interviewed. Many of the participants claim that they are aware that ART works effectively with time. This according to the participants has made them to be very conscious about the time to take the ART so that they will not forget.

Araba described the situation as;

*Factors influencing adherence to ART among PLWHIV*

*“I am very conscious of the time. I run vigorously when the time is due for taking the ART. I make sure that latest by 7:30am I stop whatever household chore or any activity I am doing, find food to eat and take the drugs on time”. (Araba)*

Another participant had this to say;

*“Before I go to bed at night I take the shirt I would use and put the ART I will use inside. At my workplace, 30 minutes after taking some food, I take the ART. Indeed, I am conscious of the time because I know the drug works well with time”. (Nana)*

The participants indicated that they were asked during counselling to choose a time that is convenient for them to take their ART. The participants claimed this was done to ensure continuity of treatment. According to the participants their ability to choose their own time has made it easier for them to remember to take the ART on time. This has made adherence better.

Nana had this to say;

*“During counselling i was asked about the time that will be convenient for me to take my ART. I told her 8pm will be convenient for me. She also told me that even if I forget to take my ART, the time should not be more than two hours. She told me a lot of things which I abided to. I have been taking ART since 2008. And since I started the ART I have realized a lot of improvement.” (Nana)*

*Factors influencing adherence to ART among PLWHIV*

Majority of the participants have devised various strategies to remind them of the time, some claimed they have programmed it on their phone so that they can take their ART on time. Mr Kay reported that:

*“As for the medicine I don’t usually forget even if I am walking I am conscious about the time because I have programmed it on my phone so I don’t usually forget.”(Mr. Kay)*

Ayerki also mentioned that:

*“Yes I am very conscious about the time because I sell rechargeable cards. I use the phone all the time, whenever it is 8 I know it is 8 and therefore it is time to take my ART.”  
(Ayerki)*

Some of the participants indicated that because they are conscious of the time, it has enabled them to adhere to their ART regime. Araba had this to say:

*“The ART is taken with time and that differs from every individual. For me I have set an alarm at 8:00 am and 8:00pm on my watch. This is what I use as a reminder to be conscious of the time”. (Araba)*

Other participants also mentioned that they use other means such as the after news and certain programmes on the media to enable them take their ART on time. This is how Nana and Eben respectively reported this:

*“Right after the news, I know that it is 8pm then I take my ART after which i go to bed. Even if I am in town and I get home late*

*Factors influencing adherence to ART among PLWHIV*

*after the news I know it is 8, I then find something to eat relax for thirty minutes then I take my ART.” (Nana)*

*“Mostly in the morning I used Kwame Sefa Kayi’s morning radio programme on peace FM to remind me of the time to take my ART, because I listened to the programme every day.”*

**(Eben)**

#### **4.6.4 Confidence in Art**

The participants were confident in the treatment regime because they claim that they are healthier and stronger now with ART as compared to when they were not on ART. The participants also indicated that the difference is clear and they are sure and confident that it is the ART that is working for them; as described by Lamiley below:

*“Since 2009, the ART has been working well. I will probably be dead without the ART, I am confident it is the ART working”.*

**(Lamiley)**

Some of the participants said that sometimes when they come for their ART at the clinic, the number of medicine is so much. This is because sometimes they give them the ART for three months and the number of medicine is so much yet they are confidence that the drug will help them get better. They indicated that they do not get frightened by the number of ART they have to take; Mr kay describes this assertion below:

*“At times when I come in for my ART I realize it is a lot. This is because initially they use to give me for three month. Then I ask*

*Factors influencing adherence to ART among PLWHIV*

*myself am I going to take all these medication. But I tell myself it's not going to be difficult because when you take medicine it is good. As for me coming here I have seen a change in my life. Knowing I have such a disease which requires daily medication that can help me, I will not be deterred by the number of ART. I am confident in the ART". (Mr. Kay)*

In contrast to the above statement some of the participants were also of the view that, sometimes the number of ART was a source of worry for them. They indicated that sometimes they wish to be given daily dosing or once a month treatment which will make it easier for them to adhere to the ART, as narrated by Cece:

*"I am just saying that 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 that you can take once in a month; most of us forget a lot that is one problem that affect us all the time".(Cece)*

Confidence in ART also stems from the fact that majority of the participants who were diagnosed during antenatal services indicated that their children were all negative. They said this has improved their confidence in the ART. Lamiley who has two children who are all negative expresses her confidence this way:

*"I had my first born in 2009. The same year I was diagnosed. I have been on ART since then, I am sure it is because I adhered*

*Factors influencing adherence to ART among PLWHIV*

*to all the ART instruction that is why all my children are negative". (Lamiley)*

Yaa whose child is negative had this to say:

*"I am sure had it not been the ART, my child would have been positive, I have seen people whose children are positive because they did not adhere to the ART" ( Yaa)*

#### **4.7 Environmental influences**

This deals with aspects of the environmental setting that influence the individual's ability to successfully complete behaviour. In other words, these are factors which make the environmental condition conducive for improved self-efficacy, which may result either in adherence or non-adherence to ART. The sub-themes that emerged from environmental factors were: disclosure, attitude of personnel, disguising of medication and social support.

##### **4.7.1 Disclosure of status**

Disclosing of positive status to others was very difficult and a daunting task for most of the participants. Participants claim that they did not want other people to know their positive status because of fear of stigmatization. The stigma attached to the disease makes it very difficult for most of the participants to disclose their status to relatives, friends and neighbours. Almost all the participants said that they did not want to disclose their status to any family member or friends. Yaa expressed her uneasiness about telling relatives her positive status. This was how she sadly narrated her experiences;

***Factors influencing adherence to ART among PLWHIV***

*“As for my relatives I do not want any of them to know my status. It was due to the disease that the guy left me. They would not even allow the guy to marry me in the first place. When one hear that a person has HIV/AIDS then their response is that I will not buy anything from such person. I realized that if they get to know my status they will do the same to me. In my hometown, there is a girl who is living with the disease. There are rumours all over concerning her status and people do not even go close to her. I visited her and encouraged her to take the ART and rather ignore how she is being regarded in the society. I did not tell her I was also positive, She also added that the way people treated her may result in her dying before her time.” (Yaa)*

Another participant said apart from his two brothers no one else knows about his status. This is what he had to say;

*“No, apart from my two brothers no one else knows my status. Due to the stigma associated to this infection it makes it very difficult to disclose your status to people around you. Family members are no exception to that. That is one reason why I do not even want to go to Kumasi to my wife”. (Eben)*

Again when Eben was asked why he does not want to disclose his status to the wife she has lived with for the past twenty years this was his reply:

*Factors influencing adherence to ART among PLWHIV*

*“I can tell her but the issue of ladies and their behaviour with such issues can be very complicated at times that is why I cannot tell her.” (Eben)*

Nii also had this to say:

*“As for me I did not tell anybody. (Nii)*

The issue of PLWHIV having to carry this burden alone is one thing that worries them. According to them they will rather resort to secrecy than disclosing their status and end up enduring stigmatization and sometimes which may result in death before their time is due. They are so cautious about who they talk to. This is how Cece, a forty year old graduate described this situation;

*“There are some people who don’t want anybody to hear about their status. That is one killer factor. Somebody can just call you and ask whether you have taken your ART. If someone calls you like that then you will know that he or she loves you very well and wants the best for you. (Cece)*

Most of the participants feel comfortable talking with people who are in similar situation as their own. They said that they prefer disclosing their status to others who are positive rather than people who are thought of as negative.

Adez reported this:

*Factors influencing adherence to ART among PLWHIV*

*“When I came I hear. We share our problems and talk to each other, I am comfortable talking to the people here than my relative.” (Adez)*

Some of the participants also said that they were even advised by people not to disclose their positive status to other people because of stigma. This is how Ayerki confirmed the above statement:

*“I told my aunty because she is not a talkative and she has even advised me not to tell anyone”. (Ayerki)*

#### **4.7.2 Attitude of health personnel towards PLWHIV**

Attitude means a predisposition or the tendency to respond positively or negatively towards a certain object, person or situation. The attitude of health personnel emerged as an environmental factor. The health personnel had both positive and negative attitude toward PLWHIV.

##### **Positive attitude**

Narrations from most of the participants indicated that the attitude of the staff was positive, that is they were happy with the way they are treated at clinic. This in turn encourages them to come to the clinic when the time is due for review. The participants claimed that the way the health personnel such as nurses related to them when they come for reviews made them comfortable. The participants also indicated that the way and manner they are received by the staff when they come for reviews made them feel more accepted. This was how Eben described the attitude of the staff at the clinic:

***Factors influencing adherence to ART among PLWHIV***

*“Aunty M is my counsellor and when I defaulted my mind was on her. I thought about what she will say when I come back. I was a little bit relieved because she empathized with me. I informed her and she spoke to the pharmacist on my behalf and that is how come I am here”. (Eben)*

Cece also had this to say:

*“The staffs here are fine they treat me well. They encourage us, they make us feel at home, They tell us that this is not something that you should cry you have it but some people even without the disease die so it is not a death sentence.”(Cece)*

The positive attitude shown towards patients may be a contributory factor when it comes to follow up or attending reviews. Many of the participants recollected their first visit and how they were counselled and encouraged not to take their own lives. Since treatment is available this made them relieved and relaxed. Araba narrated her encounter with the staff and what happened later;

*“When I started visiting the unit for the ART, I initially went through counselling services. The staffs were kind to me. Indeed with my first visit here, they related to me very well and I was relaxed, and that is why I always come.” (Araba)*

This is what Jay had to say:

*“As for the staff here they treat us well and this encourages us to come for reviews”. (Jay)*

*Factors influencing adherence to ART among PLWHIV*

**Negative attitude**

Some of the participants have one way or the other had some scuffles with a staff, one lady recounted her ordeal with a staff when she went for antenatal care.

*“I remember meeting a staff nurse during the period of my pregnancy. I cried whenever she spoke to me. I do not know her name. She said I will die and that my child will also be infected and will die. When I came here aunty M told me that it was not going to happen to me and encouraged me” (Yaa)*

Negative attitude of some of the personnel tend to cause many problems for patients. Some of the participants claimed they felt sad, worried and scared when they had those bad encounters with health personnel. Yaa once again recounted another experience with a nurse at the ANC clinic which she once visited;

*“I remember once I was pregnant and my status was written at the back of my folder. One of the nurses did not even want me to get close to her. She was like; “stand there, stand there” and her behaviour really made me felt like I was not a human being and may infect her by getting close to her.” (Yaa)*

By this bad encounter as she indicated, her next reaction was however different;

*“So when this happened I erased my status from my folder. When I was due for delivery I informed the nurse about my*

*Factors influencing adherence to ART among PLWHIV*

*status. That was even done after delivery. I informed them that my child is to be given ART.”(Yaa)*

**4.7.3 Hiding and disguising of ART**

The disguising of ART was an environmental factor that emerged. Many of the participants said that they hide their medication so that people will not know their positive status. Some of the participants have resorted to burning of the pack while others also changed the entire packet and put it in other containers such as herbal packs. This is how Yaa describes it;

*“I hide it very well amongst my things. I usually pour it into a different container so if you ask me I will tell you it is herbal medicine.” (Yaa)*

Another lady also had this to say;

*“In the initial stages, we were very scared that people may see the drug and talk about our status. For me in particular, I had a strategy of opening the container of the ART in my bag so that I swallow it right away immediately my hand is out of the bag. This did not make people see the medicine as most people are very curious. Furthermore it is also not easy to find a place to put the ART in my room.”(Araba)*

Nii also confirmed this by the following report:

*“As for me where I hide my ART even if a friend comes to my room he will not find anything. When they give me the pack I take the box and the leaflet inside the pack and burn them. So*

*Factors influencing adherence to ART among PLWHIV*

*it will be left with the container if someone takes it, he or she will not know that it is ART, but if you take everything home then people will know that you have such a disease.” (Nii)*

Although most of the participants cannot mention the names of the drug, they claim they can recognize the drug they are taking by its shape and taste. This is how Cece described her ART;

*“I don’t really know the name but I can recognize the shape and the scent is also good.” (Cece)*

This is what Yaa said about her ART:

*“No I don’t know the name of the ART, but I can recognize by shape, it is also tasteless.” (Yaa)*

The participants also indicated the restrictions on their lives as a result of their positive status. They stated that when they need to travel, they have to think about where they can access treatment which is sometimes a source of worry, this is how Jay reported:

*“The fact that when you want to travel, you cannot do so because, you have to think about how to package your drugs and how long you can stay as well as where to access the ART when your drugs gets finish it is also very disturbing”. (Jay)*

#### **4.7.4 Social support**

Social support according to most of the participants was an environmental factor, but the issue of people shunning their company because

*Factors influencing adherence to ART among PLWHIV*

of their positive status is what is preventing them from getting the needed support required from family, friends and the society as a whole. Social support comprises the following: spousal support, family support, group support, and support from friends.

**Spousal support**

Most of the participants who were married claim they had some form of support from their spouse. The participants stated that they were reminded by their spouses constantly to take their ART and this has made it possible for them to adhere to their ART. The participants stated words of encouragement, constant reminder, finances, and provision of meals as some of the various kinds of support they got from their spouses. Adez whose husband is negative explains how her husband has helped her to adhere to ART:

*“My husband is the one who constantly remind me whether I have taken my medication or not, so he is one of the reasons I take it constantly”.* (Adez)

Alima also reported how her deceased husband who was negative encouraged her when she had wanted to terminate the pregnancy:

*“He was the one I was with at the moment, I had wanted to terminate the pregnancy because I tested positive because I was afraid that the child will also be positive but my husband was the one who encouraged me and talked to me not to.”*

(Alima)

*Factors influencing adherence to ART among PLWHIV*

Some of the men also indicated how close they have become with their spouses because of their positive status; Nana whose wife is also positive explains how his wife supports him:

*“As for my wife I have taken her as my friend so my coming here my wife is not her, I am here in her stead. If I call my wife and she is out in town, the only thing I ask is have you done your thing and if she also calls me have you done your thing? Immediately we say the thing we understand.”* **(Nana)**

Mr Kay and Cece also explains the kind of support his lady who is also positive provides him:

*“I live with her, when I started the ART at first she was the one who reminds me constantly, and before I get up to take the ART she prepares something for me to eat, she has helped me a lot.”* **(Mr. Kay)**

*“My husband is negative and is not really bothered about my positive status. In fact he really encourages me to adhere to the ART and he assures me that it’s not going to kill me, he believes there will be a cure some day and I also believe so”.* **(Cece)**

On the other hand some of the women indicated that their husband abandoned them because of their positive status and were left to fend for themselves. This was how Felicia recounted her experience:

*Factors influencing adherence to ART among PLWHIV*

*“I came back home to realize that my husband has left me and my three months old baby. He left without a message or money and since then I have not set my eyes on him again.” (Felicia)*

**Family support**

Some of the participants indicated that they are not getting any form of support from their family, because their family members do not know of their HIV positive status. The participants claim that because of the stigma attach to the HIV; they do not want their family to know that they are living with HIV. Yaa had this to say:

*“As for me none of my family members give me any support, because they do not know my status and they will never know and that is why I adhere strictly to my ART.” (Yaa)*

On the other hand some of the participants said they did get some form of support from at least a relative. The kind of support ranges from financial support, a word of encouragement as well as spiritual support. This gesture the participants claimed has enabled them to pull through despite the odds. This is how Ayerki explained the kind of support she had from an aunty:

*“My aunty works in this hospital, at first she used to pay my bills but since I started working I now do it myself. Apart from her I did not get any support from any one. Not even my mother and father.”(Ayerki)*

Araba and Cece also had this to say about the kind of support she gets from her mother:

*Factors influencing adherence to ART among PLWHIV*

*“My mother frequently reminds me of my review date. She reminds me and I quickly check on my yellow card and check the date to report for the review. I sometimes forget my review dates because of my activities in the market. She encourages me a lot and believes that there will be a cure one day.”*

**(Araba)**

*“My elder sister prays with me but apart from that she doesn’t do much.”* **(Cece)**

**Support from friends**

Some of the participants mentioned that they felt comfortable talking to their friends rather than family members. The participants stated that they had a word of encouragement and motivating words from friends which enabled them to continue taking their ART. Alima explains the kind of help she got from a friend:

*“I met an old school friend whom I narrated my story to, so she became my monitor and she informed me that the way I have reduced I should report at the clinic to check my CD4 count, she reminds me of my review date and advises me a lot”.*

**(Alima)**

Felicia also had this to say:

*“I initially came to counselling with my friend and I have told her everything so she reminds me when I have to go for the*

*Factors influencing adherence to ART among PLWHIV*

*medicines my review date. She also asks me to eat and take the drugs.” (Felicia)*

Some participants indicated that they would have loved to get some form of support from friends but because of stigma attached to the disease it is a bit difficult for that to happen. This is how Cece explained the situation.

*“Sometimes if you have friends to call you, ‘charley’ have you taken the medicine? And also encourages you. This will help you a lot to continue taking your drugs.” (Cece)*

**Group support**

Most participants are aware of the various support groups for PLWHIV but some of them were unwilling to join. Some of the participants indicated time factor and the need to be discrete about their positive status to avoid stigmatization as some of the reasons why they are not part of groups. But they acknowledged the fact that, the groups help people who are HIV positive, to realize that they are not alone. This is what Adez who is not a member of any group had to say:

*“No I don’t want to join the groups because I do not want to associate myself and be seen on TV. Moreover I do not have time, well in a way it helps because if you join and see that others too are having the same problem as you, you can share your experiences which will motivate you to adhere to your ART.” (Adez)*

Eben who is also not a member of any group had this to say:

*Factors influencing adherence to ART among PLWHIV*

*“I do not want to join any group because I do not want to be seen by people.” (Eben)*

Some of the participants claimed that the kind of people they meet at the meetings was a source of comfort for them. They mentioned financial, education and counselling as some of the support they get from the group of other PLWHIV. This is what Maame Adwoa who is a member of one of the groups had to say:

*“The group has helped me in diverse ways such as how to wear a condom during sexual intercourse. Again they encourage us to adhere to ART so as to be healthy.” (Maame Adwoa)*

Alima who was once a member of such groups explained the kind of support she got from being a member of the group.

*“We use to attend meetings and they will come and educate us on healthy living and how to adhere to ART, afterwards then they will give us money.”(Alima)*

Nii who was once a member of such group had this to say:

*“Yes such groups are important because they help PLWHIV. There was one in Tema that they had financial support from outside and they wanted to provide financial support to people who want to start business such as selling of pure water.”( Nil)*

Araba who is not a member of any group expresses her opinion this way:

*Factors influencing adherence to ART among PLWHIV*

*“To me 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 cater for themselves.”*

**(Araba)**

Some of the participants indicated their intention to join the group someday.

Ayerki who is not yet a member of any group had this to say:

*“yes I will join the group someday the reason being that when they bring you for the first time it’s not easy at all or maybe someone who has lived with the disease for a long time and you look at how they look you will forget about your own I heard they do a lot of counselling and help you adhere to ART.”*

**(Ayerki)**

#### **4.8 Major concerns on adherence**

##### **4.8.1 Adherence and spirituality**

Spirituality was one of the major adherence concerns that emerged outside the constructs of the theory. Some of the participants were aware that there were many pastors who claimed they can heal the disease. Some of the participants claim that although they believed in God they do not believe that these pastors can heal them. Other participants stated that they were aware of some cases whereby a pastor has asked PLWHIV to stop taking ART and the negative repercussion of such acts. Nii described the situation this way;

*Factors influencing adherence to ART among PLWHIV*

*“Yes there are people who believe the pastors can cure them but many of them die eventually. They will tell you not to take your ART again.” (Nii)*

A participant who went for prayers and defaulted for a year recounted his experience in this manner;

*“At Takoradi, I used to visit a church with my friends. During the prayer sessions, the man of God said that, his anointing oil will heal all health challenges. I therefore thought there could be a divine intervention from God”. (Eben)*

When he was asked about the reason for his return to the clinic again this was what he said;

*“It was on television last Monday and as part of the celebration of the World Aids Day, my attention was drawn to the fact that I need to go to the clinic. After giving it a long thought during the night after watching an AIDS programme. It was said that most of the pastors are infected and they visit the hospital for their ART. They are the same people who will advise their infected church members not to go for their ART. It occurred to me then that there were some levels of deception involved. So I therefore decided to go back and look for my yellow form and resume with the ART”. (Eben)*

Another lady had this to say:

*Factors influencing adherence to ART among PLWHIV*

*“I fasted during the first year and realized my body was better. I then decided to continue fasting but after that, I have not been ok and have lost so much weight.” (Alima)*

The issue of pastors claiming they can heal the disease is one issue that is preventing people from taking their ART. Most of the participants do not really believe in these things because they have seen the end result of other persons and will not like to fall prey to these things. The issue of spirituality and adherence seems to be of major concern to the health personnel at the clinic. According to the participants, some pastors claim they can heal HIV and are either selling anointing oil or water at exorbitant prices. This is how a lady expressed her disgust about the situation;

*“Another bad thing is that most patients listen to their pastors. They visit prayer camps and are deceived not to take the ART. They therefore expect to be healed from the prayers which eventually make them weaker and weaker. God is indeed able but not taking the ART is inexcusable in this regard. Other patient even abandons their homes in Kumasi and resort to staying in the mission houses with the pastors in places in Accra. Heavens help those who help themselves.” (Araba)*

This is how Yaa also describes this:

*“as for the pastors I do not believe them because there is one pastor who got to know that I had such a disease and he rather encouraged my husband to leave me, and since then when I call the pastor for help he doesn't want to help me so he*

*Factors influencing adherence to ART among PLWHIV*

*disappointed me he does not want me to come to him because of my status.”(Yaa)*

**4.8.2 Need for a monitor**

The policy at the clinic was that before ART is commenced there is the need for PLWHIV to undergo counselling three times. The PLWHIV is also asked to bring a relative or a friend to act as a monitor. These measures were taken to ensure that clients adhere to their ART. On the issue of counselling almost all the participants agreed that it has really helped them a lot to ensure adherence to ART. The participants also indicated that counselling services provided them has also improved their eating habit. This is how Nana explained the situation:

*“Initially when I was not on ART my eating habit was rubbish and my coming here with a lot of counselling services given to me , has helped me lot since my eating habit has improved as well as the way I adhere to the ART”. (Nana)*

Araba said this with so much pride:

*“The counselling taught me how to take my ART regularly. I was also educated on my dietary habits and avoid leaving gaps in between the intake of my drugs. 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.” (Araba)*

*Factors influencing adherence to ART among PLWHIV*

The views about clients bringing a monitor before commencing treatment were divided; some of the participants were of the view that a monitor is important while others were in disagreement. Araba who agrees with this policy had this to say:

*“I am aware of the rules that before taking the drugs, you present a person who will be monitoring you during the medication period, this has helped me a lot since my monitor calls me sometimes to remind me of my review date.”*

**(Araba)**

Adez explains how her monitor has helped her:

*“My monitor has really helped me in taking and adhering to my ART. He has also helped me on how to live healthy and how to take care of myself .He calls me often and reminds me of the review date because had he abandoned me because of my positive status, I would have been dead by now.”* **(Adez)**

Those in disagreement stated the issue of others getting to know their status through the monitor which will result in stigmatization. This is how Nii expresses his disagreement:

*“Do you get me? This monitor who will call you that it is 9 so have you taken your medication maybe will be with someone at the time he calls you, that person will also ask what kind of medicine and why but the monitor may say to that person it is none of your business but the person might have heard*

*Factors influencing adherence to ART among PLWHIV*

*something then the news will spread and people will start shunning you.” (Nii)*

Yaa also said this:

*“As for me I do not think the monitor is important because you are sick and you have come for medicine you have to take it period. It is the monitors that really spread the news.”*

**(Yaa)**

Again some of the participants agreed with the use of text messaging or calling of PLWHIV to remind them to take their ART on time, and also remind them of their review date. Araba had this to say:

*“Calling the patients is a right choice for me.” (Araba)*

Other participants were also against texting of patients. This is how Mr Kay expressed his disagreement:

*“Looking at it I don’t think the text messaging is good and will work well because you will send text message about something and then someone else will read it and get to know that you have such a disease.” (Mr. Kay)*

Nana also had this to say:

*“As for my telephone number no, I don’t like either the texting or the calling.” (Nana)*

*Factors influencing adherence to ART among PLWHIV*

In summary, the findings of this study revealed the factors that influence adherence to ART amongst PLWHIV. The study employed the social cognitive theory to get the themes and sub themes but other themes that emerged were content analysed. The demographic characteristics of participants from the study showed that almost all participants had some form of formal education at various levels with only one being a graduate. Most of them are self-employed. Eight of the participants were married; two were co-habituating, one divorced and three not married. Narrations from the participants revealed the behavioural adherence, personal and cognitive factors, treatment and self-efficacy and environmental influences. Institutional policy and adherence and spirituality were also evident. Participants expressed various view and opinions on these themes. The sub-themes that emerged were fear of health outcome, avoidance of suspicion, and avoidance of reprimandment, depressive mood, and physical function, improved health outcome, time consciousness and confidence in ART. The others were disclosure of status, attitude of health personnel, hiding and disguising of ART, and social support. The sub-themes threw more light in exploring the factors influencing adherence to ART, this was supported by using quotes to authenticate the findings.

The findings of the study showed that PLWHIV were willing to adhere to their ART. This was affirmed by a significant majority of 12 participants who were influenced to adhere to the ART by the fear of health outcomes if they should discontinue their ART. Depression and physical function also influenced patients' adherence to ART. This was because they do not feel like taking the ART when they are sad and feels rejected.

*Factors influencing adherence to ART among PLWHIV*

Treatment efficacy was a very influential factor in ensuring patients adherence to ART in the study. Most of the PLWHIV affirmed that they were motivated to take the ART because they observed that ART was indeed working. To some degree, some patients however perceived that they will one day be cured. Environmental influence emerged as one of the finding that enhance ART adherence. Participants were not willing to disclose their status due to the fear of stigma associated with HIV, hence had to hide their ART. In this regard they had no social support from family or friends.



## CHAPTER FIVE

### 5.1 DISCUSSION OF RESULTS/FINDINGS

This chapter discusses the findings of the study. References are made to the existing literature in order to incorporate the findings within the context of nursing knowledge. The discussion begins with the demographic characteristics followed by the main themes.

#### 5.2 Demographic Characteristics

The participants in this study were both males and females who have been diagnosed with HIV. Majority of the participants were in their prime ages of life. This perhaps may be the reason why they want to adhere to the ART so as to be healthy and live long. Another reason may be due to the fact that most of the women in the study have husbands and children whose statuses were negative. All participants in the study have had some form of formal education with one being a graduate. This perhaps explains why they are willing to adhere to the ART as instructed. Almost all the participants in the study were self-employed with only one working with a private firm. This also may be the reason why they come for reviews often because they are not working for any organization.

Sociodemographic and psychological factors influenced the degree of adherence to antiretroviral therapy (Victoria et al., 1999). Their study assessed the degree of compliance with antiretroviral therapy in HIV-infected patients, and identified which sociodemographical and psychological factors affecting them.

### **5.3 Behavioural adherence to ART**

Fear may be caused by not knowing what to expect after a person has been diagnosed with HIV, or also by him or her not knowing how others will treat them if they find out that they have been diagnosed with HIV. Findings from this study, revealed that fear of health outcomes of non-adherence was the major reason why some of the participants adhere to the ART. The participants were able to recollect what was happening to them before treatment was commenced and how they felt in terms of physical appearance, well-being and their state of health. According to the participants, they experienced various illnesses such as malaria, tuberculosis and other minor ailments when they were not on ART and that is why they want to adhere to their ART. The participants in this study adhered to the ART so that people will not be suspicious about their status. This is because they are aware that they will grow lean and lose weight. When this happens, people will get to know their status. Some of the participants claim they have experienced the consequences of defaulting, while others also saw people who lost so much weight for defaulting. Based on this observation, they do not want to default. This assertion is consistent with findings of Beer et al., (2009) who reported that patients adhered to their ART because they needed to avoid suspicion. Participants in this study were aware that their physical health has improved significantly with ART. Therefore, not adhering to their ART regimen may result in consequences such as becoming sick and losing so much weight. When this happens people will be suspicious of their physical changes. One significant sign that tend to disturb PLWHIV is the severe loss of weight. This study also revealed that the participants adhered to the ART, because they do

*Factors influencing adherence to ART among PLWHIV*

not want to be reprimanded by health workers. According to the participants, the best way to avoid being reprimanded by health workers is to adhere to the ART regimen. The participants claim that when they come for review the drugs are checked, counted and calculated to check for adherence and if this does not tally, then one will be reprimanded. Perhaps the need for a more objective assessment tool is required to be used at the clinic sites. This will ensure that monitoring of adherence to ART among PLWHIV is done in an objective and unbiased manner.

#### **5.4 Cognitive and other personal factors**

Depression as a personal and cognitive factor affected patients' adherence to ART. Depression is a feeling of sadness and rejection. In this study most of the participants reported that they have gone through some form of depression during the course of treatment. Depression stems from the fact that the participants claim that HIV is deadly and there is no cure (Nyamathi et al., 2000).

This present study also found that, there were suicidal tendencies when some of the participants were informed about their positive status. The participants claimed that they felt sad and dejected; most of them said they were confused and did not know what to do and who to talk to. The participants reported being so scared that they felt like ending their lives. Some of the participants even considered drinking poison to end their lives. The findings of this present study are congruent with a study by Dunear-Jacob, Erlen, Schlenk, Ryan, and Sereika, (2000) who concluded that patients desire to end their lives was due to the fact that they felt so traumatized when

*Factors influencing adherence to ART among PLWHIV*

they noticed they had HIV. This perhaps explains why participants wanted to end their lives because they considered the diagnosis of HIV as synonymous to a death sentence. The participants from this study claimed that, those depressive moods they experienced tend to sometimes affect the way they adhered to the ART as reported by DiMatteo et al., (2000) who also established a positive relationship between depression and HIV medication adherence.

Furthermore, findings from this present study revealed that most participants generally reported that, they have seen that their physical function has improved tremendously with ART. The participants from this study claim that, they can attest that there has been some level of improvement with their physical functioning and health. The participants reported that they are physically active and attend to their everyday activity and chores just like everybody does. The participants believed that their physical strengths are comparable to those of people who are HIV negative because they are on ART. The finding of this study is congruent with a study by Moyle, Daar, Gertner, and Kotler, (2004) who concluded that there is an overwhelming increase in weight and body functions in ART treated HIV infected subjects.

**5.5 Treatment and self-efficacy**

Treatment and self-efficacy describes the willingness of the individual to continue to adhere to the medication regimen. The participants in this study explained that the treatment regimen is effective. They reported that ART is effective if adhered to as instructed. The participants acknowledged that the treatment was indeed working for them and that their general well-being has

*Factors influencing adherence to ART among PLWHIV*

improved with ART. This improvement in health as a result of the effectiveness of the ART however, may result in some of the participants not adhering to their ART. Quite remarkably, this finding, is similar to findings of Kesteren, Hospers, Kok, & Empelen, (2005) who affirmed that HIV-positive men who have sex with men always adhered but they ended their ART when they observed that, treatment is effective and there is improvement in their health.

Almost all the participants were concerned about the need to eat well before taking the ART because they have been educated that ART is effective when taken with food. They indicated that when ART is taken without a good meal, the individual may experience some level of discomfort such as dizziness and nausea. Many Studies have established numerous relationships between good dieting and ART (Cunningham et al., 2005; Wanke et al., 2000; Mangili, Murman, Zampini, Wanke, & Mayer, 2006)

The participants in this present study also reported the need to add multivitamin to the ART regimen because they believe that the ART is effective and work better when multivitamins are added. On the other hand the need to eat well before taking the ART was a source of worry for some of the participants who were on twice and thrice daily dosing. According to Au et al. (2006), on access to adequate nutrition as a major potential obstacle to ART adherence among HIV-infected individuals in Rwanda. The study concluded that ART initiation and adherence for patients is influenced by the fear of developing too much appetite without enough to eat. It also concluded that access to adequate nutrition was a major determinant of long-term adherence to ART. Some of the participants in the present study, also indicated that, they

*Factors influencing adherence to ART among PLWHIV*

do not like eating very early in the morning, before taking the ART, which tends to affect the way they adhere to the ART. Other participants on the other hand reported their crippled financial status as a source of worry for them to eat well before taking the ART. Some of the participants reported that they have lost their jobs because of the disease. This has made it quite difficult for them to get three square meals a day before taking the ART. Thus, the need to eat well before taking the ART is making adherence difficult for some of the participants.

The participants from this study explained self-efficacy as what encourages and motivates them to continue adhering to the ART. Some of the participants claim that their source of motivation for adhering to the ART was by comparing themselves to other PLWHIV, who have been living with HIV and are doing well and healthy. They explained that such PLWHIV in the society make them come to the realization that they can also do it and that is what keeps them going. As a result, their source of hope was from other PLWHIV who are peer counsellors at the clinic. This finding is in line with a study by Oursler et al.,(2011) who reported that most of the patients learnt from the advice, experiences and observations of other people who are living with the disease and this made them stronger as they adhered to their ART. Other participants also reported being, inspired to adhere to the ART because of the counselling sessions. The participants explained that during counselling they are given the opportunity to decide the time that is convenient for them to take the ART. In these counselling sessions, participants reported being educated on challenges they may encounter during the course of treatment as well as measures and strategies on how to cope with the challenges. This

*Factors influencing adherence to ART among PLWHIV*

perhaps explains why PLWHIV continue to adhere to their ART because they feel they have been part of the decision making process. This gesture according to the participants makes adherence a lot easier, unlike when decisions such as the time to take the ART, is imposed on them.

Most of the participants in this study reported being, very conscious about the time to take their ART. In their view, this has made it possible for them to adhere to their ART regimen (Reback et al., 2003). Meanwhile, Nel and Kagee, (2011) revealed that poor adherence may be due to forgetfulness, lack of information, symptom side effects, treatment fatigue, and lack of social support. On the contrary, some of the participants also reported that sometimes being away from home made it difficult for them to adhere to the ART on time.

According to some of the participants their confidence in the ART is as a result of the negative status of their children. The confidence in the ART may perhaps be a contributory factor to their adherence. Despite the confidence of most participants in the use of the ART, some of the participants reported experiencing side effects such as paleness, numbness and nausea but were willing to continue with the ART regardless of those side effects as asserted by other participants in a previous study (Ammassari et al., 2001).

### **5.6 Environmental influences on adherence**

The environmental setting influenced the participants' ability to successfully adhere to their ART. According to Giles-Corti & Donovan, (2002) providing appropriate support and materials either improve adherence or result in non-adherence. The participants reported issues of status

*Factors influencing adherence to ART among PLWHIV*

disclosure, disguising or hiding of ART, attitude of health personnel and social support as some of the environmental factors that influenced adherence to ART. For instance some of the participants reported not disclosing their status to any family member or friends as a result of the fear of stigma associated with HIV. The participants based their fear of stigmatization to their claim that PLWHIV have been neglected and abandoned by friends and family members because of their positive status and thus, making life very difficult for them. For this reason, the participants claimed that they are very cautious about disclosing their HIV status to others. A study by Stirratt et al., (2006) on the role of serostatus disclosure in ART medication adherence revealed that participants who reported greater serostatus disclosure to others demonstrated higher rates of adherence. This may imply that lack of disclosure of status may tend to affect adherence. Therefore there is the need for further research to be done to establish the relationship between status disclosure and adherence to ART within the Ghanaian context.

The attitude of health personnel is another environmental factor that also affected how participants adhered to their ART. Most participants reported that the way nurses related and exchanged pleasantries with them, tend to make them more relaxed and comfortable to come to the clinic at all times, and this gesture in turn motivates them to adhere to the ART. A study by Wu et al., (2002) laid more emphasis on the positive relationship between patients and nurses during hospital reviews. The positive attitude shown towards participants perhaps may be a contributory factor when it comes to follow up or attending reviews. The participants stated that a word of encouragement, praise for adhering to ART, as well as a bit of pampering may

*Factors influencing adherence to ART among PLWHIV*

help increase one's ability to adhere to the ART and improve adherence. On the other hand, some participants who experienced negative attitudes from health personnel reported that the negative attitude affected their ability to return to the health facility. According to Genberg et al., (2009) negative attitude of health personnel tend to cause many problems for PLWHIV. Participants in this present study reported feeling sad, worried and degraded, when they encountered negative attitude from health personnel.

Most of the participants in this present study reported, the hiding or disguising of their ART, as another environmental factor that influenced their adherence to the ART. Hiding or disguising their ART was a strategy to prevent people from knowing their status. Similarly some participants resorted to burning of the pack that contained the ART. Others changed the entire pack and put the medication in other containers such as herbal packs. This finding found consistency with a study by Wyatt, Tugenberg, & Ware, (2006) who reported fear of stigma and disclosure from participants as effort made by PLWHIV to disguise their medication in order to progress in their career and to also associate with social groups and organizations. There is therefore, the need for more public health education on HIV, so that PLWHIV will not resort to secrecy. This may help improve adherence.

Another environmental influence reported was the restrictions on their lives because of their HIV positive status. For instance some of the participants indicated that they may not be able to even travel outside the country because of their HIV status, even if they are able to travel accessing ART is another source of worry. In view of this, there is global need for

*Factors influencing adherence to ART among PLWHIV*

clinics and hospitals to be made HIV friendly for PLWHIV to feel safe whenever they visit these places. On the issue of social support as an environmental factor influencing adherence to ART, some of the participants who have disclosed their positive status to either a family member or a friend, indicated that they do get some form of social support such as a word of encouragement or a call from a friend or family member. They also reported that sometimes the people call to find out whether they have taken the ART or to remind them of their review date. The participants reported that these things done by their friends and family have helped improve their adherence to ART. On the other hand some of the participants claimed they do not get any form of support from any family member or friends. The lack of support from family and friends may perhaps affect the way some of the participants adhere to the ART, as indicated by Gonzalez et al., (2004) that greater social support is related to better adherence whereas lack of support result in non-adherence to ART.

**5.7 Major concerns on adherence**

A study by McDonnell-Holstad et al., (2006) affirmed a relationship between spirituality and adherence to ART. Some of the participants were aware that there were many pastors who claimed they could cure HIV. Some of the participants claim that although they believe in God they do not believe that these pastors could heal them. Other participants reported that there have been instances where a pastor has asked PLWHIV to stop taking ART. This finding is consistent with a previous study by Dalmida, (2006) who revealed that most pastors attributed spirituality to the HIV infection amongst HIV

*Factors influencing adherence to ART among PLWHIV*

positive in Atlanta Georgia. This affected their adherence. They inspired the PLWHIV to discontinue taking their ART and rather stick to prayer and fasting.

The participants stated some of the negative repercussions as, worsening of one's condition and eventually lost of one's life. In this study, a participant defaulted because he was convinced by a pastor that the disease was as a result of spiritual consequences. Several pastors appear to claim that they can heal the HIV and this may be one of the impediments to ART adherence amongst PLWHIV. The participants in this study reported that, some pastors are selling anointing oils at exorbitant prices claiming that it can heal the disease. Therefore the issue of spirituality and adherence seems to be of major concern to the health personnel in the management of HIV.

The participants in this study were aware of the need to present a monitor before ART was commenced. However some of the participants were not in agreement with this institutional policy because of confidentiality and the fear that these monitors may disclose their HIV positive status to others. The fear of stigmatization is one of the major reasons why people refuse to check their status. Perhaps there is the need for more intense education about HIV in all sectors of life. A qualitative study conducted by Gale et al., (2013) reported that the need for a person to monitor is unnecessary because of confidentiality. Contrary to the need for a monitor, some participants were in favour of this assertion because they claimed the monitors constantly remind them when the time is due for their ART. Participants emphasized on the need

*Factors influencing adherence to ART among PLWHIV*

for PLWHIV to be very careful when choosing monitors. This is because of the fear of wrongful disclosure resulting in stigmatization.

In summary the participants explained various factors that influenced their adherence to ART. On the issue of behavioural adherence they stated fear of health outcome, avoidance of suspicion and reprimandment as some of the reason why they adhere to the ART. The participants reported that depressive moods affect the way they adhere to their ART but they adhere when there is improvement in physical functioning or in physical condition. This assertion was made under cognitive and other personal factors. Under treatment and self-efficacy the participants mentioned that the effectiveness of ART, confidence in ART and peer counsellors are some of the factors that influence adherence to ART. They further explained that positive attitude of health personnel, support from family and friends improves adherence, on the other hand the participants explained that lack of social support, hiding or disguising of medication, and lack of disclosure resulting in stigmatization as some of the factors that can result in non-adherence to ART. They made these assertions when they were asked about environmental influence that can influence adherence to ART. On issues about major concerns on adherence to ART, the participants reported that, they are aware that some pastors can influence PLWHIV to stop ART and rather resort to prayers resulting in non-adherence. The views of participants on the need to bring a monitor before ART is commenced were divided. Some participants stated that it will help improve adherence. On the other hand those against this policy stated that these monitors may reveal their positive status to other people which will result in stigmatization.

## **CHAPTER SIX**

### **6.1 SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS**

The chapter presents the summary of the study, implication of the findings, the limitations as well as conclusion and recommendations.

#### **6.2 Summary of the study**

The study explored the factors that influence adherence to ART amongst PLWHIV. The study was guided by the social cognitive theory. Data collection commenced, after ethical clearance was given by Noguchi ethical review board, approval sought from the authorities of Ridge Hospital. The instrument guide was pre-tested at the Korle bu fevers unit to ensure that it was free from ambiguous questions, and also to make sure that the data reflects the right views and opinions of participants as purported. Recruitment of participants, interviews and transcription of data was done concurrently. The recruitment began in November 2014 and ended in March 2015. The participants consented to do the interviews and signed the consent form upon agreeing to be interviewed. The data collected was audio taped and transcribed verbatim. Data analysis was done based on the constructs of the social cognitive theory and other themes that emerged from content analysis.

The findings of the study revealed the factors that influence adherence to ART amongst persons living with HIV. Narrations from the participants revealed the behavioural adherence, cognitive and other personal factors influencing adherence, treatment and self-efficacy factors and environmental influences. Some major concerns on adherence also emerged.

*Factors influencing adherence to ART among PLWHIV*

The findings showed that PLWHIV were willing to adhere to their ART. The fear of health outcomes due to non-adherence was the major reason why some of the participants adhered to the ART. They were able to recollect what was happening to them before treatment was commenced and how they felt in terms of physical appearance, well-being and their state of health which is why they want to adhere to their ART. This was affirmed by a significant majority of participants who were influenced to adhere to the ART by the fear of health outcomes if they should in any way discontinue their ART. Participants also adhered to the ART, so that people will not feel suspicious about their status. They reported that by not adhering to the ART will result in the likelihood of them growing lean and losing weight which will make it possible for their status to be known. Depression and improved physical function also influenced patients' adherence to ART. Because participants reported that the zeal to adhere to the ART is low when they are sad and feel rejected.

It was also evident in the study that treatment and self- efficacy was a very influential factor in ensuring PLWHIV adherence to ART. Most of the PLWHIV affirmed that they were motivated to take the ART because they observed that the ART was indeed working and effective. However the participants stated that complex medication regimen can affect adherence. To some degree, some participants however, perceived that there will be a cure someday.

Environmental influence emerged as one of the factors that either enhanced ART adherence or may result in non-adherence. Participants were

*Factors influencing adherence to ART among PLWHIV*

not willing to disclose their status due to the fear of stigma associated with HIV; hence they tend to hide or disguise their ART. Participants reported the lack of social support and stigma associated with adherence. The participants mentioned positive attitude of health personnel as one of the factors that influenced adherence. Participants stated that when they are actively involved in their care it enables them to adhere to the ART regimen.

### **6.3 Implications**

The findings of this study revealed some implications that require attention for nursing education, nursing practice, nursing research, and policy formulation.

#### **6.3.1 For nursing education**

The unprofessional attitude of nurses and other health professionals at the clinic was revealed as one of the factors that affected adherence. The need for this to be addressed and given the necessary attention cannot be over emphasized. The curriculum of all categories of nurses as well as other health professionals in the training institution should be upgraded and must reflect the changing health needs of society. Interpersonal communication and counselling should be well incorporated in the curriculum to enhance the knowledge and skills of nurses and other health professionals so as to enable them provide tailor made services to PLWHIV. Continuous in-service training should be organized for the nurses especially those at the counselling units in order for them to be abreast with current policies on HIV. The ethics and morals of nursing should be adequately taught in order to equip the trainee

*Factors influencing adherence to ART among PLWHIV*

nurses with the knowledge and skills of handling confidential issues about PLWHIV.

**6.3.2 For nursing practice**

The findings revealed that actively involving PLWHIV in their care and decision making process promotes health and enhances adherence to ART. The use of assessment monitoring tools is required in the clinical settings so that an objective assessment and monitoring of PLWHIV on adherence to ART can be done. The health personnel at the clinic should be educated to be able to identify PLWHIV who are at risk of defaulting and putting in measures and strategies to mitigate such occurrences. For example the use of text messaging and calling of PLWHIV to remind them of their review date will be a step in the right direction.

**6.3.3 For nursing research**

This study revealed the need for further research on adherence to ART among PLWHIV. In this study, the factors influencing adherence to ART was explored. Future research to explore the factors that influence adherence from the perspectives of the Health personnel is necessary. This will provide a rich knowledge from both side of the care giving processes. Another area of research interest is the development of adherence monitoring tools to effectively measure adherence behaviour amongst PLWHIV. This will also provide a more in depth knowledge on measures to be employed in all health institutions and ART clinic sites to ensure that adherence is measured in a fair, unbiased and objective manner within the Ghanaian context.

*Factors influencing adherence to ART among PLWHIV*

#### **6.3.4 Policy formulation**

Findings from the study revealed that there is lack of adequate tools to assess and monitor adherence of PLWHIV on ART. The need for the formulation of policies to provide guidelines on how to adhere to ART cannot be over emphasized.

#### **6.4 Limitations of the study**

The study was done only at the Ridge hospital and therefore the findings may not be generalized to other hospitals in Ghana. Because of the use of a qualitative approach for this study, a few participants were recruited to get **an in depth** description of the participants experiences. This therefore limits the generalization of the findings of the research. However transferability may be done when the context is the same for another research work.

Some participants, though assured of confidentiality, were still very cautious and wary of coming out with their experiences. As a result, there is the possibility of participants withholding some vital information for fear of stigmatization.

#### **6.5 Conclusion**

Some of the findings of this study were consistent with the constructs of the social cognitive theory. For example behavioural adherence, personal and cognitive factors, treatment and self-efficacy and environmental influences were some of the factors that influence adherence to ART amongst PLWHIV. However there were some major concerns on adherence such as spirituality on adherence and need for a monitor before ART is commenced

*Factors influencing adherence to ART among PLWHIV*

which were not consistent with the constructs of the theory. The findings revealed that PLWHIV had several factors that influence the way they adhere to the ART regimen. Factors such as confidence in ART, simple dosing, improved physical condition and functioning, positive attitude of health personnel, counselling especially from peers were indicated as important factors that influence adherence. On the other hand they revealed that depressive moods, negative attitude of health personnel, lack of social support and prophesy from pastors who claim they can cure HIV/ AIDS can result in non-adherence to ART. Consequently there is the need for continuous education of PLWHIV on the benefits of adherence to ART as well as the formulation of policy that can monitor and guide PLWHIV on adherence to ART.

## **6.6 Recommendations**

Based on the findings of the study, recommendations were made to the following bodies and institutions:

### **6.6.1 To the Ministry of health (MOH)**

The MOH should:

- Collaborate with other stake holders to ensure that simple dosing are supplied adequately to improve adherence.
- Collaborate with other stake holders to formulate policies on the rights of PLWHIV.
- Formulate policies on guidelines to taking ART to help PLWHIV continue adhering to their ART.

*Factors influencing adherence to ART among PLWHIV*

**6.6.2 To Ghana health services (GHS)**

The GHS should:

- Ensure that effective adherence assessment tools are developed and used at the clinical setting in order to assess adherence objectively.
- Replicate the model of hope concept or peers health counselling at all ART clinical sites to improve adherence to ART among PLWHIV.

**6.6.3 To the Ridge hospital**

The management of Ridge Hospital should:

- Organize continuous in-service training for nurses and other health personnel especially at the ART unit so as to be abreast with the pattern of the changing health needs and trends of PLWHIV.
- Reward nurses who exhibit good behaviour to motivate them as well as the formation of complaints unit to address grievances and complaints of clients and relatives who visit the facility.
- Ensure that the atmosphere at the clinic be made client friendly to make clients feel more relaxed and comfortable and assured of confidentiality.
- Collaborate with all the various groups that look at the welfare of the PLWHIV.

**6.6.4 To the client**

PLWHIV should:

- Make conscious effort to learn the names of the ART they are taking.

*Factors influencing adherence to ART among PLWHIV*

- Be actively involved in the decision making process so as to improve adherence.



*Factors influencing adherence to ART among PLWHIV*

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*Factors influencing adherence to ART among PLWHIV*

**Appendices**


**Appendix A: Ethical Clearance (Noguchi Memorial Institute for Medical Research – Institutional Review Board)**

**NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH**  
*established 1979* A Constituent of the College of Health Sciences  
University of Ghana

**INSTITUTIONAL REVIEW BOARD**

Phone: +233-302-916438 (Direct)  
          +233-289-522574  
Fax: +233-302-502182/513202  
E-mail: [nirb@noguchi.mimcom.org](mailto:nirb@noguchi.mimcom.org)  
Telex No: 2556 UGL GH

Post Office Box LG 581  
Legon, Accra  
Ghana



File Ref. No: DF.22  
Your Ref. No:

5<sup>th</sup> November, 2014

**ETHICAL CLEARANCE**

**FEDERALWIDE ASSURANCE FWA 00001824** **IRB 00001276**

**NMIMR-IRB CPN 025/14-15** **IORG 0000908**

On 5<sup>th</sup> November 2014, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

**TITLE OF PROTOCOL** : **Exploration into factors that influence adherence to antiretroviral therapy among persons living with HIV in Accra.**

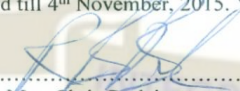
**PRINCIPAL INVESTIGATOR** : **Priscilla Cobblah, MPhil Cand.**

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 4<sup>th</sup> November, 2015. You are to submit annual reports for continuing review.

Signature of Chair: .....  
Mrs. Chris Dadzie  
(NMIMR – IRB, Chair)

cc: Professor Kwadwo Koram  
Director, Noguchi Memorial Institute  
for Medical Research, University of Ghana, Legon

*Factors influencing adherence to ART among PLWHIV*

**Appendix B: Introductory Letter**

**SCHOOL OF NURSING  
COLLEGE OF HEALTH SCIENCES  
UNIVERSITY OF GHANA  
LEGON**

Telephone: 021-513255 (Dean)  
Ext. 6206  
021-513250 } Secretary  
028 9531213 }

Fax: 513255  
E-mail: [nursing@ug.edu.gh](mailto:nursing@ug.edu.gh)

Our Ref: SON /F11  
Your Ref: .....

P. O. Box LG 43  
LEGON, GHANA

November 20, 2015

The DDNS  
Ridge Regional Hospital  
Accra.

Dear Madam,

**INTRODUCTORY LETTER**

I write to introduce to you Priscilla Cobblah, an M.Phil student of the University of Ghana, School of Nursing. She is seeking your permission to collect data for her research on the topic **“Factors Influencing Adherence to ART among PLWHIV in Accra.”**

I would be grateful if you could kindly assist her with the information that she may require for her thesis.

Thank you.

Yours faithfully,



Dr. Florence Naab  
SUPERVISOR

**INTEGRI PROCEDAMUS**

*Factors influencing adherence to ART among PLWHIV*

**Appendix C: Information Sheet**

**TITLE OF STUDY: FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY (ART) AMONG PERSONS LIVING WITH HIV (PLWHIV) IN ACCRA METROPOLIS.**

**NAME OF PRINCIPAL INVESTIGATOR: PRISCILLA COBBLAH**

**ADDRESS: P.O. BOX 1617 OSU, ACCRA**

**TELEPHONE NUMBER: 0244265449**

**EMAIL: awuradede1@gmail.com**

**Dear Participant,**

My name is Priscilla Cobblah, an Mphil student of University of Ghana, Legon. The study forms part of the requirement for my Master of Philosophy in nursing degree at the University of Ghana Legon.

You are invited to participate in a research that is intended to explore the views and opinion of PLWHIV on the factors that influence adherence to ART. I would want to know the factors that influence your adherence to the ART regime and the strategies that health personal can employ to improve adherence to the ART. This would help inform health care providers of the Ghana health Service adopt strategies to be implemented to improve on adherence to ART among PLWHIV.

If you agree to be part of this study, you will be asked a few questions about the factors that influence your adherence to your ART. The interview will last for between 30 to 45 minute, which will be conducted at a decent place and time that will be convenient for you. There will be no cost to you

*Factors influencing adherence to ART among PLWHIV*

because the researcher will travel and bear the cost. The interview would be audio taped. I therefore ask your permission for the interview to be recorded.

Your participation will be required between periods of November 2014 to April 2015. Some of the question that may be asked during the interview may make you feel uncomfortable and emotionally disturbed. Should this happen, you would be assisted through counselling and referral to appropriate counsellor specialized in dealing with matters of this nature so that you will be able to effectively deal with such feelings or you have the right to refuse answering such questions. You also have the right to end the interview at any point in time or to withdraw from this interview. You will not be punished for withdrawing from this research neither would any services be withheld from you.

The information collected from you will be stored on the computer with a password on it and will not be accessible to others. The audiotape and other documents will be protected and kept for a period of five years. There may be no direct benefit to you as a participant. However the information you share would assist nurses, doctors and other health personnel to plan better care that would support you take your medication well. You would be given snack and handkerchief for your time spent during the interview.

You are assured of anonymity because you will be assigned a number and false names as well. I will not disclose any information to anyone except my supervisors. Again you are assured of confidentiality because the information you give to me would not be disclosed to your health care provider.

*Factors influencing adherence to ART among PLWHIV*

The research findings would be made available to the Graduate School, Noguchi, the management of Ridge Regional Hospital, Ghana Health Service and the Ministry of Health. This will help the hospital to adopt and implement appropriate strategies to improve on adherence to ART among PLWHIV. Findings will also be presented during seminar presentation at School of Nursing, University Of Ghana Legon. Last but not the least the findings will also be published to get the public informed.

**PARTICIPANT DECLARATION**

**“I have had the opportunity to ask questions about the Research work and any question I have asked have been answered to my satisfactions. I consent voluntarily to participate as a participant in this study and understand that I have the right to redraw from the study at any time without it affecting health care services provided to me.”**

**Date**

**Signature / Thumb print**

.....

.....

**IN CASE OF ANSWERS TO PERTINENT QUESTIONS ABOUT THE RESEARCH, CONTACT THE FOLLOWING PERSONS**

**Principal Investigator:** Priscilla Cobblah

School of Nursing,

College of Health Sciences,

*Factors influencing adherence to ART among PLWHIV*

University Of Ghana, Legon

Telephone: 0244265449

Email: awuradede1@gmail.com

**Supervisors:** Dr. Florence Naab, PhD, MPhil, BA, RM, SRN

Department of Maternal and Child Health

School of Nursing,

College of Health Science,

Post Office Box LG43,

University of Ghana, Legon

Telephone: 0204522332

Email: florencenaab@yahoo.com

**Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB): If you have any questions, about your rights as a research participant you can contact IRB Office between the hours of 8am-5pm through the landline 0302916438 or email address: [nirb@noguchi.mimcom.org](mailto:nirb@noguchi.mimcom.org)**

*Factors influencing adherence to ART among PLWHIV*

**Appendix D: Consent Form**

**Consent Form**

**Protocol Title:** Exploration into factors influencing adherence to antiretroviral treatment among PLWHIV in Accra.

**Principal Investigator:** [Priscilla Cobblah]

**Address:** School of Nursing, College of Health Sciences, University of Ghana, Legon

**General Information about Research**

The importance of taking medications rightly as prescribed cannot be over emphasized. However, sometimes remembering to take medication could be very challenging and others miss follow-up date. This study seeks to explore the factors that influences adherence to ART as well as measures that can be implemented to improve adherence to ART. When you agree to be part of this study, you will be invited for an interview lasting for forty-five (45) to ninety (90) minutes the researcher would discuss with you when it is convenient for you to meet; the time and the place you prefer to meet. You would be expected to answer some questions in an interview which will be audio taped. You are free to choose to answer only questions about things you are ready to share.

**Possible Risks and Discomforts**

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 free counselling and referral to appropriate counsellors specialized in dealing with matters of this nature so that you will be able to effectively

1



***Factors influencing adherence to ART among PLWHIV***

deal with such feelings. The counselor will be Miss MaameYaaKwakye at the Ridge Hospital ART unit.

**Possible Benefits**

There are no direct benefits to you as a participant. However the information you share would assist nurses, doctors and other health service providers to plan better care for other people living with HIV.

**Confidentiality**

The information you provide would be protected. The information on the consent form will be separated from the data collected so that it will be impossible for anyone to link your name to the information provided. You are assured that neither your name nor initials or anything that could be used to trace you would be mentioned to others who are not directly working with the research team.

**Compensation**

There is no financial benefit if you participate in this study. However snacks will be given to you and a handkerchief for your time spent during the interview.

**Voluntary Participation and Right to Leave the Research**

You are free to withdraw from the study at any time and this will not affect the treatment and care you receive at the facility.

**Contacts for Additional Information**

2



***Factors influencing adherence to ART among PLWHIV***

Priscilla Cobblah

School of Nursing

College of Health Sciences

University of Ghana

Legon

Email: [awuradede1@gmail.com](mailto:awuradede1@gmail.com)

Tel: 0244265449

Dr. Florence Naab; PHD,

Maternal and Child Health;

School of Nursing, University of Ghana

Phone Number: 0204522332

Email: [florencenaab@yahoo.com](mailto:florencenaab@yahoo.com) or [fnaab@ug.edu.gh](mailto:fnaab@ug.edu.gh)

**Your rights as a Participant**

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: [nirb@noguchi.mimcom.org](mailto:nirb@noguchi.mimcom.org)



***Factors influencing adherence to ART among PLWHIV***

**VOLUNTEER AGREEMENT**

The above document describing the benefits, risks and procedures for the research title *(exploration into factors influencing adherence to antiretroviral therapy among PLWHIV in Accra, Ghana)* has been read and explained to me. I have been given an opportunity to ask any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

\_\_\_\_\_  
Date Name and signature or mark of volunteer

**If volunteers cannot read the form themselves, a witness must sign here:**

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

\_\_\_\_\_  
Date Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual

4



*Factors influencing adherence to ART among PLWHIV*

**Appendix E: Interview guide**

You are invited to take part in a study to explore the factors influencing adherence to ART amongst persons living with HIV. This will help me understand what you think about the disease, some of the difficult situations you go through in adhering to your medication as a result of the disease as well some of the things that can be done to improve adherence to medication. The interview is expected to last for forty five (45) to ninety (90) minutes and it will be audio tape recorded. Thank you.

**SECTION A: Demographic Data**

1. Please tell me about yourself?
2. How old are you?
3. What is your marital status?
4. What is your level of education?

**SECTION B: Guiding questions**

**Cognitive and other personal factors influencing adherence to ART**

1. Tell me about your experience living with HIV
2. How long have you lived with the disease?
3. What makes you take your medication? Tell me about some of the things you do so you will always remember to take your medicine
4. What are some of the things that makes it difficult for you to remember to take the medicine on time

*Factors influencing adherence to ART among PLWHIV*

**Behavioural adherence to ART**

1. What treatment are you on at the moment?
2. How often are you expected to take your medications
3. Tell me about some of the instructions about taking your medication
4. Tell me about how you deal with issues such as remembering to take the medicine on time
5. Some people complain about how the medicine makes them feel tell me about your own experience of taking the medicine

**Treatment efficacy**

1. What do you think about your medication regimen?
2. Do you think your medication is working?
3. Are there any side effects of your medication?

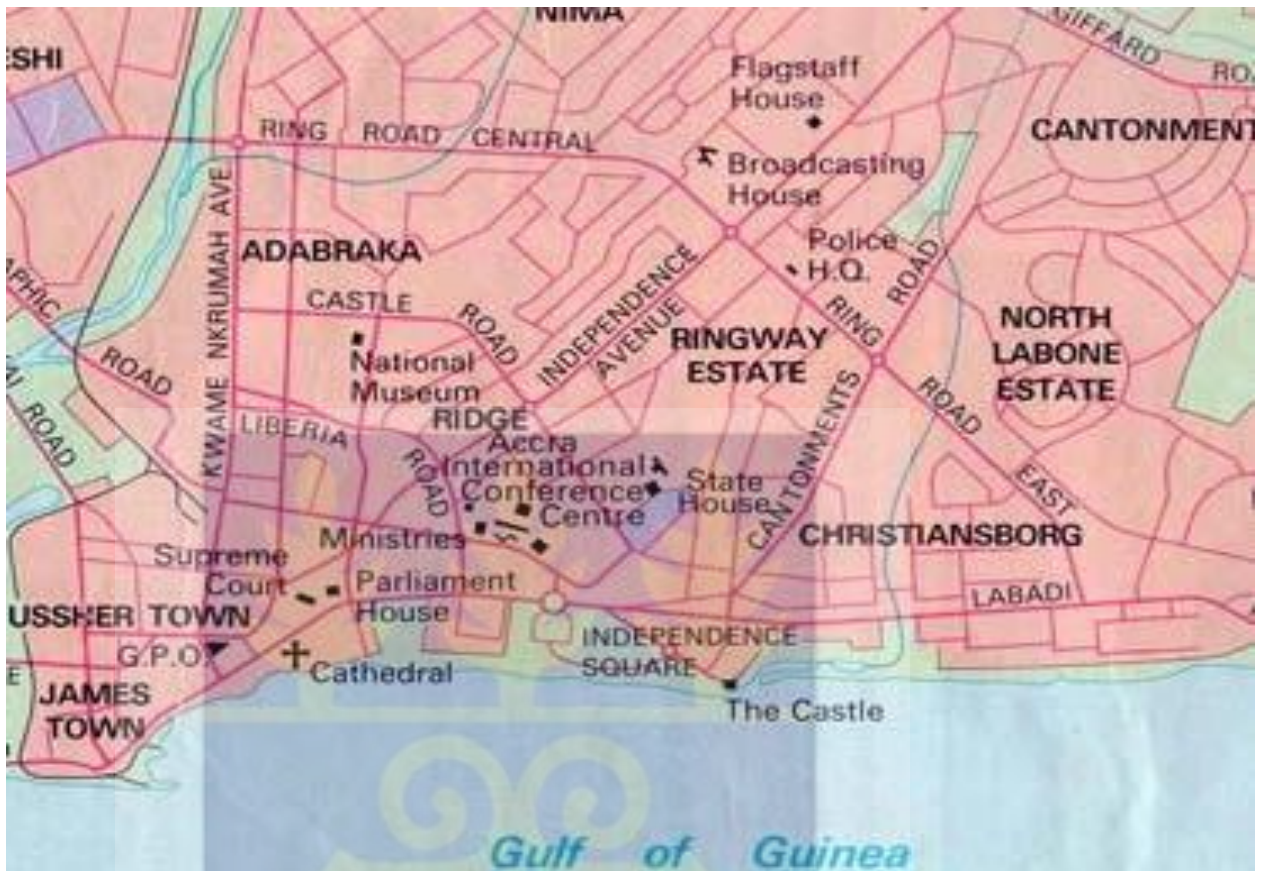
**Environmental influences affecting adherence.**

1. How has your informing a member of your family or spouse helped you to continue taking your medicine
2. Tell me about some of the things that happen at the hospital that has helped you to continue taking the drugs
3. How has your association with those living with the illness or other support groups assisted you in taking your medication?
4. Do you have anything more to add to what you have said so far?
5. Do you have any questions for me?

**Thank you**

*Factors influencing adherence to ART among PLWHIV*

**Appendix F: Map of greater Accra**



*Factors influencing adherence to ART among PLWHIV***Appendix G: Budget and Budget Justification**

Activities	Cost in Ghana Cedis	Justification
Stationaries	400.00	Typing, printing, photocopy and binding of researching documents
Transportation	50.00	Fuel to site
Local Running	600.00	For local running for data collection.
Data Analysis	400.00	Payment for data Analysis using SPSS
Miscellaneous	200.00	For any contingency during the research.
<b>TOTAL</b>	<b>1650.00</b>	



*Factors influencing adherence to ART among PLWHIV*

**Appendix H: Summary of Demographic Characteristics of Participants'**

**Table 1: Concise Summary of Demographic Characteristics of participants**

<b>Participant Name</b>	<b>001/ 2014</b>	<b>002/ 2014</b>	<b>003/ 2014</b>	<b>004/ 2014</b>	<b>005 /2015</b>	<b>006/ 2015</b>	<b>007/ 2015</b>	<b>008/ 2015</b>	<b>009/ 2015</b>	<b>010/ 2015</b>	<b>011/ 2015</b>	<b>012/ 2015</b>	<b>013/ 2015</b>	<b>014/ 2015</b>
<b>Pseudonym</b>	Mame Adwoa	Mr. Kay	Ayerki	Nana	Araba	Yaa	Nii	Cece	Lamiley	Eben	Alima	Jay	Felicia	Adez
<b>Ages (years)</b>	25	39	35	40	33	34	40	40	45	47	35	30	40	37
<b>Educational level</b>	JHS	Form 4	SHS	Class 4	SHS	JHS	JHS	Graduate	JHS	Form 4	SHS	SHS	Class 4	JHS
<b>Occupation</b>	Trader	Spare Driver	House-help	Architect	Trader	Trader	Tailor	Secretary	Trader	Unemployed	Trader	Self-employed	Trader	Trader
<b>Ethnicity</b>	Ewe	Akan	Akan	Akan	Akan	Akan	Ga	Akan	Ga	Akan	Hausa	Akan	Akan	Akan
<b>Religion</b>	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Muslim	Christian	Christian	Christian

*Factors influencing adherence to ART among PLWHIV*

<b>Marital Status</b>	Married	Co-habitat-e	Single	Married	Co-habitat-e	Single	Single	Married	Married	Married	Wido-w	Single	Divorc-ed	Marrie-d
<b>Number of children</b>	4	None	None	2	2	1	1	None	2	4	2	1	1	2
<b>Duration of illness (years)</b>	2	4	5	6	5	4	5	4	6	3	6	4	8	7
<b>Diagnosi-s</b>	A.N.C.	Hospit-al	Hospit-al	Hospit-al	Hospit-al	A.N.C.	Hospit-al	Health Screening	A.N.C.	Hospital	A.N.C	Hospital	A.N.C	A.N.C.
<b>Partner's status</b>	Negativ-e	Positive	N/A	Positive	Negati-ve	N/A	N/A	Negativ-e	Positive	Unknown	Negati-ve	N/A	Negati-ve	Negati-ve



*Factors influencing adherence to ART among PLWHIV***Appendix I: Thematic Codes and Description****Table 2: Description of Themes and Subthemes**

Themes and subthemes		Codes	Description
<b>1.</b>	<b>Behavioural adherence</b>	bea	The attitude of the PLWHIV towards the ART regimen.
	<b>i. Fear of health outcomes</b>	foh	The fear of negative health implication when PLWHIV do not adhere to their ART.
	<b>ii. Avoidance of suspicions</b>	aos	This is the possible fear of people wanting to know what is wrong with PLWHIV.
	<b>iii. Avoidance of reprimandment</b>	aor	The fear of being talked to in a harsh or inappropriate manner because of non-adherence to ART
<b>2.</b>	<b>cognitive and other personal factors</b>	cop	This deals with whether the individual has self-positive attitude towards adherence to ART.
	<b>i. Depressive mood</b>	dem	Depression is a feeling of sadness and rejection. In this study most of the participants reported that they have gone through some form of depression during the course of treatment.
	<b>ii. Physical function</b>	phf	What PLWHIV were capable of doing physically in terms of when they were not on ART

*Factors influencing adherence to ART among PLWHIV*


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			and when treatment began.
<b>3.</b>	<b>Treatment and self-efficacy</b>	tse	The difficulty that the PLWHIV believe that they can surmount to adhere to a treatment regimen.
<b>i.</b>	<b>Treatment efficacy</b>	tef	The effectiveness of the ART.
<b>ii.</b>	<b>Self-efficacy</b>	sef	Treatment and self-efficacy describes the willingness of the individual to continue to adhere to the medication regimen.
<b>iii.</b>	<b>Time consciousness</b>	tic	The ability of the individuals to be conscious about the time to take ART.
<b>iv.</b>	<b>Confidence in ART</b>	cia	This described whether patients believed that the ART was working for them.
<b>4.</b>	<b>Environmental influences on adherence</b>	eia	This is the environmental settings that influenced the participants' ability to successfully adhere to their ART.
<b>i.</b>	<b>Status Disclosure</b>	std	The tendency of PLWHIV to tell others about their positive status.
<b>ii.</b>	<b>Attitude of Health personnel</b>	ahp	The feelings, actions and thoughts of health personnel towards PLWHIV.

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*Factors influencing adherence to ART among PLWHIV*

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<b>iii.</b>	<b>Hiding and disguising</b>	had	Prevention from being discovered or making their ART unrecognizable.
<b>iv.</b>	<b>Social support</b>	sos	Provision of moral or psychological support, aid, or courage to PLWHIV by other people.
<b>1.</b>	<b>Major adherence concern</b>	mac	Important issue on adherence
<b>i.</b>	<b>Adherence and spirituality</b>	aas	Religious influence on adherence to ART
<b>ii.</b>	<b>Need for a monitor</b>	nfm	Provision of another person as a reminder to help the PLWHIV adhere to ART.

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