

**A BEST-PRACTICE GUIDELINE FOR FACILITATING ADHERENCE  
TO ANTI-RETROVIRAL THERAPY FOR PERSONS ATTENDING  
PUBLIC HOSPITALS IN GHANA**

by

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## DECLARATION

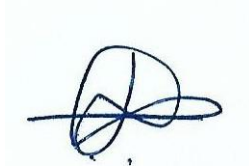
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In accordance with Rule G4.6.3, I hereby declare that the above-mentioned thesis is my own work and that it has not previously been submitted for assessment to another University or for another qualification.

A handwritten signature in blue ink, appearing to be 'Joana Agyeman-Yeboah', enclosed in a light blue rectangular box.

JOANA AGYEMAN-YEBOAH

**Date:** April 2017

Port Elizabeth

## **DEDICATION**

To God be the glory great things he has done. I dedicate this work to my beloved husband, Patrick Agyeman-Yeboah who has supported me and has been a great pillar in my life. I also dedicate it to my dear daughter, Grace Agyeman-Yeboah.

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## ABSTRACT

The retention of persons on an HIV programme has been a global challenge. The success of any strategy to optimize adherence to anti-retroviral therapy (ART) depends on the intensive and effective adherence counselling and strategies. It is important to research whether persons receiving anti-retroviral therapy in public hospitals in Ghana are receiving the needed service that would optimize their adherence to the anti-retroviral therapy. Therefore, this study explored and described the experiences of healthcare professionals providing care, support and guidance to persons on ART at public hospitals in Ghana, as well as the best-practice guideline that could contribute to facilitating the ART adherence of patients. This study also explored and described the experiences of persons living with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) on ART, regarding their adherence to the therapy.

The study was organized into three phases. In Phase One: a qualitative, exploratory, descriptive and contextual design was employed. The research population included healthcare professionals, providing services at the HIV clinic at the public hospitals in Ghana, namely the Korle-Bu Teaching Hospital; the 37 Military Hospital and the Ridge Hospital. The healthcare professionals comprised of doctors, nurses, pharmacists and trained counsellors employed in any of the three public hospitals. Persons receiving ART at any of the three public hospitals were also part of the research population. Semi-structured interviews were conducted with healthcare professionals and persons receiving ART.

Data were collected from healthcare professionals in relation to their experiences regarding the provision of ART services, their understanding of evidence-based practice and best-practice guidelines, as well as data on the experiences of persons receiving ART in relation to their adherence to the therapy. The data were analysed using Creswell's six steps of data analysis; and the coding of the data was done according to Tesch's eight steps of coding. Trustworthiness was ensured by using Lincoln and Guba's framework which comprised credibility, transferability, dependability, confirmability and authenticity. Ethical principles such as beneficence and non-maleficence, respect for human dignity, justice, veracity, privacy and confidentiality were considered in the study.

In phase two, the literature was searched by using an integrative literature review approach and critically appraising the methodological quality of the guidelines in order to identify the best available evidence related to adherence to ART. In Phase Three, a best-practice guideline for facilitating adherence to ART was developed for public hospitals in Ghana based on the findings of the empirical research of Phase One and the integrative literature review in Phase Two. The guideline was submitted to an expert panel for review; and it was modified, according to the recommendations of the panel.

### **KEY WORDS**

Evidence-based practice, best-practice guideline, adherence, anti-retroviral therapy, HIV/AIDS, Healthcare professional

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## LIST OF ACRONYMS AND ABBREVIATIONS

|                |   |
|----------------|---|
| <b>AGREE</b>   | - Appraisal of Guidelines for Research and Evaluation           |
| <b>AIDS</b>    | - Acquired Immunodeficiency Syndrome                            |
| <b>ART</b>     | - Anti-retroviral therapy                                       |
| <b>BASHH</b>   | - British Association for Sexual Health and HIV                 |
| <b>BHIVA</b>   | - British HIV Association                                       |
| <b>BPG</b>     | - Best-Practice Guideline                                       |
| <b>CD4</b>     | - <i>Cluster of Differentiation 4</i>                           |
| <b>DACP</b>    | - Department of AIDS Control Programme                          |
| <b>DNA</b>     | - Deoxyribonucleic Acid   |
| <b>EBP</b>     | - Evidence-Based Practice                                       |
| <b>GHS</b>     | - Ghana Health Service  |
| <b>GOI</b>     | - Government of India   |
| <b>HIV</b>     | - Human-Immunodeficiency Virus                                  |
| <b>HSS</b>     | - Health and Human Service                                      |
| <b>IAPAC</b>   | - International Association of Physicians in AIDS Care          |
| <b>IRB</b>     | - Institutional Review Board                                    |
| <b>KBTH</b>    | - Korle-Bu Teaching Hospital                                    |
| <b>MEMS</b>    | - Medication Event Monitoring Systems                           |
| <b>MOHFW</b>   | - Ministry of Health and Family Welfare                         |
| <b>MOHSSL</b>  | - Ministry of Health and Sanitation in Sierra Leone             |
| <b>NACP</b>    | - National AIDS Control Programme                               |
| <b>NICE</b>    | - National Institute of Clinical Excellence                     |
| <b>NMMU</b>    | - Nelson Mandela Metropolitan University                        |
| <b>PAGAA</b>   | - Panel on Anti-retroviral Guideline for Adults and Adolescents |
| <b>PLHIV/A</b> | - Persons Living with HIV/AIDS                                  |
| <b>RNA</b>     | - Ribonucleic Acid  |
| <b>STI</b>     | - Sexually Transmitted Infections                               |
| <b>TB</b>      | - Tuberculosis  |

- UNAIDS** - Joint United Nations Programme on HIV/AIDS
- WHO** - World Health Organization

## CHAPTER ONE

### OVERVIEW OF THE STUDY

#### 1.1 INTRODUCTION

Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) is an epidemic that is a serious public health concern; because the number of people infected is steadily increasing. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2013:4; UNAIDS, 2014:8), in 2009 there were approximately 31.3 million people living with HIV/AIDS globally. By the end of 2014, there were 36.9 million people estimated to be living with HIV; and approximately 1.2 million people died from HIV-related diseases in the same year.

Although the burden of the epidemic varies considerably between countries and regions, Sub-Saharan Africa remains the most severely affected area with an estimated 25.8 million people living with HIV in 2014. Nearly one in every twenty adults is living with HIV globally (UNAIDS, 2014:18; UNAIDS, 2014:26). HIV/AIDS is a major socio-economic and developmental problem – not only in Ghana but also in other parts of the world, particularly in Sub-Saharan Africa (Ghana Prisons Service, 2011:1). The first HIV case in Ghana was reported in March 1986. The estimated adult annual HIV prevalence in Ghana in 2014 was 1.5%; and persons living with HIV/AIDS were estimated to be 250,000, of which 230,000 were adults (Ghana AIDS Commission, 2012:1; UNAIDS, 2014:1).

Since then, however, the HIV infection in the country has become endemic and has been classified as a general epidemic in Ghana. This is based on the definition of a generalized epidemic by the World Health Organization, where a prevalence of more than 1% qualifies as an epidemic (Ghana AIDS Commission Report, 2012:21).

HIV/AIDS has been accepted globally as a chronic disease which, although not curable, can be successfully managed with anti-retroviral therapy (ART) (Colvin, 2011:1). Chronic diseases “have one or more of the following characteristics: They are permanent; they leave a residual disability; they are caused by an irreversible pathological alteration; they require special training of the patients for rehabilitation; or they may require a long period of supervision and observation of care” (WHO, 2003:4).

Eventually, every one infected with HIV will need treatment (UNAIDS, 2013:47) hence ART was introduced to help manage an incurable chronic disease and to prolong the lives of persons living with HIV/AIDS (PLHIV/A). The scaling up of anti-retroviral therapy has led to the transformation of national AIDS responses; and this has also resulted in broad-based health gains (UNAIDS, 2012:11; UNAIDS, 2013:18). The WHO recommends that ART should be initiated for all people living with HIV regardless of their WHO clinical stage and at any Cluster of Differentiation 4 (CD4) cell count (WHO, 2016:74).

The CD4 is a type of T-cell (T-Lymphocyte) assessment; it is a white blood cell that plays an important role in the human immune system. The CD4 cells send signals to activate the body's immune response as soon as they detect the presence of a "threat" such as a virus or bacteria (Carter & Hughson, 2014:1). HIV attacks and destroys the CD4 cells; and the virus uses the mechanism of the CD4 cells to make copies of itself and spread these copies throughout the body. A CD4 count is a laboratory test that measures the number of CD4 cells in a sample of blood. A normal CD4 count in a healthy HIV negative adult is between 500 and 1500 cells/mm<sup>3</sup> (Carter & Hughson, 2014:1). It may be expected that people with a CD4 cell count of less than 350 cells/mm<sup>3</sup> would die within two years – unless they can receive anti-retroviral therapy promptly (UNAIDS, 2012:50).

Anti-retroviral therapy was first made available in the public health sector in Ghana in June 2003. The number of treatment sites has steadily increased from two to over 175 (National HIV/AIDS/ STI Control Programme; Ministry of Health/Ghana Health Service, 2010:14). ART improves the wellbeing of the person; and it allows them to live out a practically normal lifespan. The ART not only improves the quality of life; it also reduces the number of AIDS-related deaths. Since the first international treatment target was set in 2003, annual AIDS-related deaths have decreased by 43%. In the world's most affected region, eastern and southern Africa, AIDS-related deaths have decreased by 36% since 2010 (WHO, 2016:1). ART is now known to prevent HIV transmission by reducing the potential for such transmission. This is because it reduces the viral load and, subsequently, it mostly increases the CD4 cell count and reduces the tendency for the HIV to be passed on to an uninfected sexual partner (UNAIDS, 2013:6, 56).

ART requires distinctive strategies to ensure that its effectiveness prevents the development of drug resistance (UNAIDS, 2012:33, 47). One such strategy is enshrined in the guidelines for anti-retroviral therapy in Ghana. This guideline was developed by the Ghana Health Service, together with financial and technical support from the World Health Organization, the Family Health International, and the Ministry of Health.

The strategy is as follows (Ghana Health Service, 2010:14):

- Capacity building; strengthening the health system to improve logistics management; the improvement of pharmaceutical and laboratory services, as well as the provision of quality of care.
- Rational selection and sequencing of the drug regimen.
- Maximising adherence to the selected regimen.
- Preservation of further treatment options.
- Use of drug-resistance testing in selected clinical settings.

The provision of comprehensive HIV care and the administering of ART aim at attaining the following goals (National HIV/AIDS/STI Control Programme; Ministry of Health/Ghana Health Service, 2010: 17):

- The suppression of HIV replication, as reflected in the plasma HIV concentration, to as low as possible, and for as long as possible.
- The preservation or enhancement of the immune function (CD4 restoration), thereby preventing or delaying the clinical progression of the HIV disease.
- Improvement in the quality of life.
- Reduction in HIV-related morbidity and mortality.
- Promotion of growth and the neurological development in children.

The above treatment goals cannot be fully achieved if the person infected with HIV does not adhere to the prescribed treatment regimen. There is an urgent need to ensure that the people enrolled in ART care and treatments are retained in the treatment programme. According to the UNAIDS report on the global AIDS epidemic, nearly half of all people who initiated anti-retroviral therapy at the same treatment centre in Malawi were no longer in care five years later; and this proportion is nearly

40% in Kenya (UNAIDS, 2012: 54). Similar studies conducted on the predictors of adherence to ART among HIV/AIDS patients in the upper West region of Ghana revealed that non-adherence to ART increased the risk of immunological failure and regular follow-up was positively associated with the patient's adherence to ART. It was concluded that maximal levels of adherence to ART are required, in order to achieve an effective ART intervention. Effective counselling sessions on adherence for patients on ART are imperative in order to realise the success of the ART programmes in Ghana (Obirikorang, Selleh, Abledu & Fofie, 2013:873).

UNAIDS has introduced the 90-90-90 target, as a means of stepping up HIV treatment. Consequently, 90% of people living with HIV must know their HIV status. Ninety percent of people living with HIV who know their status, must be enrolled on anti-retroviral treatment, and 90% of people on treatment are expected to have suppressed viral loads (UNAIDS, 2014:1). The success of the 90-90-90 target largely depends on strict adherence to the ART programme. Adherence to the programme has been defined in the guidelines for ART in Ghana, as taking one's medication exactly as prescribed. Thus, this implies the right dose at the right time and under the right conditions.

It also states that missing one single dose can lead to the development of resistant strains of the virus, and reduce the effectiveness of the treatment. Strategies to overcome the problem of non-adherence were outlined and include the use of a drug timetable, adherence monitors, pillboxes and adherence counselling (Ghana Health Service, 2010:62).

Ohene, Addo, Zigah, Newman, Lartey, Romere, Ofori, Sheriff and Ndanu (2013:1937) reported from their study in Ghana that out of the 683 participants over half (350) were said to have defaulted on a clinic appointment. One hundred and forty-six participants, which constituted 21.4%, were reported to have missed treatment doses. A cross-sectional retrospective chart review of 290 HIV-infected patients who initiated highly active ART at Korle-Bu teaching hospital in Ghana, revealed that as many as 14% of the total participants defaulted on their treatment. The above-mentioned study concluded that standardized treatment adherence counselling sessions were necessary for ensuring a favourable treatment outcome (Wilhelm, Paci, Lartey & Kwara, 2012:264).

The need for substantially greater success in closing gaps in the treatment continuum is amongst the strategies adopted by UNAIDS to maximize the therapeutic and preventive benefits of treatment. This could be done by ensuring that people living with HIV are diagnosed early in the course of infection – via testing services that are simple and easy to implement. Those who test positive must be linked to care that can be easily accessed and swiftly evaluated. ART must be initiated in a timely manner. People must be retained in treatment programmes and individuals must receive support in adhering to the prescribed regimen. The last step in the strategies adopted by UNAIDS comprises measures to ensure that individuals who initiate ART are retained in their treatment programmes (UNAIDS, 2012:56).

Healthcare professionals play a key role in the adherence to ART by PLHIV/A. A study that investigated whether healthcare professionals could improve the adherence to ART in the USA reported that a healthcare professional's contact over a period of time was associated with improvement in ART adherence. The frequency of contact with healthcare professionals put the client in a better position to understand fully the need for adherence (Kenya, Chida, Symes & Shor-Posner, 2011:527). Similarly, the institution of adherence counselling covering the benefits of ART and the dangers of defaulting were among the concerns highlighted by the healthcare professionals to improve adherence to ART. This was according to Boateng, Kwapong and Agyei-Baffour (2013:4) reporting in their study on the knowledge and perceptions of ART, the prevention of mother-to-child transmission, and the adherence to ART in HIV-positive women.

A significant factor that contributes to adherence to ART is the patient-provider challenge. The challenges include: poor relationships and conflict with healthcare professionals, lack of confidentiality, poor treatment by hospital staff and language barriers that prevented patients from understanding specific instructions given regarding ART. These were among the findings on barriers to anti-retroviral therapy adherence in rural Mozambique (Groh, Audet, Baptista, Sidat, Vergara, Vermund & Moon, 2011:3-4).

The trust that the patient has in the healthcare professional and the guidance they provide to the patients has been found to facilitate this adherence (Wasti, Simkhada, Randall, Freeman & Teijlingen, 2012:414). This guidance is provided by the healthcare



professional in the form of counselling. The success of any adherence strategy is founded on the education of the patient before the ART is initiated. This provides the client with basic information on HIV and the ART, the need for the therapy and the importance of adhering strictly to the prescribed regimen as well as an opportunity to assess the client's readiness to commence treatment (WHO, 2006:70). It is therefore imperative for the patient on ART to understand fully the importance of adherence to the therapy.

There is documented evidence that patients who are knowledgeable about the potency of ART associated with its viral resistance and the treatment failures associated with poor adherence have a greater ability to adhere to their medications (Hardon, Davey, Gerrits, Hodgkin, Trunde, Kgatlwane, Kinsman, Nakiyemba & Laing, 2006:126; Watt, 2007:92). It is clear that a high level of ART adherence is necessary to suppress viral replication, and to improve the immunological and clinical outcomes, in order to decrease the risk of developing anti-retroviral drug resistance. Furthermore, this reduces the risk of transmitting HIV to others (WHO, 2013:6, 56).

It is important that the provision of care to persons on ART, based on evidence, be implemented in order to facilitate their adherence to the treatment. This is referred to as evidence-based practice (EBP). Evidence-based practice is practice that is supported by clear reasoning, taking into account the patient's preference, and using the healthcare professional's own judgment (Aveyard & Sharp, 2013:6). It can be conceptualized as clinical decision-making that considers the best available evidence including the context in which the care is delivered, the client's preference and the professional judgement of the healthcare professional. Using this information, healthcare professionals are in a position to make evidence-based decisions (Pearson, Jordan & Munn, 2012:2). Such EBP "integrates the best research evidence, the healthcare resources, the patient's preference and action, clinical settings and circumstances – in addition to the clinician's judgment with regard to clinical decision-making" (Dicenso, Guyatt & Ciliska, 2005:4-5).

Evidence-based practice is viewed as a rational approach to providing the best possible care, with the most cost-effective use of the resources available. Professional practice needs to be based on evidence that is based on practice; because it enables the delivery of the best possible patient care, rather than relying on outdated practices

(Polit & Beck, 2012:27). Nursing, which focuses on evidence-based practice and the use of the best research evidence, has the potential to promote the linking of theory, research and practice. Issues relevant to clinical decision-making are best addressed from best-practice guidelines (BPGs) (Chinn & Kramer, 2011:230).

Best-practice guidelines represent the effort needed to develop essential meaning, or ideas from a large body of evidence, into a manageable form. They are usually based on systematic reviews, provide specific recommendations for evidence-based decision-making and are developed to guide clinical practice. The development of best-practice guidelines typically involves the consensus of a group of researchers, experts and clinicians (Polit & Beck, 2012:31).

This research seeks to develop a best-practice guideline for facilitating adherence to ART by persons attending public hospitals in Ghana. It will explore the experiences of healthcare professionals in the provision of care, support and guidance to persons receiving ART, as well as the lived experiences of persons receiving ART at public hospitals in Ghana on their adherence to the therapy.

## **1.2 THE PROBLEM STATEMENT**

The data on clients receiving anti-retroviral therapy in public hospitals in Ghana reveals that they do not adhere strictly to their treatment. The most common cause of ART failure is poor adherence. The optimal suppression of HIV would require about 90-95% level of adherence to ART. Lesser degrees of adherence are often associated with virological failure (National AIDS Control Organization, 2013:64). The table below shows the statistics and evidence of non-adherence to ART over a period of 5 years by persons receiving ART from 37 Military Hospital, one of the public hospitals in Ghana.

**Table 1.1: Cumulative numbers of clients on ART and clients' failure to follow up, receiving ART in 37 Military hospital from 2009-2013**

| Year | Cumulative number on ART | Number of new persons on ART | Persons lost to follow up |
|------|--------------------------|------------------------------|---------------------------|
| 2009 | 326                      | 124                          | 46                        |
| 2010 | 428                      | 144                          | 55                        |
| 2011 | 525                      | 160                          | 55                        |
| 2012 | 677                      | 152                          | 90                        |
| 2013 | 793                      | 147                          | 114                       |

Source: Ghana National AIDS/STI control programme, ART Statistical Report: 37 Military Hospital (Raw data: unpublished)

Table 1.1 (above) indicates that there is an obvious increase in the number of clients enrolled in the ART each year; and this is evidenced in the cumulative numbers of clients on ART, as well as the number of new clients on ART over the five-year period. In 2009, 326 clients were on the ART. This number increased to 428 in 2010 and to 793 in 2013. The number of clients lost to follow-up was 46 in 2009, and this increased to 114 in 2013. Those lost to follow-up would imply that they had defaulted in their treatment and hence they are no longer adhering to their prescribed ART.

The researcher identified a gap concerning the adherence counselling that the clients receive on the ART both before and after the initiation of the ART. The guidelines for anti-retroviral therapy by the Ghana Health Service are those used by the healthcare professionals during the adherence counselling sessions before and after the commencement of ART in public hospitals in Ghana. Specifically, the patient is expected to understand the goal of the therapy, the fact that ART is not a cure and that the virus can still be transmitted while on ART. Preventive measures should still be implemented and the importance of good nutrition and adherence to the ART programme should be emphasized (Ghana Health Service, 2010:43).

The main strategies on adherence counselling are broadly stated above. The explanation of the detailed point is given by the healthcare professional based on his or her understanding and experience. To ensure the standardization and quality of care of PLHIV/A, there are many guidelines and policies in place, but there is no national guideline on facilitating adherence to anti-retroviral therapy in Ghana. The information that the clients receive on how to take their medication, how to adhere to

the therapy, the importance of adhering to the therapy, the side-effects of the medications and how to overcome the challenges that impede adherence is provided verbally by the healthcare professional during the adherence counselling.

This implies that when the client forgets an instruction given during the adherence counselling session, he or she has to wait for another counselling session, or visit the ART clinic for a reminder on the needed information; hence he or she is likely not to adhere to the treatment.

The success of adherence to ART depends on the quality of the information provided by the healthcare provider both before and after the initiation of the ART to the person living with the HIV/AIDS. There is the need to conduct research into adherence to ART, in order to explore and describe the experiences of healthcare professionals providing care, support and guidance to persons on ART, and on the experiences of persons receiving ART regarding their adherence to the therapy at public hospitals in Ghana. It is also important to explore, describe, appraise, extract and synthesize the available literature – and to guide the development of best-practice guideline for facilitating adherence to ART.

The focus of the research study will be developing a best-practice guideline that would contribute to facilitating adherence to ART.

### **1.3 RESEARCH QUESTIONS**

The research questions that underpinned this study included:

1. What are the experiences of healthcare professionals with regard to the care, support and guidance that they provide to persons on anti-retroviral therapy?
2. What do healthcare professionals understand about Evidence-Based Practice and Best-Practice Guidelines?
3. What are the experiences of persons receiving anti-retroviral therapy at public hospitals in Ghana on adherence to the treatment?
4. What is the best available evidence from guidelines related to the facilitation of adherence to ART?

5. What should the content of a best-practice guideline be for facilitating adherence by persons receiving anti-retroviral therapy at public hospitals in Ghana?

#### **1.4 PURPOSE OF THE STUDY**

The purpose of this study was to develop a best-practice guideline for facilitating adherence to ART by persons receiving treatment at public hospitals in Ghana, based on the research findings and the integrative literature review related to adherence to ART.

#### **1.5 RESEARCH OBJECTIVES**

1. To explore and describe the experiences of healthcare professionals with regard to the care, support and guidance given to persons on anti-retroviral therapy.
2. To explore and describe healthcare professionals' understanding of Evidence-Based Practice and Best-Practice Guidelines.
3. To explore and describe the lived-experiences of persons receiving anti-retroviral therapy at public hospitals in Ghana on their adherence to the therapy.
4. To explore, describe, appraise, extract and synthesise the existing literature to guide the development of a best-practice guideline that would facilitate adherence to ART by persons receiving treatment at public hospitals in Ghana.
5. To develop a best-practice guideline for facilitating adherence to ART by persons receiving therapy at public hospitals in Ghana.

#### **1.6 CLARIFICATION OF CONCEPTS**

The concepts used in this research have been defined and clarified as follows:

##### **1.6.1 Best-Practice Guidelines**

Best-Practice Guidelines (BPG) are “developed using the best available evidence, in order to provide clinicians with evidence-informed recommendations that support clinical practice and guide practitioners’ and patients’ decisions regarding [the] appropriate healthcare in specific clinical practice settings and circumstances” (Australian Nursing and Midwifery Federation, 2012:1). This study seeks to develop a

best-practice guideline for facilitating adherence to ART for persons attending public hospitals in Ghana.

### **1.6.2 Human Immunodeficiency Virus (HIV)**

The Human Immunodeficiency Virus is the virus that causes AIDS. It breaks down the body's defence against infection and disease by infecting specifically white blood cells thereby leading to a weakened immune system. This results in the body's loss of protection against illness, together with the possible development of other serious and deadly diseases. When a person is infected with HIV, the person is known as "HIV-infected"; while "HIV-positive" is used when a person is living with HIV (Ghana Health Service, 2010:5).

The WHO defined a case of HIV infection as any individual with HIV infection, irrespective of the clinical stage, confirmed by laboratory criteria, according to the country's definition and requirement (WHO, 2011: 8). The focus of the study will be on persons living with HIV who are receiving anti-retroviral therapy at public hospitals in Ghana.

### **1.6.3 Acquired Immunodeficiency Syndrome (AIDS)**

Acquired-immunodeficiency syndrome indicates a group of serious illnesses and opportunistic infections that develop after being infected with HIV for a long period of time (Ghana Health Service, 2010:5). In this study, clients diagnosed with AIDS and who are receiving anti-retroviral therapy at public hospitals in Ghana, are the focus of the study.

### **1.6.4 Persons Living with HIV/AIDS**

The Oxford Advanced Learner's Dictionary defines a person as an individual (Hornby, 2010:1092). In this study, persons living with HIV/AIDS will mean men or women diagnosed positive with HIV-infection/AIDS, who are aware of their status, and are living with the condition. Persons diagnosed with HIV/AIDS, and who have started on anti-retroviral therapy, will also be the focus of the study.

### **1.6.5 Anti-retroviral therapy**

The retrovirus is a virus containing ribonucleic acid (RNA) that converts its genetic material into deoxyribonucleic acid (DNA); this enables it to become integrated into the DNA of its host cells (Oxford mini-dictionary for nurses, 2003:549). Anti-retroviral therapy is the combination of several anti-retroviral medicines used to slow the rate at which HIV makes copies of itself in the body of the host. (WebMD, 2014:1). The study will explore the experiences of persons receiving anti-retroviral therapy at public hospitals in Ghana, and on their adherence to the prescribed therapy.

### **1.6.6 Adherence**

Adherence implies behaving according to a particular rule (Hornby, 2010:17). Treatment adherence has been defined by the WHO (2013:1), as the “extent to which a person’s behaviour – taking medications, following a diet, and/or executing lifestyle changes – corresponds with [the] agreed on recommendations from a healthcare provider”. This study will focus on the development of best-practice guidelines that facilitate the adherence to ART.

### **1.6.7 The healthcare professional**

Healthcare has been defined as the service of providing medical care. Professional, on the other hand, is someone connected with a job that needs special training, or skills, and a high level of education (Hornby, 2010:694, 1170). In this study, a healthcare professional will refer to a Doctor, Nurse, Pharmacist or a trained Counsellor who provides health services to persons on anti-retroviral therapy.

### **1.6.8 Facilitate**

To facilitate is to make easy or less difficult or more easily achieved, to assist, support, enable, allow promote, encourage and to make way for (Allen, 2007:188). In this study, the term facilitate will refer to implementing the best practice guideline in order to make it easier for the patients to adhere to anti-retroviral therapy.

## **1.7 PARADIGMATIC PERSPECTIVE**

A paradigm is the net that “holds the researcher’s ontology, epistemology and theoretical position/perspective” (Mayan, 2009:24). The theoretical framework that has

been chosen for this research is the Joanna Briggs Institution (JBI) model of evidence-based health care. The theory aims to enhance improvement in health care through the development of a pluralistic step-by-step model for facilitating evidence-based practice. The JBI model stipulates four main components for putting practice into action (Woods, 2011:3).

### **1.7.1 Healthcare-Evidence Generation**

The JBI model asserts that evidence may derive from experience, expertise, inference, deduction or the results of a rigorous inquiry; but it recognizes that “the results of well-designed research studies grounded in any methodological position are seen to be more credible as evidence ... than anecdotes or personal opinion” (Pearson *et al.*, 2012:2). This includes evidence collected, via qualitative and quantitative research, from patients on their healthcare experiences and preferences and from the experiences and judgments of healthcare professionals.

In this study, the qualitative data were collected from healthcare professionals on their experiences in providing care, support and guidance to persons on ART, as well as their understanding of evidence-based practice and best-practice guidelines. The data were also collected from persons receiving ART at public hospitals in Ghana, together with their experiences with adherence to the therapy.

### **1.7.2 Evidence Synthesis**

Evidence synthesis is the evaluation or analysis of research evidence and opinions on a specific topic to assist in decision-making in healthcare (Pearson *et al.*, 2012:2). In this study, the data collected and analysed from the interviews were utilised in conjunction with an integrative literature review and a Best-Practice Guideline for facilitating adherence to ART was developed. The Best-Practice Guideline for facilitating adherence was submitted to a panel of experts for review. Feedback from the reviewers was considered to prepare the final evidence-based Best-Practice Guideline for facilitating adherence to ART for public hospitals in Ghana.



### **1.7.3 Evidence Transfer**

This component of the model relates to the act of transferring evidence (knowledge) to individual health professionals, health facilities, and health systems globally by means of journals, other publications, guidelines, electronic media, education and training, and decision-support systems. Evidence transfer is seen to involve more than merely disseminating or distributing information; it should include the careful development of strategies that identify target audiences such as clinicians, managers, policy-makers and consumers, as well as methods to package and transfer information that are understood and used in decision-making (Pearson *et al.*, 2012:3). The final Best-Practice Guideline for facilitating adherence to ART will be transferred to public hospitals, healthcare professionals, as well as to persons on ART.

### **1.7.4 Evidence Utilization**

This relates to the implementation of evidence in practice, as is demonstrated by practice and/or system change. It identifies the following elements: Evaluating the impact of the utilization of evidence on the health system, the process of care and health outcomes, practice change and the acquisition of evidence through systemic/organizational change (Pearson *et al.*, 2012:3-4). The best-practice guideline for facilitating adherence to ART will then be utilized by healthcare professionals and its impact will be evaluated. This step will however not be part of this study but will be the focus of a postdoctoral research study.

## **1.8 RESEARCH DESIGN**

A qualitative research design, which was explorative, descriptive and contextual in nature, was implemented by the researcher in order to address the research questions. A detailed description of this design will be presented in Chapter Two.

## **1.9 RESEARCH METHODS**

Research methods have been defined by Richards and Morse (2007:2) as “a collection of research strategies and techniques, based on theoretical assumptions that combine to form a particular approach to [the] data and [the] mode analysis”. The method used in this research was organized in three phases. Phase One comprised of the collection and analysis of qualitative data from healthcare professionals and persons on ART.

Phase Two consisted of the conduction of integrative literature review and Phase Three comprised the development of a best-practice guideline based on the findings from phase one and phase two. Details of the research methods will be described in Chapter Two of this study.

### **1.10 MEASURES TO ENSURE TRUSTWORTHINESS AND AUTHENTICITY OF THE STUDY**

Trustworthiness is the degree of confidence that qualitative researchers have in their data; and this can be assessed by using the criteria of credibility, transferability, dependability, confirmability and authenticity (Polit & Beck, 2012:745). Trustworthiness is also establishing the validity and the reliability of a qualitative research project. Qualitative research is said to be trustworthy when it accurately represents the experiences of the study participants (Streubert & Carpenter, 2011:455).

The researcher will judge the trustworthiness through the development of criteria for dependability, credibility, transferability, confirmability and authenticity as proposed by Guba and Lincoln (Guba & Lincoln, 1985 as cited by Mayan, 2009:103). Each of these criteria will be discussed in more detail in Chapter Two.

### **1.11 ETHICAL CONSIDERATIONS**

The research proposal was submitted to the Department of Nursing Science Research committee for appraisal and approval. Thereafter it was sent to the Faculty of Health Sciences' Research, Technology and Innovation Committee and finally to the Research Ethics Committee (Human), of the Nelson Mandela Metropolitan University (NMMU) for approval. Informed consent was obtained from the research participants. Details of ethical principles applied in this study will be discussed in Chapter Two.

### **1.12 CHAPTER DIVISION**

The research study will be divided into six chapters; and the format will be:

- Chapter 1: Overview of the study
- Chapter 2: Research design and method
- Chapter 3: Data analysis and discussion

Chapter 4: Integrative literature review report

Chapter 5: Development of a Best-Practice Guideline

Chapter 6: Summary, conclusion, limitations and recommendations

### **1.13 SUMMARY OF THE CHAPTER**

This Chapter provided a brief overview of this study. The above-mentioned discussion highlights a brief review of HIV/AIDS and the introduction of ART, together with its importance for the survival of persons living with HIV/AIDS. The problem statement and the research objectives are stated within the context of the research. The study aims to develop a best-practice guideline that will facilitate adherence to ART for persons receiving treatment at public hospitals in Ghana. The next chapter will describe and discuss the research design and the methods used in this study.

## **CHAPTER TWO**

### **RESEARCH DESIGN AND METHODS**

#### **2.1 INTRODUCTION**

The previous chapter provided an overview of the research, together with a brief background and introduction to the study. The objectives of the research were introduced, the paradigmatic perspective was described as well as a brief description of the research design and methods. The research design and methods will be discussed in more detail in this chapter. Furthermore, in this chapter, the purpose and the objective of this study will be put into context.

#### **2.2 PURPOSE OF THE RESEARCH**

The purpose of this study was to develop a best-practice guideline for facilitating adherence to ART by persons receiving treatment at public hospitals in Ghana, based on the research findings and the integrative literature review related to adherence to ART.

#### **2.3 RESEARCH OBJECTIVES**

The following objectives were proposed in order to achieve the overall purpose of the study:

1. To explore and describe the experiences of healthcare professionals with regard to the care, support and guidance given to persons on anti-retroviral therapy;
2. To explore and describe health professionals' understanding of Evidence-Based Practice and Best-Practice Guidelines;
3. To explore and describe experiences of persons receiving anti-retroviral therapy at public hospitals in Ghana on their adherence to the therapy;
4. To explore, describe, appraise, extract and synthesise the existing literature to guide the development of best-practice guideline that would facilitate adherence to ART by persons receiving treatment at public hospitals in Ghana.
5. To develop a best-practice guideline for facilitating adherence to ART by persons receiving therapy at public hospitals in Ghana.

The following paragraphs describe the research design and the methods utilised in this study to achieve the purpose and objectives of the research project.

## **2.4 RESEARCH DESIGN AND METHODS**

A research design is defined by Grove, Burns and Gray (2013:214), as a blueprint for conducting the study that maximises control over factors that could interfere with the validity of the findings. Research methods are the techniques employed to structure a study, and to gather and analyse the information relevant to the research questions (Polit & Beck, 2012:12).

The research process was carried out in three phases. Phase One involved an empirical study to establish data on adherence of persons to ART. In Phase Two, an integrative literature review for best-practice guidelines was conducted and critically appraised. From the literature, the data were extracted and synthesised. In Phase Three, the data analysed in Phase One and Two were integrated leading to the development of a best-practice guideline for facilitating adherence to anti-retroviral therapy.

### **2.4.1 Phase One: Empirical Research**

Phase one of the study comprised conducting a qualitative study to explore and describe experiences of healthcare professionals providing care, support and guidance to persons on ART. It also explored and described the experiences of persons living with Human Immunodeficiency Viral and Acquired Immunodeficiency Syndrome (HIV/AIDS) on ART.

#### **2.4.1.1 Research Design**

Research designs “are procedures for collecting, analysing, interpreting and reporting data in a research study” (Creswell & Clark, 2011:53). A qualitative research approach was used to conduct Phase One of the study. The research design used was explorative, descriptive and contextual in nature, which addressed the first two research questions.

#### **2.4.1.1.1 Qualitative research**

A qualitative research approach is a systematic, interactive, subjective approach used to describe the patients' life-experiences and to give them meaning. This type of research is conducted to explore, describe and promote the understanding of human experiences (Grove *et al.*, 2013:23). This research design was appropriate for this study; because the researcher explored and described the experiences of healthcare professionals with regard to the care, support and guidance to persons on anti-retroviral therapy, as well as the experiences of persons receiving anti-retroviral therapy at public hospitals in Ghana on their adherence to the therapy.

#### **2.4.1.1.2 Exploratory research**

Exploration is the act of travelling through a situation or a place in order to find out about it, or to look for something in it (Hornby, 2010:516). Exploring the data in a qualitative data analysis involves reading through all the data to develop a general understanding of the database (Creswell & Clark, 2011:411). Exploratory studies are not intended for generalization to large populations. They are designed to increase the knowledge in the field of study (Grove *et al.*, 2013:370). The experiences of healthcare professionals were explored with regard to the care, support and guidance to persons on anti-retroviral therapy, as well as the lived-experiences of persons receiving anti-retroviral therapy at public hospitals in Ghana on their adherence to the therapy.

#### **2.4.1.1.3 Descriptive research**

According to Grove *et al.* (2013:26), "descriptive studies are ways of discovering new meanings, describing what exists, determining the frequency with which something occurs, and categorizing the acquired information. Descriptive studies are usually conducted when little is known about a phenomenon". The qualitative descriptive method is usually employed if a basic description and summary of the phenomenon is desired (Mayan, 2009:52). In this study, a detailed description has been presented on the experiences of healthcare professionals with regard to the care, support and guidance that they provide to persons on anti-retroviral therapy in relation to their adherence to anti-retroviral therapy, as well as the lived-experiences of those persons receiving ART.

#### **2.4.1.1.4 Contextual research**

Contextual research comprises systematic and repeatable techniques used to carefully learn about the circumstances in which events occur. The context in this research was the “fevers unit” of the Korle Bu teaching hospital, the 37 Military Hospital, and the Ridge hospital. These are the three big public hospitals in Accra. The Korle Bu Teaching hospital (hospital one) is Ghana’s biggest hospital. It is situated in Accra; and it was established in 1923. Korle Bu teaching hospital currently has a capacity of 2000 beds, together with 17 clinical and diagnostic departments/units. The hospital has an average daily attendance of 1500 patients; and it provides admission to about 250 patients daily.

The fever unit is the isolation unit of the hospital in the Department of Medicine. The name fever was used to reduce the potential stigma of people treated at the unit. The unit treats cases, such as Chicken pox, Measles, Rabies, TB in children, Tetanus, HIV infection with lobar Pneumonia, Pharyngeal Candidiasis, Deep-vein thrombosis, Cryptococcus Meningitis, Cerebral toxoplasmosis, Disseminated Koch’s, Liver failure, Urinary-tract infection, Cardio-vascular Accidents, Septicaemia, Chronic diarrhoea, Renal failure and Peripheral Neuropathy. The fever unit was established in 2003; and among the services provided at the unit, are the voluntary counselling and testing for HIV, administration of ART and the prevention of mother-to-child transmission (Korle Bu Teaching Hospital, 2014:1-5).

The 37 Military Hospital (hospital two) is the second biggest hospital in Accra; and it is a 400-bed hospital located in the Ayawaso East electoral constituency. The hospital serves as the Government’s Emergency and Disaster Hospital; and it is the United Nations Level IV hospital in the West Africa sub-region. The Hospital consists of 12 wards, where patients with various conditions are admitted and treated. There are four emergency departments that accept only emergency cases; they detain patients when necessary but for not longer than 48 hours. Thereafter, such patients are either admitted to a ward for further treatment; or they are discharged and sent home.

These emergency departments are medical, obstetrics/gynaecology, paediatrics and trauma/surgical emergency units. Patients with medical conditions are first seen and detained at the medical emergency; and those with surgical conditions report at the surgical/trauma emergency before their admission to the ward, should this be

necessary. Patients can also report at either the Medical or Surgical Out-patient Department on appointment with their specialist, with either medical or surgical conditions respectively. They may be treated and discharged for home, or be admitted straight from the Out-patient Department to the ward. Those patients diagnosed with HIV are admitted and treated at the Simango ward, which is the isolation ward of the hospital under the Department of Medicine. Those who received their ART on an out-patient basis are cared for at the ART clinic, which falls under the Public Health Department of the hospital (Military Hospital Maiden Brochure, not dated).

The Ridge hospital (hospital three) is the regional hospital in the greater Accra region; and the HIV clinic of the hospital falls under the Medical Department of the hospital. Doctors, Nurses, Pharmacists and trained Counsellors provide anti-retroviral therapy here; additionally, patients receive their ART in these three public hospitals in Ghana. These individuals comprised the participants in this study.

#### **2.4.1.2 Research Methods**

This phase describes the research population, the sampling techniques and procedure, a description of the participants, the data-collection process and how the data were analysed.

##### **2.4.1.2.1 Research population**

According to Babbie (2007:190), “a study population is that aggregation of elements from which the sample is actually selected”. It consists of all those individuals or objects with common defining characteristics (Polit & Beck, 2012:59). The population of this study comprised healthcare professionals, who provide care, support and guidance to persons on anti-retroviral therapy. They were Doctors, Nurses, Pharmacists and trained Counsellors working at the Korle-Bu Teaching Hospital, 37 Military Hospital and Ridge Hospital. Persons diagnosed with HIV/AIDS and on anti-retroviral therapy, who receive their treatment from any of the three hospitals mentioned above, formed part of the study.



**Table 2.1: Size of the Target Population**

| <b>HOSPITAL</b>            | <b>HEALTHCARE PROFESSIONALS AT THE ART CLINIC</b> | <b>REGISTERED CLIENTS ON ART</b> |
|----------------------------|---|----------------------------------|
| Korle Bu Teaching Hospital | 26  | 10 000                           |
| 37 Military Hospital       | 25  | 800                              |
| Ridge Hospital             | 15  | 1 901                            |
| Total                      | 66  | 12 701                           |

The above table reflects the size of the target population for the three public hospitals in which the research was conducted. The total number of healthcare professionals working at the Korle Bu Teaching Hospital, 37 Military Hospital and Ridge Hospital were 26, 25 and 15 respectively. The total number of registered clients on ART at the Korle Bu Teaching Hospital were 10 000, 37 Military Hospital were 800 and at the Ridge Hospital were 1 901.

#### **2.4.1.2.2 Sampling**

Sampling is the process of selecting cases to represent an entire population so that inferences from the population can be made (Polit & Beck, 2012:275). Purposive sampling technique, also known as judgmental sampling, was employed in selecting the research sample. This sampling method uses the researcher's knowledge of the population to select sample members. Sampling is used to select people who are judged as typical of the population, or particularly knowledgeable of the issue under study (Polit & Beck, 2012:279). In purposive sampling, the researcher intentionally recruits participants who have experienced the key concept being explored in the study (Creswell & Clark, 2011:173). The sample was categorised into groups A and B.

Group A consisted of those healthcare professionals who provide care, support and guidance to persons on ART; while group B consisted of those persons who are on anti-retroviral therapy, and who receive their drugs from any of the three public hospitals in Accra, Ghana. The healthcare professionals in Korle-Bu teaching hospital were approached through the gatekeeper who was the Deputy Director of Nursing Services in charge of the fever unit. Those in 37 Military Hospital were approached through the programme manager of HIV at the Public Health Department, who served

as the gatekeeper, while at Ridge hospital, this was accomplished through the Deputy Director of Nursing Service in charge of the HIV programme at the hospital. The purpose of the study was explained to them; and they were also invited to participate in the study.

The persons receiving the ART were contacted through the gatekeeper, who in this case, was the nurse in-charge of the HIV clinics, with the exception of 37 Military Hospital. The same persons served as the gatekeeper for the two groups. The purpose of the study was explained to them. All participants were assured of their anonymity and confidentiality; and they were invited to participate in the research.

### **Group A**

The healthcare professionals were interviewed, because they are in direct contact with the patients who receive the ART; and they educate and counsel them on how to adhere properly to their treatment regimen. The inclusion criteria included:

- Healthcare professionals who are employees of any of the three public hospitals used for the study.
- They must have had at least one year of experience in the provision of health services to PLHIV/AIDS on ART;
- They must be willing to participate in the study.

A minimum of one year was required because, in order to describe an experience with the care, support and guidance to persons on ART, the health-care professional needs to have had some working experience in the field. The assistance of the gatekeeper for the healthcare professionals was required in order to identify those who met the above-stated criteria.

**Table 2.2: Demographic particulars of healthcare professionals in group A**

| Hospitals                             | Nurses  | Doctors | Pharmacist | Trained counsellors |
|---------------------------------------|---------|---------|------------|---------------------|
| Korle –Bu teaching hospital           | 2       | 1       | 1          | 1                   |
| 37 Military Hospital                  | 1       | 1       | 2          | 1                   |
| Ridge Hospital                        | 3       | -       | 1          | 1                   |
| Age Range in years                    | 26-56   | 40-42   | 45-55      | 32-39               |
| Years of experience at the ART clinic | 1 ½ -23 | 6-10    | 9-12       | 5-8                 |

**Group B**

This research population included all those persons who have been receiving their drugs from any of the three public hospitals used for this study. The ART drugs are usually issued to PLHIV/AIDS for two weeks for the first time; thereafter, an appointment for a follow-up would be made within the next two weeks. The second issue of the ART is also given for the next two weeks, then subsequently for one month for three consecutive months; then it would be issued for three months; and thereafter, the patients would be given three-monthly appointments. The inclusion criteria for selecting the participants included:

- Any person living with HIV/AIDS
- Must be able to communicate in English;
- Must be receiving his or her treatment from any of the three public hospitals being used for the study
- Must have had a minimum of six months' experience on the treatment; and
- Must be willing to participate in the study.

A minimum of six months' experience was required; because it is expected that the patient should have visited the clinic on at least five occasions for his or her ART; and therefore, would have had lived-experiences related to the therapy to share,.

**Table 2.3: Demographic particulars of persons on ART in group B**

| Hospitals                  | Male | Females | Number of years or months on ART |
|----------------------------|------|---------|----------------------------------|
| Korle-Bu teaching hospital | 4    | 1       | 4-11 years                       |
| 37 Military hospital       | 2    | 3       | 9 months -10 months              |
| Ridge hospital             | 1    | 4       | 3-7 years                        |

#### 2.4.1.2.3 Entry to site

In any research, formal permission is very important; and it is required for the protection of both the researcher and the participants. The study was first approved by the Research Ethics Committee – Human (H14-HEA-nur-029) of the Nelson Mandela Metropolitan University (see Annexure G). Ethical clearance was also obtained from the Institutional Review Board of the 37 Military Hospital and also from the Ghana Health Service (see Annexures H & I). The researcher sought permission to conduct the research from the directors of medical services of Korle-Bu teaching hospital, 37 Military hospital and Ridge hospital, respectively.

The medical directors in the three hospitals were approached first by means of a formal written request (see Annexures C, D & E). The researcher was granted permission to conduct the study by the medical directors of the first two hospitals, while the director of the third hospital minuted the letter and informed the researcher to only show it to whomsoever it may concern (see Annexures J and K). This enabled the researcher to gain access to the hospitals for the study.

Permission was also sought from the HIV programme managers (see Annexure F) and the nurse in-charge of the ART clinics of the three hospitals where the researcher obtained information. The HIV programme managers and the nurses in charge of the clinics were used as “gatekeepers”. “A gatekeeper is an individual in the organization [who is] supportive of the proposed research, [and] who would essentially ‘open up’ the organization” (Creswell & Clark, 2011:175).

The researcher personally met with the programme managers and the nurses in charge of the HIV clinic. They were informed of the research and were invited to participate in the study. Their willingness and preparedness to enquire from other healthcare professionals whether they would be willing to participate in the study was

sought. They were requested to compile a list of the names, telephone numbers, and e-mail addresses of all the healthcare professionals who meet the inclusion criteria and who had agreed to participate in the study.

The researcher contacted the healthcare professionals personally; they were informed of the purpose and the aims of the research and were invited to participate in the study. An appointment for interviews was made with those who agreed to participate in the study. The nurse in charge of the HIV clinics of the three public hospitals used for the research was requested to enquire from the persons who receive their ART from the clinics whether they were willing to participate in the study. They were requested to compile a list of names, telephone numbers and e-mail addresses of all the persons on ART, who met the inclusion criteria, and who agreed to participate in the study. The list was handed over to the researcher, who contacted some of them personally; but most of the contacts were made by the gatekeepers.

The purpose of the research was explained to them, and an appointment for semi-structured interviews was made with them. An informed consent form was given to each participant (see Annexure A & B). The date, time and place for the interviews were arranged with the participants. They were allowed to read the consent form and explanations were given on the content of the form; and any issues that arose from the consent form were addressed; and they were allowed to sign the form. The healthcare professionals and the persons on ART were interviewed until the dataset was saturated.

#### **2.4.1.2.4 Data-collection methods**

Data collection “is the precise systematic gathering of information relevant to the research purpose, or the specific objectives, questions or hypothesis of a study” (Grove, *et al.*, 2013:45). Semi-structured interviews were used as the data-collection method in this study. This is a common form of interviews in qualitative research. The researcher has a fair idea of what is going on regarding the phenomenon; and s/he to be able to develop questions on the topic but not enough to predict the answers (Mayan, 2009:71). The data from both the healthcare professionals and the persons on ART were collected by means of a semi-structured individual-interview schedule. The interviews were recorded with the permission of the participants. This method for

data collection was chosen by the researcher; because it encouraged the participants to express themselves, and to talk freely on the research topic.

### **Group A**

The participants were informed by the researcher that the interview would be recorded on a voice-recorder; hence their permission was sought. This enabled the researcher to capture all the words of the participants during the interview; and it also allowed a verbatim translation of the recording to be produced. The participants in group A were interviewed until saturation was reached that is, when no new data emerged and when all the leads had been followed (Mayan, 2009:63).

The questions for the healthcare professionals were based on the following:

- Tell me about your experience in providing ART;
- What is your understanding of evidence-based practice?
- What is your understanding of best-practice guidelines?
- What policies and guidelines direct your practice?
- What do you think should be included in a best-practice guideline that would assist you to facilitate your patients' adherence to ART?

### **Group B**

Semi-structured interviews were employed as the appropriate data-collection method for this group in order to establish the lived-experiences of persons receiving anti-retroviral treatment at public hospitals in Ghana. The following questions were put to each participant:

- How have you experienced receiving your ART from the staff at a public hospital?
- Explain to me how it is for you to manage your ART on a daily basis?
- What do you think could further assist you to learn how to manage your disease on a long-term basis?

Interviews continued for group B until data saturation was reached.

During the interviewing for both groups, field notes were kept. Field notes describe the researcher's reflections, feelings, ideas, moments or confusion, hunches and interpretations about what is observed (Mayan, 2009:77). These field notes will contain a narrative account of what can be expected to happen on the field during the data collection; and they will also serve as the data for analysis (Polit & Beck, 2012:548).

#### **2.4.1.2.5 Data analysis**

The analysis of data in qualitative research is an active and interactive process. Qualitative analysis has been noted as a "process of filtering the data together, of making the invisible obvious, of linking and of attributing the consequences to antecedents. It is a process of conjecture and verification of corrections and modification of suggestions and defence" (Morse & Field, 1995:126, as cited by Polit & Beck, 2012:557). The data were analysed, using the six steps of data analysis prescribed by Creswell (2014: 197- 200). These are as follows:

##### **Step 1**

The data were organized and prepared. This involved transcribing the interviews, the typing up of the field notes, cataloguing all the visual material and sorting and arranging the data into different types, depending on the sources of information.

##### **Step 2**

All the transcribed data were well scrutinised before coding commenced.

##### **Step 3**

All the data were coded. Coding "is the process of identifying persistent images, words, phrases, concept or sounds within the data. This was done, so that the underlying patterns could be identified and analysed" (Mayan, 2009:94). During coding, Tesch's eight steps in the coding process (Creswell, 2014:197- 200) were employed as follows:

- All the transcriptions were read carefully to get a sense of the whole.
- One document was chosen for further analysis of any underlying meanings.
- This process was continued for several documents; and a list of the topics, clustering those that were similar, was made.

- Codes were assigned to the topics, the data were returned; and the codes were assigned to the appropriate segments.
- Categories were assigned to the topics, they were grouped together; and any interrelationships were indicated.
- An abbreviation for each category was decided on.
- A preliminary analysis was performed by assembling the data for each category together.
- Where necessary, the existing data were recoded.

#### **Step 4**

The coding process was used to generate a description of the setting, or the people, as well as the categories or themes for analysis.

#### **Step 5**

An explanation was provided on how the descriptions and themes would be represented in a qualitative narrative.

#### **Step 6**

A final step in the data analysis involved making an interpretation in qualitative research of the findings or of the results.

#### **2.4.1.2.6 Pilot study**

A pilot study is a small-scale version or trial run designed to test the methods to be used in a larger or more rigorous study (Polit & Beck, 2012:195). The pilot study in this research was conducted by following the same procedure as that utilised in the main study. Permission was sought from one of the three health institutions to conduct the pilot study; and purposive sampling techniques were employed to sample the participants. The purpose of the study was explained to the participants; and those who fell within the inclusion criteria and who agreed to participate in the study were given the consent form, in order to obtain their consent to participate in the study.

A semi-structured interview was conducted with one of the healthcare professionals while one person receiving ART from the 37 Military Hospital was also interviewed.



The data collected were analysed, using Creswell's six steps of data analysis as described above. The aim of the pilot study was to assess the interview schedule to be sure that the researcher collected the required data needed to answer the research questions. The pilot study also assisted in modifying the interview schedule where necessary before embarking on the main research. There was no problem after the pilot study; and consequently, no changes were made to the research design and methods, hence the data in the pilot study were included in the main study.

#### **2.4.2 Phase Two**

In this phase, a search for best-practice guidelines in order to facilitate adherence to anti-retroviral therapy was conducted by means of an integrative literature review. In evidence-based practice research, a high-quality review may be sufficient to provide the needed information on the existing evidence (Polit & Beck, 2012:95). It is essential to conduct the integrative literature review after analysing the data; the purpose is to place the findings of the study in the context of that which is already known; and also to tell the reader how the findings fit into what is already known about the phenomenon (Streubert & Carpenter, 2011:27).

According to Torraco (2005:356), an integrative literature review is a form of research that reviews, critiques and synthesizes representative literature on a particular topic in an integrated way so that a new framework and perspectives on the topic are generated. The integrative literature review was carried out in this study by employing the 5-step review approach described by Whitemore and Knafl (2005:548). These are problem identification, literature search, data evaluation, data analysis and data presentation

##### **Step one: Problem identification**

This step is when the review question is formulated and the question is asked when using the population, intervention, context and outcome (PICO) format (Melnyk & Fineout-Overholt, 2011:11). This was applied in this study as follows:

**P** (population): HIV positive adult patients

**I** (intervention): Adherence to anti-retroviral therapy

**C (context):** Public hospitals

**O (Outcome):** Facilitated adherence

The review question that was formulated and used was: “What is the best available evidence with regard to adherence to anti-retroviral therapy amongst HIV patients at public hospitals?”

### **Step two: The Literature search**

At this stage, the literature search was carried out as follows:

- The electronic database was searched to identify and become familiar with the relevant keywords contained in the titles, abstracts and subject descriptors. Various articles on facilitating adherence and evidence-based practice were consulted.
- A wide variety of electronic databases, including PubMed, Google Scholar, (CINAHL, ERIC, Academic search complete, E-journals, Psycinfo and MEDLINE) via EBSCOHOST, EMERALD INSIGHT, JSTOR, and SCIENCE DIRECT, FINDPLUS were searched.
- All databases, including electronic journals were searched using the identified key words and key phrases such as evidence-based practice, best-practice guidelines, HIV/AIDS, anti-retroviral therapy, adherence to ART, healthcare professionals’ experience on ART, and lived-experience of persons on ART, ART-adherence guidelines, adherence-facilitating guidelines. These were used for the search.
- Reference lists and bibliographies of all papers were searched for additional studies.

### **Step three: The data evaluation**

At this stage, the data gathered were critically appraised, using the appropriate appraisal tool. The Appraisal of Guidelines for Research and Evaluation II (AGREE II) Instrument was used as a framework for the assessment of the quality of practice guidelines available. The AGREE II is designed to assess the guidelines developed by local, regional, national or international groups or affiliated governmental

organizations. This tool allows for evaluation in six key dimensions: Scope and purpose; stakeholder involvement; rigour of development; clarity and presentation; applicability; and editorial independence. This instrument assesses the methodological rigour and transparency whereby a guideline is developed (Brouwers, Kho, Browman, Cluzeau, Feder, Fervers, Hanna and Makarski, 2010:4, 10).

The AGREE II instrument is a 23-item tool that consists of six quality domains; each domain captures a unique dimension of guideline quality. The AGREE II instrument can be used by healthcare professionals, guideline developers, policy-makers and educators (Brouwer *et al.*, 2010:4). The domains of the AGREE II are as follows:

### **Domain 1: Scope and Purpose**

This domain is concerned with the overall aim of the guideline, the specific health questions and the target population (items 1-3).

### **Domain 2: Stakeholder Involvement**

This focuses on the extent to which the guideline was developed by the appropriate stakeholders and the extent to which it represents the views of its intended users (items 4-6).

### **Domain 3: Rigour of Development**

This domain relates to the process used to gather and synthesize the evidence, the methods to formulate the recommendations, and to update them (items 7-14).

### **Domain 4: Clarity of Presentation**

This domain deals with the language, structure, and format of the guideline (items 15-17).

### **Domain 5: Applicability**

This pertains to the likely barriers and facilitators in the implementation strategies to improve uptake, and to the resource implications when applying the guideline (items 18-21).

## **Domain 6: Editorial Independence**

This domain is concerned with the formulation of recommendations, which are not unduly biased with competing interests (items 22-23).

The service of an independent reviewer was engaged to assist with the critical appraisal and discussions were held with her in order to reach consensus to ensure trustworthiness.

### **Step four: Data analysis**

Data analysis was carried out by taking the data (guidelines) in a systematic and repeatable way and grouping them together. The data were analysed and scrutinised to retrieve the relevant information from the data source. This is where the extraction of the data from the appraised guidelines was carried out. The data were extracted by assessing the eligibility, the quality, the characteristics and the findings.

### **Step five: Data presentation**

At this stage, the extracted data was presented in a table format, stating the authors' main findings for each guideline and making recommendations. Phase Two of the research methods ended with the extracted and presented data from the guidelines.

### **2.4.3 Phase Three**

Phase Three consisted of the development of a best-practice guideline for facilitating adherence to ART by persons receiving treatment at public hospitals. This was accomplished by integrating the analysed data in Phases One and Two. This research applied the eight-step approach in guideline development devised by the National Institute for Health and Clinical Excellence (NICE) clinical advisory committee in England (NICE, 2012).

The steps are as follows:

- **Identify the aims/purpose of the guideline**

The aim and purpose of the guideline developed from the study was to provide recommendations, based on the best available evidence, to assist healthcare professionals in facilitating adherence to ART.

- **Choice of guideline-development method**

There are various methods for the development of guidelines. Generally, there are three identified different methods of guideline development. These are: informal consensus, formal consensus and evidence-linked constructions (Woolf, as cited by Linskey & Kalkanis, 2010:4). The first method is usually found in guidelines that are developed by advocacy groups or patients' support groups; and they are usually produced without any systematic evidence review and grading. The second method utilizes evidence from the reviewed literature; but the evidence may or may not be graded. The third method is the highest quality construction methodology possible. Evidence tables are provided for independent verification (Woolf, as cited by Linskey & Kalkanis, 2010:5). In this study, the developed guideline was based on the evidence from systematic reviews; hence the evidenced-linked guideline development method and the formal-consensus approach of guideline development were used.

- **The Literature review.**

An integrative literature review was conducted on the available literature; and this was done by using the existing guidelines on adherence to ART. This type of review critically appraises the literature in an area but without a statistical analysis, this amounts to the broadest category of review. The data were extracted, analysed and synthesized before the development of the best-practice guideline for facilitating adherence to anti-retroviral therapy for persons attending public hospitals in Ghana.

- **Search for other clinical guidelines**

Other guidelines relevant to the best-practice guidelines to facilitate adherence to ART were sought. The search was done to identify the existing guidelines on the research topic. This was carried out on the literature published nationally and internationally. The available guidelines were critically appraised, using an appraisal tool from the AGREE II instrument.

- **Formulation of draft guidelines**

A draft guideline was formulated, based on the results from the individual semi-structured interviews on the experiences of healthcare professionals providing care, support and guidance to persons on ART, and the lived-experiences of

persons on ART, as well as the integrated literature review that was conducted. The formulation of the draft guideline employed the structure and layout as set out in the AGREE II appraisal tool. The formulated guideline consists of six sections:

1. Scope and purpose: where the objectives, clinical review questions and target group for whom the guideline was developed are addressed.
2. Rigour of development: this section addresses the methods for searching for evidence, inclusion and exclusion criteria, methods for formulating the clinical guidelines and expert panel inclusion.
3. Results and discussion: This was aimed at discussing the results and the recommendations derived therefrom. The presentation and clarity of the recommendations and results are also addressed.
4. Clarity and presentation: This deals with the language, structure, and format of the guideline.
5. Editorial independence: This is concerned with the formulation of recommendations not unduly biased by competing interests.
6. Stakeholder involvement: This is to give the reader information about the stakeholders involved in the review of the guidelines.

- **Expert panel selection**

To ensure the validity of the guideline, an expert panel from appropriate disciplines was selected to review the guideline. The expert panel acted as reviewers of the draft best-practice guideline and comprised six members. The expert panel included two professional nurses holding a PhD in Nursing, two medical specialists, one specialist in HIV/AIDS and one educationalist with experience in the development of practice guidelines. A letter requesting voluntary participation to review the guideline was sent to the expert panel (see Annexure N).

- 1. Review of the guidelines by the panel of experts**

The draft of the best-practice guideline was sent to the panel of experts for their review comments and recommendations. A reviewer assessment sheet (see Annexure O), which was based on the AGREE II tool, outlined the important

components to be included in a guideline and was attached to the draft guideline sent to the expert panellists.

## **2. Final revised best-practice guidelines**

A revision of the draft best-practice guidelines was compiled from the comments of the panel of experts. Adjustment to the best-practice guideline was made based on the comments and the final best-practice guideline was then formulated.

The development of the draft guideline and the final best-practice guideline for facilitating adherence to ART is discussed in Chapter Five.

## **2.5 MEASURES TO ENSURE THE TRUSTWORTHINESS AND AUTHENTICITY OF THE STUDY**

Trustworthiness is the degree of confidence that qualitative researchers have in their data and can be assessed by using the criteria of credibility, transferability, dependability, confirmability and authenticity (Polit & Beck, 2012:745). Trustworthiness means establishing the validity and the reliability of a qualitative research project. Qualitative research is said to be trustworthy when it accurately represents the experiences of the study participants (Streubert & Carpenter, 2011:455). The researcher will judge the trustworthiness through the presentation of the following, as proposed by Guba and Lincoln (Guba & Lincoln, 1985, as cited by Mayan, 2009:103).

### **2.5.1 Dependability**

According to Streubert and Carpenter (2011:49), “dependability is the criterion met once the researcher has demonstrated the credibility of the findings”. It refers to the opportunity *post hoc* of reviewing how a decision was made through the research; and this is attained through the use of an audit trail (Polit & Beck, 2012:175). To ensure dependability in this study, a stepwise and detailed description of the research method is provided as this would grant other researchers the ability and opportunity to replicate the study in a different setting. The developed best-practice guideline was reviewed by an expert panel and their comments were considered in the final best-practice guideline.

### **2.5.2 Credibility**

Credibility replaces the criterion of internal validity; and assesses whether the research findings make sense and whether they are an accurate representation of the participants and/or the data (Mayan, 2009:102). Strategies that would be used to assist in achieving credibility would include member checks, in which the participants would acknowledge the findings of the study as being true in their experiences, prolonged engagement in the setting and triangulation of the data (Mayan, 2009:102). To achieve these objectives, the researcher ensured that engagement with the participants was sustained, in order to confirm their initial statements.

A minimum of 45 minutes was spent with the participants with the aim of maintaining rapport and building a trusting relationship with them to ensure the acquisition of credible data. A voice recorder was used to record the information from the participants. A pilot study was first conducted to ensure that these semi-structured interview guides were trustworthy. measured what they were intended to measure. An expert panel from appropriate disciplines were also selected to review the guideline.

### **2.5.3 Transferability**

According to Streubert and Carpenter (2011:49), transferability refers to the probability that the study findings would make sense to others in a similar situation. Thus, it replaces external validity; and will only be acquired in this study through a clear, in-depth and accurate description of the selection and characteristics of the participants. A description of how the data were collected; and the process of analysis were provided by the researcher. This serves as a means for another researcher to replicate the study in a different setting. Furthermore, a rigorous presentation of the findings together with appropriate quotations has been documented, in order to enhance the transferability of the data.

### **2.5.4 Confirmability**

Confirmability replaces objectivity; and is used during the data collection and analysis phase to ensure that the findings are logical (Mayan, 2009:102). Confirmability was ensured in this study through an audit trail, triangulation and reflexivity. An audit trail comprises a variety of research-generated decisions that must be consistently and



conscientiously recorded and skilfully organized throughout the research process (Morse & Field, 1995, as cited by Mayan, 2009:102).

The immediate recording of spontaneous notes, ideas generated during planned analysis and note-generation sessions was ensured. The interview tapes, the transcribed data and the field notes, which served as an audit trail for an objective assessment and confirmation of the documented information, will be made available to the researcher's promoters.

### **2.5.5 Authenticity**

The extent to which researchers fairly and faithfully show a range of reality is referred to as authenticity and emerges in a report, when it conveys the tone of the lives of the participants as they are lived. "When a text achieves authenticity [the] readers are better able to understand the lives being portrayed" (Polit & Beck, 2012:585). In this study, authenticity was achieved by portraying the experiences of healthcare professionals with regard to the care, support and guidance of persons on ART in relation to adherence as well as the lived experiences of persons receiving ART in their therapy.

## **2.6 ETHICAL CONSIDERATIONS**

According to Streubert and Carpenter (2011:56), distinct and conceivable unanticipated ethical issues emanate from the unpredictable nature of the qualitative research. Ethical issues and standards must, therefore, be critically considered in qualitative research. The research proposal was submitted to the Department of Nursing Science Research Committee for their appraisal and approval. Thereafter, it was sent to the Faculty of Health Sciences Postgraduate Studies and then to the Research Ethics Committees (Human) of the Nelson Mandela Metropolitan University (NMMU), for their approval.

The research proposal was also sent to the ethical review committee of the Ghana health service, as well as that of the 37 Military Hospital for their approval. The researcher requested permission in writing from the medical directorate of the Korle-Bu Teaching Hospital, the Ridge Hospital and the 37 Military Hospital to conduct the research, using participants from the healthcare professionals providing ART services

and patients receiving anti-retroviral therapy from their institutions. Informed consent was obtained from the research participants, by issuing each participant with a consent form at the study site. This was explained to the participants, as well as the purpose and objectives of the study (See Annexures A & B).

The Belmont Report articulated three broad principles, on which the standards of ethical conduct in research are based: Beneficence; respect for human dignity; and justice (Polit & Beck, 2012:152). Ethical principles, such as beneficence and non-maleficence, respect for human dignity, justice, veracity, privacy and confidentiality were considered in this study.

### **2.6.1 Beneficence and non-maleficence**

Beneficence imposes a duty on the researcher to minimize harm and to maximize benefits. Non-maleficence is the researcher's obligation to avoid, prevent, or minimize harm (Polit & Beck, 2012:152). The researcher ensured that none of the participants was subjected to any risk, exploitation or harm. This was ensured by obtaining informed consent and recognising that all the research participants were autonomous and that they had the right to refuse to participate and could also withdraw from the research project at any time during the course of the project.

### **2.6.2 Respect for human dignity**

According to Polit and Beck (2012:154), the respect for human dignity includes the right to self-determination and the right to full disclosure. Self-determination means that the prospective participants can voluntarily decide whether to take part in a study without the risk of prejudicial treatment. It also means that people have the right to ask questions, to refuse to give information and to withdraw from the study. The right to full disclosure, on the other hand, requires that people's right to make informed, voluntary decisions about participation in the study requires full disclosure. The right to self-determination and the right to full disclosure are two major elements, on which informed consent is based.

In this study, the researcher fully described the nature of the study, the person's right to refuse participation, the researcher's responsibility, as well as any possible risk and benefit to the participants in order to ensure respect for their dignity.

### **2.6.3 Justice**

The principle of justice includes the right to fair treatment, as well as the right to privacy. Justice is concerned with the equitable distribution of benefits and the burden of research. The researcher will ensure that the participants' selection is based on the requirements of the study, and not on their vulnerability (Polit & Beck, 2012:155). The researcher ensured that there was a fair and non-discriminatory selection of the participants and non-prejudicial treatment of those individuals who declined to participate or who chose to withdraw from the study. The researcher honoured all agreements made and adhered to the procedures outlined. The researcher was also respectful and courteous at all times.

### **2.6.4 Veracity**

Veracity simply means the quality of being true (Hornby, 2010:1653). The researcher provided participants with all the needed information, which helped them to make an informed choice on their participation in the study. They were told the truth about the study and they were not manipulated or coerced to participate in the study.

### **2.6.5 Privacy and Confidentiality**

Privacy is "an individual's right to determine the time, extent and general circumstances under which personal information will be shared with or withheld from others" (Grove *et al.*, 2013:169). According to Polit and Beck (2012:162), a promise of confidentiality is a pledge that any information participants provide will not be publicly reported in a manner that identifies them, and that such information would not be accessible to others. Privacy and confidentiality were ensured in this study by maintaining the privacy of the participants; they were given a code number and a master list of the participants' names; and their code numbers were kept in a locked place.

The master list of the participants and the code numbers were kept separate from the data collected. Privacy and confidentiality were adhered to at all times. This was ensured by not using any names or any other identifying data of the participants and institutions. The researcher ensured that there was no link with the data obtained and with any particular participant. The researcher ensured that the participants were fully

informed about their privacy and confidentiality, in order to allay any fears related to their names being mentioned and others subsequently becoming aware of their participation in the study.

## **2.7 SUMMARY OF THE CHAPTER**

The research design and methods used to conduct this research were discussed in this chapter. The exploratory, descriptive and contextual aspects of this qualitative study were specifically described. The purpose and research objectives were stated within the context of the research. The ethical principles applied in this study were also described. An explanation of the three phases of the research method was also given. Finally, a description of the proposed process for the development of a best-practice guideline for facilitating adherence to ART was outlined in this chapter.

## **CHAPTER THREE**

### **DATA ANALYSIS AND DISCUSSION**

#### **3.1 INTRODUCTION**

The research design and the research methods used to conduct this study were discussed in depth in Chapter Two. The analysis of the data collected from the individual interviews conducted with the healthcare professionals (HCPs) related to their provision of care or support to patients on ART and the experiences of patients with regards to their adherence to ART will be presented in this chapter. Shortly after the completion of the semi-structured interviews, the researcher read the field notes and the information was added to the data that will be described in this chapter. A literature control was conducted, in order to allow for the verification of the findings; and hence, the results will be discussed, together with the literature control.

#### **3.2 OPERATIONALISING FIELD WORK**

All the participants interviewed were informed by the researcher (interviewer) about the purpose and the objectives of the study as well as their expected roles before the interview commenced. They were also given a consent form to read, which contained information relating to the purpose and objectives of the study as well as the intention to use a voice recorder. All the concerns raised with regard to the confidentiality of the participants were addressed by the researcher before the participants agreed to participate in the study. Informed consent to participate in the study was obtained from the participants by requesting them to sign the informed consent form provided.

Although the use of the voice recorder was stated in the consent form, some of the participants requested further clarification on why the interviews were being recorded. The rationale was explained to them to their satisfaction and a better understanding of such participants was obtained. They were assured of their confidentiality. The participants were requested not to mention their names; and they were addressed as Madam and Sir during the interviews. They were informed of their voluntary participation and were assured of their liberty to decline to participate at any time in the course of the interview.

The participants freely shared their experiences of either providing care or support to persons on ART in the case of the HCPs, or their experiences in adherence to ART in the case of patients on the regime. All the HCPs were asked the same five questions; and the patients on ART were asked the same three pre-set questions. As each interview progressed, the researcher probed further. This was to encourage the participants to further describe or explain the initial response given. The HCPs were asked the following questions:

- What can you tell me about your experience in providing ART to clients attending the public hospitals?
- What is your understanding of evidence-based practice?
- What is your understanding of best-practice guidelines?
- What policies and guidelines direct your practice?
- What do you think should be included in a best-practice guideline that would assist you to facilitate your patients' adherence to ART?

The Patients on ART were asked the following questions:

- How have you experienced receiving your ART from the staff at a public hospital?
- How do you manage your ART on a daily basis?
- What do you think would assist you in managing your disease on a long-term basis?

### **3.3 DATA ANALYSIS**

A detailed description of the analysis of the data was provided in Chapter Two; hence the researcher will only briefly describe the data analysis since it is the focus of this chapter. The data collected during the semi-structured individual interviews were analysed using the six steps of data analysis described by Creswell (2014:200) and coding of the data was also carried out using Tesch's eight steps of coding. The identification of the themes was carried out with the assistance of an independent coder. Several discussions ensued between the researcher, the independent coder and the promoters and consensus was reached before the themes could be finalized. Appropriate verbatim quotations from the collected data were used to substantiate the

narratives provided by the researcher, when discussing the themes and the sub-themes. Appropriate literature from related studies was used to compare and contrast the research findings relating to the HCPs on the provision of care and support to patients on ART, as well as the experiences of such patients related to their adherence to ART.

### 3.4 IDENTIFIED THEMES AND SUB-THEMES

The data obtained from the individualised interviews conducted with the healthcare professionals and patients were analysed. Four main themes, together with their respective sub-themes were identified.

**Table 3.1: Themes and subthemes regarding the experiences of participants relating to receiving ART and the experiences of HCPs in relation to providing care, support and guidance to patients taking ART and their understanding of EBP and BPGs**

| Main Themes   | Subthemes   |
|---|---|
| <p><b>Theme 1:</b><br/>Participants' experiences in relation to having been diagnosed and living with HIV</p> | <p>1.1 Participants experienced various emotions after being diagnosed with HIV</p> <p>1.2 Participants had diverse experiences related to stigma and discrimination due to their HIV status</p> <p>1.3 Participants experienced the side-effects of anti-retroviral therapy</p> <p>1.4 Misdiagnosis of the type of HIV has significant consequences.</p> <p>1.5 Participants acknowledged that managing HIV requires a change in lifestyle</p> <p>1.6 The participants experienced improved health on anti-retroviral therapy</p> <p>1.7 Participants cited diverse challenges with regard to adherence to treatment</p> |

| Main Themes  | Subthemes   |
|--|---|
| <p><b>Theme 2:</b><br/>Healthcare professionals (HCPs) expressed a range of experiences related to their patients taking Anti-retroviral Therapy</p> | <p>2.1 HCPs recognised the need to provide effective counselling, monitoring, and support for patients taking anti-retroviral therapy</p> <p>2.2 HCPs described the factors that influenced adherence to anti-retroviral therapy</p> <p>2.3 HCPs described the policies and protocols used when patients are not adhering to their anti-retroviral therapy</p>                                      |
| <p><b>Theme 3:</b><br/>Healthcare professionals shared their understanding of evidence-based practice and best-practice guidelines</p>               | <p>3.1 HCPs understood Evidenced Based Practice to be research-based showing what is proven and tested</p> <p>3.2 HCPs understood Evidenced Based Practice to be a standardised, systematic way of doing things to guide practice</p> <p>3.3 HCPs indicated that BPGs consist of Guidelines that work well, are universally accepted and will benefit patients</p>                                  |
| <p><b>Theme 4:</b><br/>Health-care professionals made recommendations regarding what should be included in a BPG for facilitating ART adherence</p>  | <p>Best-Practice Guidelines should include:</p> <p>4.1 Suggestions for training HCPs</p> <p>4.2 Strategies to ensure education of patients on all aspects of the treatment</p> <p>4.3 Ways in which the needs of people living in resource-poor settings could be met</p> <p>4.4 Measures to improve counselling, monitoring and evaluation with regard to adherence to anti-retroviral therapy</p> |

### 3.5 DISCUSSION OF THE RESULTS

The participants consisted of 15 healthcare professionals and 15 patients. The HCPs consisted of six nurses, four pharmacists, three trained counsellors and two doctors with a minimum of one year and a maximum of 23 years' experiences in the provision of ART services. The age range of the HCPs was between 26-55 years. The patients, on the other hand, comprised seven males and eight females. The amount of time the participants had been taking ART varied from nine months to 11 years. The age range of the patients was between 27 and 63 years.



**Table 3.2: Demographic particulars of healthcare professionals**

| Hospitals                             | Nurses | Doctors | Pharmacist | Trained counsellors | Total |
|---------------------------------------|--------|---------|------------|---------------------|-------|
| Hospital one                          | 2      | 1       | 1          | 1                   | 5     |
| Hospital two                          | 1      | 1       | 2          | 1                   | 5     |
| Hospital three                        | 3      | -       | 1          | 1                   | 5     |
| Age Ranges (in years)                 | 26 -56 | 40-42   | 43-55      | 32-39               |       |
| Years of experience at the ART clinic | 1½ -23 | 6-10    | 9-12       | 5-8                 |       |

**Table 3.3: Demographic particulars of patients on ART**

| Hospital       | Males | Females | Years of receiving ART | Age range (in years) |
|----------------|-------|---------|------------------------|----------------------|
| Hospital One   | 4     | 1       | 4-11 years             | 38-63                |
| Hospital Two   | 2     | 3       | 9 months -10 years     | 40-51                |
| Hospital Three | 1     | 4       | 3 – 7 years            | 27-42                |
| Total          | 7     | 8       |                        |                      |

### 3.5.1 Theme 1: Patients' experiences in relation to having been diagnosed and Living with HIV

A diagrammatic presentation of Theme 1 with its related sub-themes is presented in Figure 3.1 below:



**Figure 3.1: Participants' experiences in relation to having been diagnosed and living with HIV**

Experience has been defined as a particular situation that happens to the person and which affects them (Hornby, 2010:514). From the research findings, it became obvious that the patients had various experiences in relation to having been diagnosed and living with HIV. The various experiences shared with the researcher related to the emotions that they went through, when they were first told of their HIV positive status, the level of stigmatization and the extent to which they were discriminated against by their families, spouses, friends and neighbours, their suffering with the side-effects associated with the treatment, as well as the significant consequences linked with the

misdiagnosis of the type of HIV and the various challenges they experienced in adherence to ART.

Furthermore, the experiences of lifestyle modification made by the participants and their improved health status while on ART were also shared by the participants with the researcher. The seven sub-themes that emerged from Theme One, as depicted in Figure 3.1 above, will further elucidate the various shared experiences of the participants in the following paragraphs.

### **3.5.1.1 *Sub-theme 1.1: Participants experienced various emotions after being diagnosed with HIV***

The participants indicated that they had experienced various emotions after receiving a positive diagnosis of HIV and these emotions were expressed in various ways. The various emotions experienced by the participants included shock, disbelief, surprise and fear of death. The various emotions that the participants experienced will be highlighted and described in the paragraphs below.

The participants expressed being shocked, when they received the news of their positive HIV status. This was attributed by some of the participants to the fact that the diagnosis of a positive HIV status is known to be associated with promiscuity and, since they perceived themselves as not being promiscuous, the news came as a shock to them. The participants expressed being so shocked that it actually made them feel physically weak and, in some cases, they were unable to sleep for almost three days. One participant indicated that he did not only have to deal with the shock of receiving his positive HIV status; he also had to deal with the shock of discovering that there was a possibility that his son could also be infected with HIV.

The participant indicated that he was indeed shocked when he learnt that his son who was not sexually active was infected with HIV because he was not knowledgeable about the other ways in which HIV is spread, for example, mother-to-child transmission. There appears to be a silence on other means of transmission of HIV, such as transmission from mother to child, hence the lack of knowledge expressed by a participant on this possible means of spreading the HIV virus. These views are evident in the following quotations:

*“I was just shocked. Something was just going through me. I wasn’t the type who jumps from one man to another...” (P1:1).*

*“... When I was told [that I am HIV positive] I was shocked. In fact I thought all was gone because I had no idea in fact it was not easy for me at all because telling me that alone I got weak I got totally weak and I could not sleep for almost three days (P4:3).*

*“...But what shocked me was the small boy; by then he was nine months; it was the boy, for about two or three weeks I couldn’t eat if I looked at the boy... (P10:1).*

The research findings described above are similar to the findings of Anderson, Elam, Gerver, Solarin, Fenton and Easterbrook (2010:1495) in their study. *“It took a piece of me.”* was the initial response to a positive HIV diagnosis by Caribbean people in the UK.” This described how most participants in their study reacted with total shock when informed of their HIV positive status.

Some participants expressed feelings of disbelief and being unable to accept a positive HIV diagnosis. They, therefore, went to a private pathologist to be re-tested to confirm their HIV status diagnosis. One participant indicated that she was very surprised to receive a positive HIV result because she was married and her husband had been tested, and found to be negative. Some participants even experienced suicidal tendencies when being diagnosed as being HIV positive. The following quotations indicate their expressions:

*“Actually, I did not believe it, it was... I was not scared though but I did not believe it so I had to go for a test in a private laboratory where no one asked me to go to so, I went there and then, it [HIV test] was still positive...” (P14:1).*

*“...I felt surprised, I was surprised about it [HIV positive results] because as a married woman I was told my husband was not having the disease but I had... in fact it was a surprise thing to me... very surprised.” (P7:1).*

*“...when I left the hospital on my way just at the main gate I met a man selling medicines for rats; so I said this is the best way to end it for me; so I bought it*

*and joined the car ... I alighted then I saw this tipper truck coming; because there was traffic at the other side of the road; then I said oh this is an opportunity this can even make it faster; so I stood in the middle of the road and the tipper truck was also coming; so there was this guy that was also trying to cross the road; so he came to pull me; so we all went to the other side of the road ...”* (P12:2 ).

The findings of this study described in the above paragraphs appear to be congruent with the findings of the authors Kako and Stevens (2011:283, 285) who, in their study on “*Where will this illness take me?*”, found that participants reacted with disbelief and suicidal thoughts; whilst others reacted with resistance and denial. In another study, conducted by Morphey, Kunkel-Mains and Quick (Nd: 2), it was found that people, upon discovering their positive HIV status, usually expressed feelings of hopelessness, which in turn could lead to suicidal thoughts and actions soon after being diagnosed. Anderson *et al.* (2010:1495) also found in their study, that most participants were in denial when they were informed of their HIV positive status and some also decided to commit suicide by locking themselves up and overdosing with pills.

The notion that HIV is a killer disease and has the tendency of taking the life of the patient at any time caused the participants to have sleepless nights. The fear of death shattered the participants, and made them feel distraught. They came face to face with death as this was evident to them with the experience of drastic weight loss and change in physical appearance that is typical of the terminal stage of HIV. These thoughts and feelings caused sadness, as well as depressed feelings. These are evident in the following quotations:

*“I felt very bad, very bad very bad; I thought I will die because I became very lean...”* (P6:1).

*“I did not have it easy at all; I even could not sleep; I could not eat because I heard some people say that AIDS is a killer disease it can kill you at any time; so I did not have it easy at all”* (P3:7).

*“I was very down, thinking I was going to die probably the next month or next two months to come, or a year. I was devastated and very much sad” (P15:1).*

According to Ho, Twinn and Cheng (2010:210) people are worried about death upon knowing their HIV status. This sub-theme highlighted the various emotions of shock, disbelief, denial and sadness, depressed feelings, as well as the fear of death, experienced by the participants after being diagnosed as being HIV positive.

### **3.5.1.2 Sub-theme 1.2: Participants had diverse experiences related to stigma and discrimination**

The stigma relates to the perception and the behaviour of people; while discrimination is the externalized stigma towards persons living with HIV. These are based on negative views such as unfairness, negative attitudes, abuse and ill-treatment, which are directed at people because they are seen as belonging to a particular group, or are perceived as being different (Famoroti, Fernandes & Chima, 2013:8). All discrimination is therefore intentional. The stigmatization and discrimination experienced by the participants in varied forms will be described below.

The experience of stigmatization was described by a participant as a situation where he was denied access to the family’s toilet and bathroom facilities in the house because of his HIV positive status. He indicated that the family did not appear to understand the education provided to them with regard to HIV, because they would pretend that they did not know where the key to the toilet and the bathroom was when he needed to use the facilities but, when they needed the facilities, then the key would be available for them. He was compelled to share a toilet facility with tenants in a compound who had no problem sharing with him since they did not know his HIV status. This was how he described his experience:

*“The family... I do not share things common with them. They find it difficult it seems to them the education has not gotten down well with them...at times if I want to go to toilet or bathroom the toilet is locked where is the key? They cannot find the key; but if they want to go then they will just get the key so in the compound now I am sharing everything with the tenants. The family’s own that we share together they have exempted me; but I am not worried... but the tenants are not aware of my status” (P10:1).*

To this participant, the action of his siblings was a result of their limited knowledge on the mode of transmission of the HIV virus, hence they acted ignorantly. He was very aware that the sharing of a toilet facility could not serve as a means of transmitting the virus to others; he was, therefore, not bothered much about their maltreatment.

In some instances, the family members of another participant were unwilling to accept her and live with her; as they used to do before. They stigmatized her by not wanting to drink from the same source with her. This was how one participant sadly described it:

*“ ...my sister has this daughter she was one year before I ...could carry the daughter and feed her etc; but I came back from the hospital and the little girl came to me and my sister exclaimed eehhhhh!! Sometimes when I go to visit her and I drink water and the daughter want to take she is like no let me give you another one ...I will take the water the baby will say let me drink the rest and the mother will say no no no go for another one so sometimes I sit and I am like ...my sister is doing this because of what I am going through (P2:4).*

The participants felt stigmatized because after disclosing their status to family members, they would not use items that the participants had used because of the fear of also becoming infected with HIV. Some family members did not provide support to the HIV positive participants; and they did not want to have anything to do with them. In some instances, the family food that was prepared by the participant was rejected by the family members because they had discovered her HIV positive status via her aunt, who was a midwife and worked at the hospital where she was admitted. The family members usually enjoyed the food that she cooked for the family when they were unaware of her HIV status.

Even the children of HIV positive persons were discriminated against. This was evident by family members being afraid of holding or touching their children; and they also prevented their children from playing with them. The following direct quotes illustrate this:

*“I had to disclose to my family from there; though they didn't expose me outside but within us, they do not want me to use their things they have separated from me ... so anything that I collected from them they make sure they do not use it*

*again so up till that stigma is there ... Since I had the problem to, I have not had support from any of the family...” (P10:1)*

*“I felt sick I was admitted here and so an auntie who was a midwife came to see me and she saw it in my folder... she went to the extent of telling my cousins and others in the house... in my house because she told my cousins and all the others in the house I sometimes cook for all in the house to eat and when I cook nobody will eat again and even my child nobody will even touch him or even play with the child” (P12:3).*

To substantiate the above statements on the diversity of experiences related to the stigma and discrimination of HIV positive clients, Chen, Choe, Chen and Zhang (2007:669) found that people are often distanced from people affected by HIV; because of stigmatization. At the individual level, full and accurate knowledge of the mode of transmission of HIV tends to reduce the stigmatization of persons living with HIV whilst inaccurate beliefs tend to increase the stigmatization.

The participants felt that they were being discriminated against by their spouses; according to one participant, the spouse perceived her to be useless, and someone who would soon die and hence, did not see the need to stay with her and to offer her the necessary love and support. This was how she narrated her experience:

*“I met another person he knowing my status started misbehaving seriously sometimes when he comes and we talk he sees me like even you are dying so what is the use staying by you...(P2:4).*

Another participant perceived his wife to be uncaring, discriminating and unprepared to take care of him. The wife was no longer interested in the marriage and requested that the husband live with his parents so that they could take care of him; she threatened to divorce him. He felt rejected by the wife and the participant felt so much hurt that he wished that God could punish his wife. This was how he passionately described his experience:

*“I was sick and my wife called my parents and told them that if they do not come for me and I die, they should not ask her anything... my wife says she is divorcing me...she told me you are sick why don't you resign from your work,*



*pack your things and go to the village... I mean if God is a person like you I will tell Him to punish her seriously... (P6:1).*

The findings of the study described in the above paragraph seems to be congruent with the findings of the author, Visser (2007:1), who reported that people manifest a stigma towards persons living with HIV or AIDS because of fear of the contagious nature of the disease and the fear of death. The fear of being infected with HIV leads to negative attitudes towards affected people and an unwillingness to interact with persons living with HIV.

The participants expressed various levels of stigmatization and discrimination by friends and neighbours. Most of it related to their refusal to share personal and non-personal items with them and they felt this was due to their positive HIV status. A participant felt discriminated against when his friend with whom he used to share items started complaining of not wanting him to use his bath towel because he was now HIV positive. Another participant felt discriminated against to the extent that the water was shared by all the members of the household; the HIV-positive patient was prevented from fetching water from the pipe with her own bucket because they perceived that she and all her personal belongings were infected and hence, they were afraid of being infected. And this led to serious discrimination and stigmatization.

The following quotations describe how participants' experiences were described:

*"...I was using someone towel but then I had left my place and I was residing somewhere when I was discharged from the hospital...and the person complained..." (P8: 54).*

*"There was this advert on HIV ambassadors I was also one of them; so the day I came out they saw that thing on television and people were like hey...even I rented a single room that I was staying with the child then my landlord I think they saw it then they started. That day I went home and I wanted to fetch water, she shouted and said do not fetched madam move away. Then I was like what is it so in that house again they started like nobody in the house talk to me ..."* (P12:3).

To substantiate the above quotations, a study by Santos, Kruger, Mellors, Wolvaardt and Ryst (2014:9) reported that one of the great concerns of participants in their study was the relatively high level of discriminating reactions from spouses, friends, neighbours and work colleagues. According to Gilbert and Walker (2009:143), the family can isolate and embarrass the person living with HIV. Due to the fear of stigmatization and discrimination, some participants felt that it was better not to disclose their HIV status.

The experience shared by participants on their difficulties in the disclosure of their HIV status was considered by them as a means of protecting their relationship with other close relatives and friends. Most of them confirmed that they had not experience any form of stigmatization or discrimination because they had not disclosed their status. Some were compelled to disclose their status to at least one person who could serve as a treatment supporter, which was a prerequisite in the initiation of the ART. They felt very comfortable keeping their status as a private and personal secret and that they experienced difficulty in disclosing their status to fellow employees, parents, siblings and friends.

*“Nobody knows in the work side nobody knows...”* (P6:4).

*“I do come to the hospital with my mum; but she doesn’t know my status...”*  
(P14:2).

*“...I haven’t told anyone of my status apart from my family. I do not believe in telling people, that is one thing about me. With my job you go to people’s home and I hear them talk about it and the way a manner they act is like hey you have to be very careful...”* (P1:4).

For fear of stigmatization and discrimination by family, spouses and friends, most of the participants refused to disclose their HIV-positive status and they felt secure and protected. Fear of stigmatization and discrimination has been the major reason why people feel reluctant to disclose their HIV status (Seid, Wasie & Admassu, 2012:99). In another study conducted by Madiba (2013:54), it was found that disclosure among persons living with HIV was delayed for fear of discrimination; hence they kept their HIV status secret. Persons infected with HIV commonly experience lack of acceptance

and the fear of disclosure (Majumdar & Mazaleni 2010:7). Likewise, participants in a study by Walcott *et al.* (2013:4-5) struggled with the thought of how they would be perceived by the community after disclosing their HIV status; hence, some of them described non-disclosure as a means of avoiding stigmatisation by the community.

The above findings are, however, in contrast to those of a study by Patel, Ratner, Gore-felton, Kadzirange, Woelk and Katzenstein (2012:5). These authors found that there was a high disclosure rate from their participants. These authors indicated that when those who are HIV positive are able to disclose their status to someone, greater self-esteem, lower symptoms and better quality of life ensue.

In a similar study, the bulk (81%) of the participants in the study disclosed their status to at least one person; and this was a deviation from the belief and perception that individuals diagnosed with HIV do not usually tell others about their HIV status (Makin, Forsyth, Visser, Sikkema, Newfed & Jeffery, 2008:912). This sub-theme highlighted participants' diverse experiences related to stigmatization and discrimination, such as rejection by family and friends.

### **3.5.1.3 Sub-theme 1.3: Participants experienced side-effects of the ART**

The side-effects experienced by the participants, whilst on ART was one of the challenges that participants highlighted. The participants indicated that they experienced side-effects such as rashes, dizziness, vomiting, nightmares, diarrhoea and generally just feeling ill. Some of the participants indicated they were informed of the possible side-effects of the drugs by the counsellor, while others claimed that they were not informed of the expected side-effects. Some of the participants felt the side effects were very prominent with some of the drugs that were administered as part of ART. The following are descriptions of how they shared their experiences with regard to the side-effects experienced:

*“... the counsellor told me about the side effects that you can have some rashes and really too I had it and some dreams and the dizziness also ... The experience I had when I started taking it, it was, em you know like a nightmare some strange dreams always feeling very dizzy. The dizziness was very serious... (P8:2&4).*

*“...some of them their eye, everybody and the reaction but me I didn't see any reaction on it only the toilet for three days... we have problem with it at times they give you some the specific one if you take it you feel fine your body will be fine at times; if they give you some you do not feel fine your body will not be fine” (P11:1).*

*“...the medication they did not tell me it will [have an effect on me]... when I started initially like for the start I will have some symptoms like dizziness. Vomiting etc with my story when I started I had this nightmare seriously...” (P2:3).*

To substantiate the above statements on participants' experience of the side effects of ART, Johnson and Neilands (2007:69) found in their study on the side-effects of anti-retroviral medication on HIV-infected individuals, that there are both predictable and undesirable side-effects, as well as dose-related pharmacological effects that occur within the therapeutic dose ranges. Gastro-intestinal problems such as nausea, vomiting, diarrhoea, as well as fat distribution and dermatological problems, such as rashes, are the most common side-effects experienced by persons on ART. There is evidence that severe side-effects occur in most patients on ART. Most of the severe adverse drug reactions were gastro-intestinal disorders, haematological and skin reactions (Bezabhe, Chalmers, Berznicki, Peterson, Bimirew & Kassie, 2014).

Agu and Oparah (2013:121) found that a total percentage of 47.7% of the participants in a study reported adverse drug reactions after initiation of ART. In a related study, 90% of 321 participants experienced at least one adverse drug reaction. It was, however, established that there is a high degree of adverse drug reaction that occur among clients who are on first-line ART with Zidovudine, Stavudine or a Nevirapine-based regimen (Shet, Anthony, Arumugam, Dodderi, Rodrigues & DeCosta, 2014:6). Fatigue joint pains, neuropathy and insomnia were noted to be the most common side-effect in terms of patients' health status (DiBonaventura , Gupta, Cho, & Mrus, 2012:750).

The side effects experienced by the participants negatively influenced their adherence to the ART regime.

#### **3.5.1.4 Sub-theme 1.4: Misdiagnosis of the type of HIV has significant consequences**

This sub-theme describes the experiences of a participant who felt she was wrongly diagnosed with the type of HIV; and that she was erroneously treated. She had a lot of unanswered questions bothering her because she encountered one doctor who diagnosed her with HIV-Type 2. She indicated that she experienced frequent changes in her ART because of her unstable immune system and her failure to respond to treatment as expected. This is how she described her experience:

*“...my medication story became something else; because today they give me this the immune goes up tomorrow I take the same medicine and the immune comes down so they had to add [additional medication]. I took almost all till today I will go they will give me this may be it will work for maybe a month or two the immune will come down again then I will have to change to another then I will wait for one or two months then it will come down again so like they were changing medicine here and there for me” (P2:3).*

This participant encountered another doctor, aside from her usual doctor, and at the time she had lost her sight after taking the ART for three years. This new doctor on enquiring what happened to her and being informed that it was as a result of the ART checked her drugs again and concluded that she had been on the wrong treatment for her type of HIV. Based on that, her ART was changed to a new one; after which she started experiencing improvement in her condition. This was how the participant narrated it:

*“...so when I met the doctor and he said the medicine I was taking was not for the type 2, it was for type 1; so he will change and let see what happens. So, the doctor changed my medication and I could see there is an improvement” (P2:3).*

This client strongly believed that her predicament and experienced side-effects of blindness was as a result of misdiagnosis of the type of HIV infection and the administration of inappropriate treatment. She perceives the medical professional as having damaged her sight with the misdiagnosis and the issuance of wrong medications. She expressed it emotionally this way:

*“...but when I sit down and I think about it that is what come in to my mind, they destroyed my eyes because if it is really type 2 and I took type 1 medication for almost 4 years before and this type one medication is linked with the eye medication then something has happened...” (P2:8).*

To authenticate the above quotations on the consequences of misdiagnosis of the type of HIV infection, a study on the re-testing and misclassification of HIV 2 and HIV 1 and 2 dually reactive patient among the HIV 2 cohort of the West African database found that out of the 312 participants who were initially diagnosed with HIV 2 infection, 16 of them, comprising 5%, were reclassified as HIV 1. Also, out of the 235 patients initially classified as HIV 1 and 2 dually reactive, only 23% were readily confirmed as being dually reactive; while 43.8% and 14% were reclassified as HIV 1 and HIV 2, respectively. This then leads to premature initiation of preferred second-line of ART in many HIV 1 infected patients in areas with limited access to treatment options (Tchounga, Inwoley, Coffie, Minta, Messou, Bado, Minga, Hawerlander, Kane, Eholie, Dabis, & Ekouevi, 2014:5).

In relation to a client suffering from an eye problem due to the effect of the ART, Parekh, Oldfield and Marik (2013:1) found in their study that the majority of the HIV-infected persons were treated for an HIV-associated eye disorder during the course of their illness. Ocular manifestations of HIV are, therefore, quite common. Proper diagnosis of the type of HIV is, therefore, very important, in order to achieve a good outcome for a patient's adherence to the therapy

### **3.5.1.5 Sub-theme 1.5: Participants acknowledge that managing HIV requires a change in lifestyle**

The participants indicated that they had to change their lifestyle, in order to manage their positive HIV status and to maintain a healthy status. The lifestyle changes made by the participants indicated in the quotes below included no alcohol consumption, dietary changes, taking dietary supplements, cutting down on sugars, doing exercises and no longer engaging in immoral sexual activities.

*“I had to just change certain things because I was sick. I use to stay out with my friend to take red wine which had alcohol but I was told not to take alcohol so I happened to change my diet and I really like to do a lot of exercises but my*

*favourite is yoga because I like to stretch a lot and once a while I go for jogging and I make sure I take my dietary supplement. I don't forget to take my water too, it is something that has to be part of me, taking a lot of water, exercising, eating well and staying away from alcohol and a lot of things that you do not have to do" (P1:1).*

*"it is that now I take very good care of myself I do not do things that will disturb me I do not eat anything, I do not do things that will disturb my life, I do not go out with friends drinking and doing all sort of immoral things; so when I close from work straight away I came to the house" (P 3:6).*

*" I was told not to take alcohol and not to take so much sugar. I was told to be exercising daily..." (P7:2).*

From the expressions above, the participants had to adapt to a new way because this is known to be a life-long chronic condition. To substantiate the above quotations, Ho *et al.* (2010:216) reported that when people are faced with a life-threatening or chronic illness, they tend to change their lifestyle, internal values and standards to accommodate the adverse circumstances.

The participants indicated that it was initially difficult to accept that they had to take medication regularly for the rest of their lives. They have now adapted to this thought over time and they appear to be comfortable and are coping with their medication regularly. Some participants shared the strategies they use to remind them when their medication should be taken.

*"You know it was difficult because for me I do not like taking medicine so when I was told I was going to be on it for life I said wow, it was not easy; but now I will say I think it is part of me now" (P15:2).*

*"Yes and I choose a time that is suitable for me by then I am up from bed I could brush my teeth and do one or two things before that time and on that same time I do take my medication then at night I do sleep late; so the same time that I take my medication in the morning I do take it the same time at night that is what is keeping me; but I have gone through this for so many years that it is part of me if I do not even have my watch on and it is my time immediately it*

*gets to me it tells me hey boy you have to take your drug; so it's kind of used to me" (P4:4).*

*"In fact I am tuned to that and I know I must take it so as soon as the time comes except that I am asleep but even if I am asleep maybe 10- 20 minutes time I will just wake up and then remember to take it" (P 9:2).*

The findings from this study described in the above paragraph appear to be congruent with the findings of Henriques, Costa and Cabrita (2012:3099) who state that patients integrate the management of their medication into their daily lives, and they seem to accept the medication as an unavoidable part of their lives in maintaining the quality of life. In another study conducted by Merello, Chynoweth, Kim, Singh and Hirsch (2011:148), it was found that the majority of the participants in their study saw medication as part of their daily routine. Adherence to the ART becomes less burdensome, when patients are able to integrate the medication-taking habits into their daily lifestyle.

#### **3.5.1.6 Sub-theme 1.6: Participants experienced improved health on ART**

The participants indicated that they experienced their health growing from strength to strength since they have been on the ART. The participants shared with the researcher that they had only experienced minor fevers since being on ART, unlike in the past when they had experienced severe fevers. Some participants indicated that the ART strengthens their immune system; while some of the participants indicated that the ART strengthened them to the extent that they were able to get up and do everything for themselves, and no longer felt weak.

*"...madam since I was put on this drug I have never been sick that I should say I am sick maybe minor cold fever not really a fever when I remember when I wasn't on this drug I could get a severe fever ...my medication is making me look good and good and good and good up to now I think the medication is really doing me good it is keeping me going" (P 4:5).*

*"My health is gradually developing because I take the drugs regularly it helps me in developing my immune system" (P13:1).*



*“...in fact at the initial stage I was weak and since I started taking it I got up and later I could do everything so I know that can help me...”* (P9:1&2).

It is evident from the above quotations that the ART improved the immune system of the participants, making them less prone to developing any illnesses. According to Bezabhe, *et al.* (2014:7), patients experienced improved health that inspired them to continue taking their medication. In another study, conducted by Stenson, Charalombous, Dwadwa, Pemba, DuJoit, Baggaley, Grant and Churchyard (2005:950) on *“Evaluating of anti-retroviral therapy-related counselling in a workplace-based ART implementation group in South Africa”*, it was found that 63% of the participants reported improvement in their health in areas such as increased strength, more energy, better appetite, weight gain and decreased symptoms of disease.

The improved health experienced by the patients on the ART served as a motivation to them and hence it enhances their adherence to the ART.

### **3.5.1.7 Sub-theme 1.7: Participants cited diverse challenges as barriers to treatment**

The participants experienced adherence to ART as challenging with numerous barriers. This sub-theme presents the various barriers experienced by the participants in adhering to ART. Participants in this current study expressed the desire to know more about HIV itself; they expressed the view that they would do better on the medication if they were better educated on it. They expressed having limited knowledge of the whole complex mechanism; and this was the information they received from the healthcare providers before they initiated the ART. The possibility of these participants defaulting, and hence not adhering to the treatment, was very high because they have inadequate knowledge on the condition and its required treatment. The following are the responses from the participants on HIV and the ART:

*“... if more education is given to me I will be ok with it...I want to know about it I want to know more about the HIV* (P15:5).

*“I was told that when I take the drug I will be very healthy and live my life like any other person... I cannot remember some of the things they told me ...”* (P13:2).

*“I was told that when I start taking the drug sometime it can give me some complication after sometime I will be normalized and that is what I also expected and it has helped me” (P 7:2).*

Lack of understanding regarding the effect of ART serves as a major barrier to adherence to the therapy. To authenticate the above, Murray (2009:4) stated that lack of understanding of treatment benefits is one of the barriers to adherence. Similarly, Muduka and Tobin-West (2015:159) reported that poor understanding of the effect of the drugs contributes to non-adherence to the treatment.

Another factor that was stated by the participants to contribute to non-adherence to the therapy was forgetting to take the drug. This is evident in the following quotations:

*“Once in a while you may go somewhere or you may be in a haste to go somewhere you forget to take your drug so you can miss it in the morning but in the evening you take” (P10:9).*

*“...what happened was I was going to bed and where my medicine was it was far from me so I was there like I will get up I will get up I was feeling lazy I will go I will go but before I realised I slept off” (P14:3).*

*“There was a time when it was almost time and I was about to take my drug then I felt sleepy [asleep]...” (P13:3)*

According to Oku, Owoaje, Ige and Oyo-ita (2013:6), the major reason cited by participants in their study for missing a dose of ART was operating a busy schedule and simply forgetting to take the medication. In the same vein, Hansana, Sanchaisuriya, Durham, Vanpharnom, Chaleunvong, Boonyaleepun and Schelpe (2013:8) also stated that forgetfulness was identified as a significant variable in predicting adherence. Similar to the above, Musumaria, Feldman, Techasrivichiena, Wouters, Ono-Kiharaa and Kiharaa (2013:1275) reported that forgetfulness was a common reason for skipping doses by the participants in their study.

The participants also cited travelling and leaving the drug behind, as one of the main challenges to adherence to the therapy. An unpredicted length of stay when they travel was a shared factor. In situations where the participant may not have a good idea of

when he or she is returning to the drug because s/he did not take the drug when travelling. This caused non-adherence to the treatment regimen. These are evident in the following quotations:

*“...in fact there was some time that I defaulted, I travelled and I was short of drug so I couldn't take it for a week and when I came back and I started taking it then that dizziness started again...” (P 8:3).*

*:...I remember I travelled to my home town and then from there I went to another town very unfortunate I forgot to take the medicine, so I returned late so when I came back when the alarm clocked then I remember that I have forgotten something so I rushed down with dropping and then told the people that I am going, so it took me about 30 minutes so as soon as I got to the town I just run and then took it. There was also one instance that one I did not take it at all till the next day” (P3:3).*

*“I think it was once I travelled at a weekend and I didn't take it for I think two days, in fact I did not know I was going to travel when I came to work before I was asked to travel, so that I didn't take it I didn't border though when I came back I reported to the doctor and said there is no problem with that so I didn't have any problem” (P9:2).*

The main reason given for non-adherence was being away from the medication at the dose time, or when they were supposed to take the drugs (Senkomagoa, Guwatuddeb, Bredac, & Kaveh, 2011:1250). Patients tend not to carry their medications with them when they travel and hence they see travelling as a vacation from medication (Taylor, Reyes, Levine, Khan, Gardun˜o, Donastorg, Hammer, Brudney & Hirsch, 2014:291).

Financial difficulty was one aspect of the challenges to adherence to the therapy that the participants shared. Their inability to afford transport to the ART clinic to collect their anti-retroviral therapy, the lack of money to purchase food that the body needs before taking the drugs, as well as their inability to pay for the highly subsidized ART served as potential barriers to their adherence to the treatment. The following quotations depict their shared experiences:

*“... if they do not have families who will step in then definitely you will die because to get what to eat and to get money to come to the hospital will be a problem, most of the frustrations will make you go...” ( P10:6).*

*“ooh in fact, eemm, right from the beginning it was very difficult for me because the medications are quite solid quite big you know my type of medication that I am taking the Alluvia the Abacavir they are quite thick so initially taking it was quite difficult but I have gotten used to it that I do not bother any more ...but when things were bad and sometimes I do not have anything to eat taking the medications scares me because I know what I am going to face after one hour if I do not get anything to eat” (P4:8).*

*“We buy the drugs at GHS 5 so if they can make it free it will help because somebody do not have, they do not have money that is why they do not come if they do not have money they will not go and people do not take because it will finish so if you can tell them that the drug should be free” (P5:4&5).*

To substantiate the above quotations from the participants, Taylor *et al.* (2014:291) cited the rising cost of transport to ART clinics for clients living quite a distance away from the clinic, as a barrier to adherence to the treatment. Similar findings from a study by Musumari, *et al.* (2013:1275) indicated that patients expressed difficulty in securing money for transport to visit the clinic. Furthermore, Bezabhe, *et al.* (2014:7) stated that participants in their study missed pills and stopped collecting drugs from clinics when they could not afford to buy food. The various barriers discussed above contribute substantially to participants' non-adherence to the ART regimen.

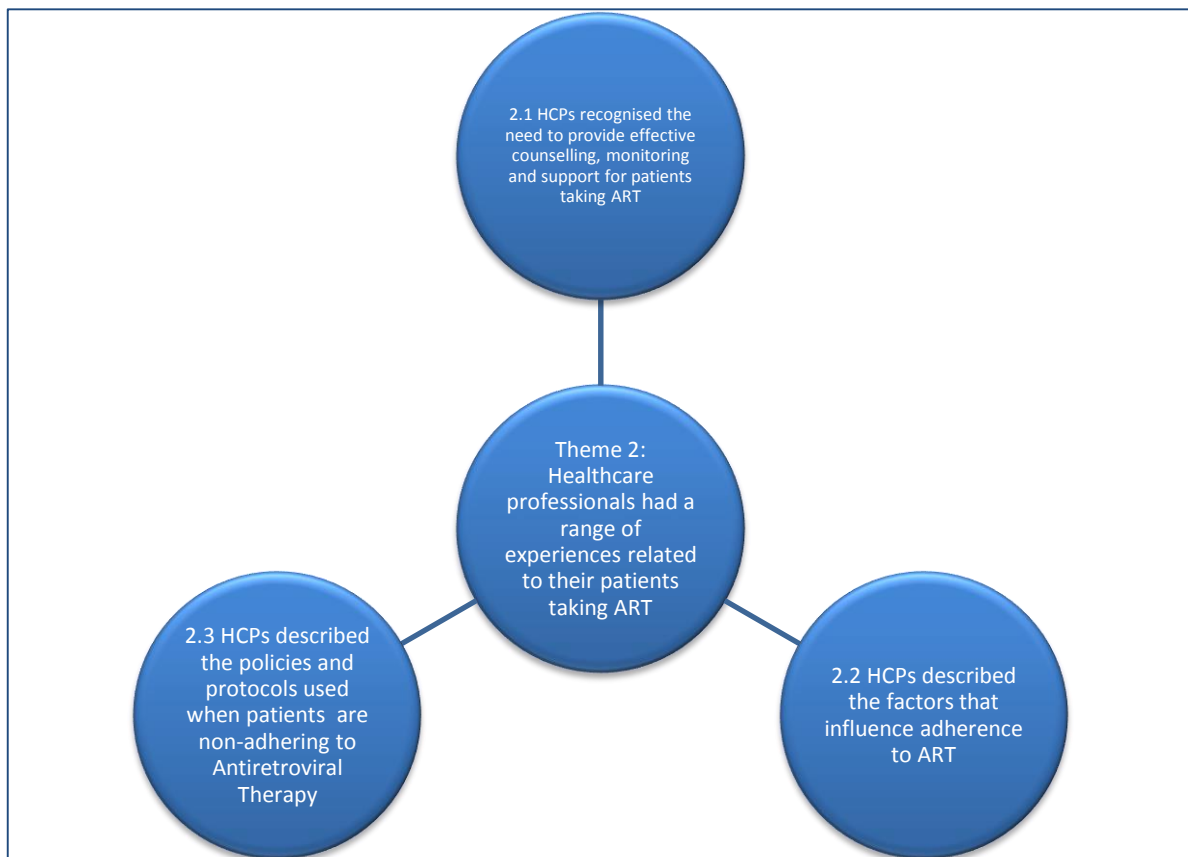
### **3.5.1.8 Summary of theme 1**

Seven sub-themes emerged in theme one, which highlighted the experiences of the participants in living with HIV. The main significant experiences expressed by the participants included expressions of shock, disbelief, surprise and fear of death. Participants also experienced stigmatization and discrimination because of their HIV status as well as the side-effects of the ART. These side-effects comprised dizziness, vomiting, nightmares, diarrhoea and feeling unwell.

Further, they experienced some expected lifestyle changes when managing HIV. These included changes in eating, drinking and sexual habits, as well as the daily habits of swallowing drugs. Diverse challenges cited by participants as influencing their adherence to ART included lack of understanding of the condition, forgetting to take the drug, travelling without the drug and financial difficulties.

### 3.5.2 Theme 2: Healthcare professionals had a range of experiences related to their patients taking ART

Generally, in theme 2, the experiences of healthcare professionals in relation to patients taking ART were shared. Below is the diagrammatic presentation of theme 2 with its related sub-themes.



**Figure 3.2: Healthcare professionals' range of experiences related to their patients taking ART**

According to Figure 3.2 above, three sub-themes emerged relating to the range of experiences of healthcare professionals with regard to their patients taking ART. The three sub-themes will be described below.

### **3.5.2.1 Sub-theme 2.1: HCPs recognised the need to provide effective counselling, monitoring and support for patients taking ART**

Healthcare professionals expressed the need for the patients receiving ART to be provided with effective counselling, monitoring and support. According to the HCPs, the counselling provided to the patient focuses on information relating to what the patient needs to do or not to do, in relation to taking ART, the possible side-effects of the ART, the importance of good nutrition, the need to adhere strictly to the treatment and how to live a safe lifestyle. The following quotations depict their views:

*“...but when it comes to the drug itself you need them to know the do’s and don’ts ...also made them aware of the various side effects of all the drugs...how to manage these side effects at home...so when it happens like that they do not stop....we happen to tackle smoking, alcohol abuse and all those things can reduce the efficacy of the drug. And then also when it comes to drug adherence too we do not have anything like drug holiday you should appreciate that you are taking the drugs for the rest of your life unless of course it has to be changed and that, it should be the physician or the health worker to decide” (P 27:2).*

*“We emphasize on the nutrition aspect too so we talk about a balanced meal, and what makes up a balance meal. Again, we draw attention to it that it is not the cost but it is the choices that people make; so why are we eating balanced meals because that will help the immune system to develop faster and I will not end by not talking about fruits and vegetables the roles that they play in our diet so we mention all that... remind them about the way we can spread the virus again and caution about prevention so the condom use and not sharing personal things like the toothbrushes etc” (P 21:4).*

*“...we talk about the HIV virus itself ...the ways of contracting the virus and then we talk about how to take care of themselves, eating good nutrition when we talk about not taking alcohol, not smoking and other things that you cannot do... the last thing we talk about is the medication itself trying to get you to understand what is going on before we tell you about the medication; so after you have understood all this, is how the medication is; so, if you do this and this then I think that you will have a normal life” (P 19:3).*

The findings of this study described in the above paragraph appear to be congruent with the findings of Holtzman, Brady and Yehia (2015:449) who state that there must be provision of general education and counselling in order to ensure that the clients remain on ART. According to MacPherson, Munthali, Ferguson, Armstrong, Kranzer, Ferrand and Ross (2015:1019) for patients who received counselling on ART adherence, the chance of adhering to ART was greater than with those who did not receive counselling. Low perceived quality of information from healthcare providers has been identified to be among the factors that remained significantly associated with subnormal adherence to ART (Do, Dunne, Kato, Pham & Nguyen, 2013:5).

Healthcare professionals from this study also described the importance of providing effective monitoring for patients taking ART. The participants indicated that they monitor the drug-taking habits of the participants by speaking to the individual patients and enquiring from them whether they are taking their medication regularly on time and whether they had missed any doses. The self-report provided by the patients in this regard assists the HCPs to have an idea of the patients' adherence to the treatment. The following quotations describe how self-reports from the patients serve as a means of monitoring their adherence:

*"When the patient comes like sometimes we talk to them individually I sometimes do one on one with them like you ask them 'are you taking your medications well? What time do you take it? Have you missed a pill before? Why did you miss a pill?'... " (P28:2).*

*"...you know, asking them how they are taking the medicine the timing...you have a chat with them... but if a person wants to lie I tell you he will lie and there is nothing you can do about it; so we ask them 'are you taking your medication? Are you taking it on time? How are you taking it?'... sometimes me, I will ask for them to bring it or to show me which one you are taking at what time ... you know just to be sure that the person is taking the right medication at the right time" (P19:3).*

*"I usually ask when was the last time that you forgot to take your medication? And they are taken off-guard; so they say it or, are you still taking it at 7pm;*

*meanwhile the person takes the medication at 9 and they says yes; so is it 9 or 7 ...” (P24:2).*

The above description is in agreement with the findings of Holtzman *et al.* (2015:449), who maintain that there must be periodic monitoring of medication adherence among the patients using a patient self-report to ensure ART adherence.

The use of self-reporting was verified by the HCPs with pill counting, which was described as a means of physically counting the drugs that the patients brings from home to the clinic, and comparing it with the amount of drugs issued at the last review date, in order to determine whether the patient is adhering to the therapy, or not.

*“Sometimes too you have to count their pills to see whether based on the pill count you will know whether the patient is taking it or not” (P28:2).*

*“Then you check the date that they have been on the drug and you count the pill[s] that is when you find out that they have been defaulting; because if you want to rely on their own submission you will not reach anywhere” (P23:3).*

*“...we request that they bring their drug packs that they have; so every visit we see their drug packs and we see how empty the drug boxes are...” (P17:5).*

Holtzman *et al.* (2015:448) described pill counting as a measure for monitoring and ensuring medication adherence; because pill counting involves counting the number of remaining doses with the patient; so that one could detect whether the patient had missed any doses.

Apart from the self-reporting and the pill count, HCPs also indicated that they use laboratory tests to monitor patients' adherence to the ART effectively, as well as their response to the medication. The laboratory investigations are carried out, in order to ascertain the level of the viral load, the CD4 cell count and the Mean Corpuscular Volume (MCV) of the patients in response to the treatment that the patient is receiving. The various blood tests also indicate how well the patient is responding to treatment. This is done to check whether the patient is adhering and doing well or not on ART.

*“So, there are labs [tests] that we do to find out if the quantity of virus has gone down to the lowest level that we expect ...” (P21:3).*



*“... We do that by using the labs [tests], most importantly the CD4 cell count that is what we do. Normally, before they start we have the baseline we let them do all the labs [tests] the general labs [tests], the Liver Function Tests, the Blood Urea, Electrolytes, the cholesterols, the hepatitis B, Full Blood Count; so we use that as the basis for checking whether the person is doing well, or not doing well. ...We first use the CD4 and if the person is taking the drugs well under normal circumstances, the CD4 should increase...” (P21:3).*

*“But sometimes I look at the labs [tests] not only the CD4 and the viral load but some you can look at their [Mean Corpuscular Volume] MCV, which people do not know and we do not talk about it that often. Anybody on treatment I should see a change in your MCV” (P24:2).*

The findings from this study described above appear to be congruent with the findings of Holtzman *et al.* (2015:449). These findings maintain that the use of the viral load, as well as plasma concentrations of medication were means of monitoring the patient's adherence to the prescribed treatment.

Healthcare professionals also described the monitoring of the patients on the ART with the assistance of treatment monitors, who are close relatives of the patients and are living in the same house as the patients. The treatment monitors are expected to ensure that patients take their ART by reminding them when their drug doses are due. They also accompany the patients to the clinics for a repeat of their treatment. Sometimes the HCPs do check on the monitors to ensure they are playing their roles, as expected. They are also required to provide the HCP with pertinent information on the patient's whereabouts, including travels and mortalities. These monitors are described by the healthcare professionals as mandatory for the initiation of the ART.

*“...Before you can be put on the drug one of the conditions is that you bring a monitor. It is not an option, the monitor is to monitor the drug adherence of the patients, so the person has to live in the same house with the person or the same area, very close and then they should have the means of communicating. Once a while, we also call them [the monitors] to find out how they are doing, and how they are playing their role as monitors to the patients.. (P18:5).*

*“...The monitors who come with the client, because they are the principal focus in case of anything, they are the ones that we can reach out to, so we need a close relationship with those monitors to make sure that in case we are not hearing from the client ... you will just be there and they will come and tell you ohh the client is no more, or the client has travelled” (P27:4).*

*“So that person for instance is at home with you, the person knows you will go to the hospital in two weeks; so we expect that the person will find out whether you have been to the hospital, or not...the confidante at home we expect would help the patient to adhere to the treatment” (P21:7).*

A study on the role of parents and family members in ART treatment adherence by Knodel, Kespichayawattana, Saengtienchai and Wiwatwanich (2010:33) found that family members assist patients on ART to remember to take their medications; and by reminding the patients to go for new supplies of medication; they also bring them to the clinic for their appointment.

Healthcare professionals recognised the need to support the patient on ART by providing the patient with all the needed information on the condition and treatment, encouraging, praising, having a good attitude towards them, empathizing and motivating them on the treatment and also assuring them of good health if they continue to adhere to their treatment. The patients are also supported by assisting them with better timings of their medications to suite their lifestyle. They described supporting the patients in terms of listening to their concerns and assisting the patients to address them.

*“... Is more about our attitude towards them, helping them, counselling them once they come, empathizing with them... giving them the needed information and if they see the progress they are making... they are happy when you praise them you know that they are doing well so they will want to keep doing what it is that they are doing that is making them well “ (P16:10).*

*“... I think motivation can do when we motivate them it will help them to adhere to the treatment “(P22:3).*

*“...Based on the answers they give you have a way out you make it easier for them. If you need to change the time that they take it [the ART], which they set themselves anyway,... even if we need to change their doses schedule sometimes they forget the morning dose and they take the evening dose so if you can lump it all up into one dose to make sure that they take and adhere to therapy then we do that for them” (P26:2).*

According to Mishler (1984) as cited by Watermeyer and Penn (2012:609), the adherence behaviour of the patient on ART needs to be considered within the context of their circumstances, experiences, culture and psychological realities. It is therefore the responsibility of health care professionals to develop a shared understanding of each patient’s “life world”. Effective counselling, monitoring and support of patients on ART are likely to facilitate their adherence to the therapy.

### **3.5.2.2 Sub theme 2.2: Healthcare professionals described the factors that influenced adherence to ART**

This subtheme describes the various factors that HCPs perceived as having an influence on the patients adherence to the ART. The main factors that were described were patients not disclosing their HIV status, pill burden, improved health on the ART, socio-economic factors, side-effects from the medications, travelling and forgetting to take the drug, denial of the HIV positive status and blaming the cause of the HIV on spiritual forces.

Non-disclosure of the patients of their HIV status was described by HCPs as a barrier to adherence to the treatment. They shared that due to non-disclosure, patients expressed difficulty taking the medications in the presence of significant others with whom they lived but had not been able to disclose their HIV status to them. Adherence to the treatment therefore becomes a challenge to the patients. These are evident in the following quotations:

*“The challenge we were having was [patients indicating to them] ‘how will I take my medicine I have not disclose’. Disclosure became a problem so we had to counsel on those lines too.... ok some are having partners they have not disclose. [Patients asked them] ‘so how can I swallow the medicine if my partner is at home and not going away if my partner comes on leave it means I am on*

*drug holidays'...Somebody hid the medicine in the kitchen cabinet and when she is in the kitchen she takes it partner saw it and threw it away... “ (P29:2&4).*

*“Others will tell you somebody visited them who were helping take care of them and they couldn't take medication in their presence and it was so much at a point” (P30:6).*

*“...Some people they do not tell their family members of their HIV status because they will shy away from them and then it can also affect the patients from not taking their drugs because they have to hide their medication before taking it...” (P 28:2&3).*

Musheke, Bond and Merten (2012:5) state that, since the participants feared losing social and emotional support due to anticipated stigma in order to avoid involuntary disclosure of their HIV status, they opted to stop treatment in order to preserve the social support system. In another study conducted by Barnett, Patten, Kerschberger, Conradie, Garone, Cutsem and Colvin (2013:171&173) it was found that nondisclosure was cited as a barrier to adherence to ART and the patients in the study were reported to have felt the need to hide their medications and not take it in the presence of people they have not disclosed to.

Another factor claimed by HCPs to influence patient's adherence to ART was the pill burden. This was described as a situation where the patient had a lot of pills to take at a time, making it a burden for the patient; also they became fed up and tired of taking the ARTs

*“...yes pill burden when you have too many drugs to take... and every day you have to take this... it is not easy; you get fed up the medicine is there, water is here you can take it but you just do not want to take it because something in you tells you that what is it I am tired and then they just leave it. It happens sometimes so it just the encouragement that makes them adhere” (P 16:6).*

*“Some think that there is so much pill load so I cannot be swallowing [all these pills]...” (P29:5).*

Research findings suggest that fixed dose combination offers reduced pill burden and improve adherence (Ebrahim & Mazanderani, 2013:6). Even though participants in a study on the challenges of anti-retroviral therapy were committed to taking the ART for life, the situation and its sustainability was described as burdensome as they described the amount of pills to be taken as overwhelming. They therefore wished to have one pill a day or even a whole week's dose in order to lessen the burden of daily pills as well as the amount of pills that they need to take (Nyanzi-Wakholia, Larab, Munderia & Gilks, 2012:139).

Doing well on the ART was described by HCPs as one of the factors that influenced patient's adherence to the therapy. Patients tend not to adhere to the treatment when they assume they were doing well; they no longer see the need to continue to take the treatment and then default. According to the HCPs in some instances the improved health encourages and motivates the patients to adhere while in others they skipped treatment and do not adhere.

*"... When they think they are doing better some of them start skipping their drugs giving excuses for not coming in for the drug and then they start defaulting".*  
(P30:1&2)

*"...But sometimes when ...they do the CD4 and they see that it is rising it gives them some hope and they are happy. It works in two ways sometimes too when they see it [CD4] rising, then ok I am doing well so I can relax a bit... sometimes too for some of them it encourages them some too, when it is very low they say oo my God what is happening and then they start adhering seriously because they want it [CD4] to rise some too when it is low, few of them they just lose faith..."* (P16:6&7)

*"My experience is that after some years, let say the person come very unwell the person start taking the medication for one or two years then he or she feel that yes I am ok now am better now so let me stop for a while..."* (P18:5&6).

Musheke *et al.* (2012:4), in their study on factors influencing patient's attrition from ART, also found that when the patients experienced physical improvement of health they would stop taking their treatment.

Socioeconomic factors such as a lack of money for transportation to the clinic, lack of food and lack of social support were described by the HCPs as having a significant effect on the patients' adherence to the ART. The HCPs shared their experiences of encountering patients who complain of these social needs that might affect their adherence to the treatment.

*“They will be people who are complaining about transportation, who are complaining about feeding and all that. They use to get some small, small support they are now not getting so they will not come they will skip [their treatment]...” (P17:1&2).*

*“sometimes financial, sometimes they do not have the social support like from families because some people they do tell their family members of their HIV status because they will shy away from them and then it can also affect the patients from not taking.[their treatment]..” (P 28:2&3).*

*“Some it is just that they do not want to take the drug. Some will say it is financial difficulty they do have money to come to the clinic, buy the drugs and to buy food and all that so if I do not get food I do not take the drug...” (P 25:3).*

According to Joglekar, Paranjape, Jain, Rahane, Potdar, Reddy and Sahay (2011:956) patients who belong to low socioeconomic strata and were required to travel long distances to the ART centre, found it difficult to manage and get the needed money to come for their appointments, hence affecting their adherence to the therapy. The cost of transportation to the ART clinic for the treatment contributed to non-adherence as many patients may run out of drugs and until they received support from family or others to be able to come for the treatment, adherence simply becomes impossible (Ankrah, Koster, Mantel-Teeuwisse, Arhinful, Agyepong & Lartey, 2016:332).

Coetzee, Kagee and Vermeulen (2011:147) reported that patients were unwilling to take their medication on an empty stomach because they did not have money to buy food due to poverty and hence skipped their treatment. According to the HCPs, patients also skipped treatment because of the side effects they experienced whilst on the drugs. The HCPs indicated that some of the patients felt it to be better not to take

the ART and be free from the side effects rather than to take it and suffer the side effects such as nausea, vomiting and weakness.

*“They will tell you ‘I was feeling nauseated I didn’t take it because I know I will vomit, somebody will tell you because I vomited so I didn’t take it’...” (P30:6).*

*“...Mostly when you ask them ‘it is ...when I took the drug I experience...nausea usually it is nausea and vomiting’. Some will tell you ‘that if I have to take this drug and be vomiting it is better I do not take it at all’...and when they start like that ...some after taking the two weeks decide not to take it again... because they feel the drug weakens them as a result so they tell you they do not want to take it again” (P23:2&5).*

Side-effects to ART were cited as being amongst the top reasons for non-adherence to the treatment. Examples of side effects given were nausea, vomiting, stomach pains and cramping and they felt that side effects made them felt worse than before they started (Barnett *et al.*, 2013:171-172; Kim, Zhou, Mazenga, Ahmed, Markham, Zomba, Simon, Kazembe & Abrams, 2016:8). Similarly Musheke *et al.* (2012:4) found that participants in their studies discontinued treatment because they experienced side effects, and the most frequently mentioned side effects were severe stomach pains with diarrhoea, severe leg pains and headache, body rash, fatigue and vomiting. They felt that the side effects interfered with their source of revenue. Suboptimal adherence was reported to be strongly influenced by medication side effects (Do *et al.*, 2013). These findings are directly linked with the findings discussed under 3.5.1.3 above where the participants suffered the side-effects of the ARTs.

The HCPs, like the patients, indicated that travelling undertaken by patients influenced patient adherence to the therapy because they tend to forget to take their pills, forget the medication at home or they run out of medication.

*“.... Travel is another one there was a time we were trying to find out those who are not adhering, what is it and we realize that a lot of people travel so when they have travel they run out so by the time they come back they skip pills for so long, that was also another major issue we realized...” (P21:6)*

*“Yes some of the reason is travelling; a lot of them say that I travelled so it stopped ...” (P27:3)*

*“Some too when you ask them it is like they travelled; so they forgot to take the medications with them...” (P20:1).*

Forgetting to take the treatment was cited as a barrier to adherence to the therapy. Reasons given include patients being busy with work or family obligation, travelling without medication and lack of planning for treatment adherence (Barnett *et al.*, 2013:173). In the same way in another study, forgetfulness was cited as one common reason for patients missing their dose (Holtzman *et al.*, 2015:451). According to Joglekar, *et al.* (2011:965), travelling to funerals and festivals were cited as reasons for non-adherence to the ART.

Healthcare professionals also described patient’s denial of their positive HIV status as a possible factor that influences their adherence to the therapy. They described that they need to prepare the patients mentally, in order for them to be able to move from the denial stage and accept their status so that they will be able to adhere to the treatment. If the patients do not believe that they have the condition then there is a higher probability of them not adhering to the treatment, the denial is worse when they feel they are healthy and are not ill looking. They perceived the patient with HIV to look very ill and sick and since they do not look like such patients; they find it difficult to accept that they have the condition and therefore do not see the need to take the treatment.

*“Before they start the treatment most of them may be in the denial stage, they may not accept that they have the condition and sometimes we have to psyche them like talk to them psychologically for them to be able to understand what they are going do for them to be able to adhere to the therapy” (P28:1).*

*“...You realise that things did not go down well with them and when we probe further you realised that most of them still hasn’t been able to accept their status that they are HIV positive. They find it hard, difficult to accept it so when they see how healthy they are they question their status again so they decide not to*



*take the drug because they are healthy. The HIV patient they know is not healthy so that is also a factor” (P26:3)*

*“Some of them it is that some of them have not really accepted that they have the virus and taking the drug always everyday some of them it is a lot of problem for them...” (P20:1).*

Denial of one’s HIV positive results was seen as a predictor of non-adherence to the therapy. This was also noted among the most common reasons for delaying treatment (Lyimo, Stutterheim, Hospers, de Glee, van der Ven, de Bruin, 2013:103).

Healthcare professionals also shared their experiences in relation to the patient taking ART and described the patient attributing HIV to a spiritual cause as one of the factors that contributes to their non-adherence to the therapy. They believed that diseases have both medical and spiritual causes. In cases where the patient is not helpless, then the cause of the disease is likely to be attributed to spiritual rather than medical. Hence they prefer to seek spiritual solutions than take their ART and have the faith that the condition will be healed through spiritual intervention.

*“...in Ghana here, we all have dual perception of illness is either the spiritual part and the medical part ...so in most cases to the family members since the client is not helpless the family members perceive there should be a spiritual reason so you have most of them taking to the prayer camps and abandon them they make them fast for a long period without food without accessing treatment and all that, most of them even die from the various prayer camps...” (P 27:3).*

*“... Some may not want to access treatment immediately because they think it is spiritual so they have to go and work it out spiritually, some when they keep the person for a very long time and they realized the person is not improving before they will say they should bring him or her to the hospital...” (P 25:3)*

*“...Also the spiritual aspect they know when they result to a spiritual being they will become better, so after some time they results to spiritual support then they are deceived to stop then they stop...”(P 18:5&6).*

A study by Kim *et al.* (2016:9) reported that participants in their study believed that God can heal them and hence stopped taking the treatment and sought spiritual healing through prayers. The above factors described by HCPs, such as patients' non-disclosure of their HIV status, the burden of having to take a lot of pills, observed improved health on ARTs, experienced side effects from the ARTs travelling and forgetting to take the ART contributed to patients' non-adherence to the medications.

### **3.5.2.3 Sub-theme 2.3. HCPs describe policies and protocols used when patients are non-adhering to ART**

Healthcare professionals described what they do at their facilities when a patient does not adhere to treatment. According to them they do encourage the patients to adhere to the treatment. They usually ask the patient to bring an elderly person from their family before they can be issued with their treatment anytime that they do not adhere to treatment for a year or more. This elderly person may not be one who is aware of the HIV status of the patient and hence the patient may want to avoid it by adhering to the treatment. The patients are referred to the counsellors to be re-counselled after non-adherence to treatment. At times, the HCPs threaten to take the patients off the treatment or reduce the period that the patient is supposed to come for the review. The patient would want to avoid coming to the hospital more often for the medication, hence may adhere to the treatment next time.

*"... Now we have told them, anybody that defaults for a year or two when you are coming you come with your head of clan and so I do not want my head of clan to see what I am taking then I should live well" (P29 :4).*

*"...if the pharmacist realise this particular client have not adhere well, she will bring the patient back to us to do drug adherence counselling again then we have to start all over again" (P30:5).*

*"...sorry; if it is a flimsy useless reason I will just check you out, and tell you that you are wasting the medicine and sometimes the threat to take them off the medication causes them to come back or rather than giving you one month, two months [review date] I will give you two weeks so if you have to come here more often than you use to come, you know it is a form of a punishment" (P24:3)*

To substantiate the above statements on policies and protocols used when participants are non-adherence to ART, patients were referred to the adherence counsellor in circumstances where the incorrect number of pills was returned to the healthcare provider, which was evidence of non-adherence to the treatment. Participants were also more than twice as likely to have been referred for eliciting poor knowledge of drugs during instructions (Loggerenberg, Grant, Naidoo, Murrman, Gengiah, Gengiah, Fielding & Karim, 2014:152).

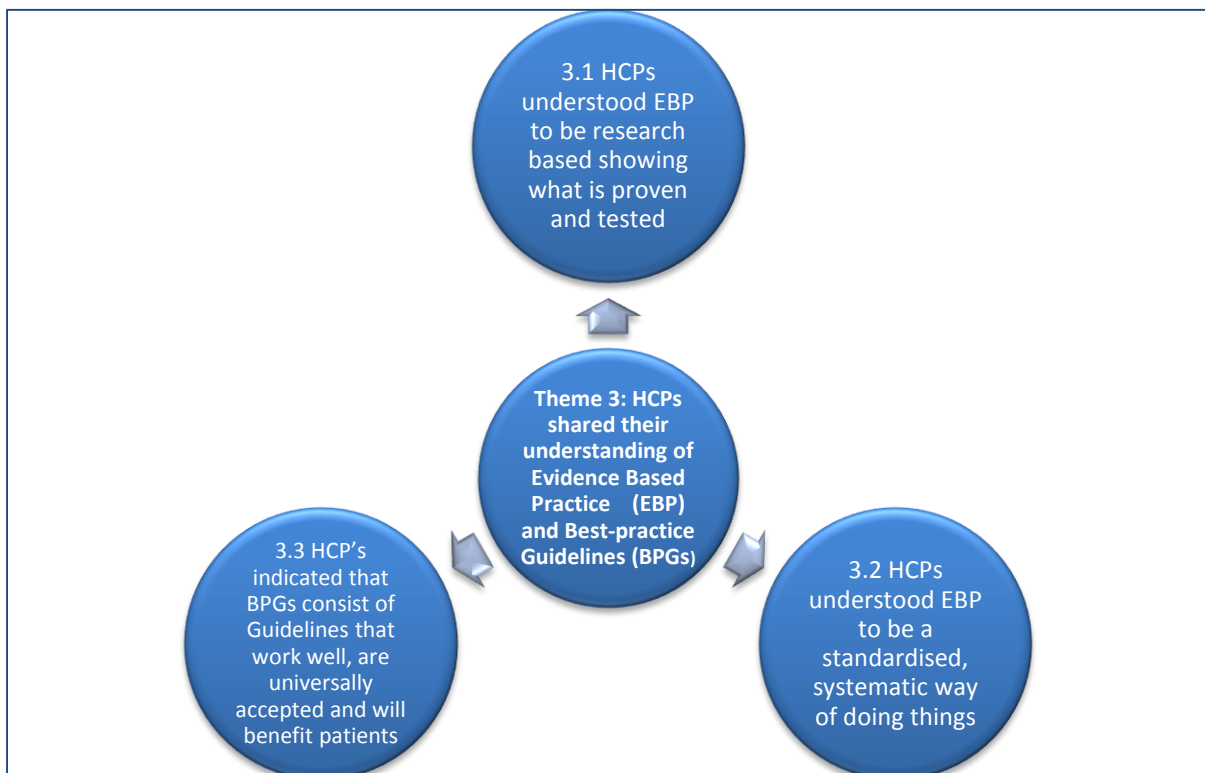
#### **3.5.2.4 Summary of theme 2**

Three subthemes emerged from theme two, which highlighted HCPs experiences related to their patients taking ART. The main experiences expressed by the HCPs in the three subthemes will be summarized in the following statements. The significant experiences emphasised included HCPs' recognition of the need to provide effective counselling, monitoring and support for patients taking ART, factors that influenced patient's adherence to the ART which included non-disclosures of their HIV status, pill burden, improved health on ART, socioeconomic factors, side effects from the treatment, travelling and forgetting to take the treatment, denial of their positive HIV status and believing the cause of the HIV to be spiritual. These factors contributed to patients' non-adherence to the ARTs. Also, policies and protocols employed when a patient have defaulted on the ART were emphasised. Essential among them was referring the patient to the counsellor for re-counselling on adherence to the treatment.

#### **3.5.3 Theme 3: HCPs shared their understanding of Evidence Based Practice (EBP) and Best-practice Guidelines (BPG)**

Evidence-Based Practice is a "problem-solving approach to clinical decision making within a healthcare organization. EBP use the best and latest research evidence to produce high quality health care" (Newhouse, Dearholt, Poe & White, 2007:3). According to Baumann (2010:227), EBP seeks to replace current practices with health care practices guided by rigorous outcome averted research and is meant to provide secure grounds upon which to based clinical decision. Best-Practice Guidelines (BPG) on the other hand are "developed using the best available evidence, in order to provide clinicians with evidence-informed recommendations that support clinical practice and guide practitioner and patient decisions regarding [the] appropriate healthcare in

specific clinical practice settings and circumstances” (Australian Nursing and Midwifery Federation, 2012:1). The HCPs understanding of EBP and BPGs were sought in this study to establish whether they have a good understanding or not so that the need for training could be identified, since the focus of this study is on developing an evidence-based guideline that will be utilized by the HCPs. When healthcare professionals shared their understanding of EBP and BPGs, three sub-themes emerged. A diagrammatic presentation of theme three with its respective sub-themes is presented in Figure 3.3 below:



**Figure 3.3: HCPs understanding of Evidence-Based Practice (EBP) and Best-Practice Guidelines (BPG)**

Figure 3.3 above demonstrates that the participants understood EBP to be research-based, showing what is proven and tested. The participants also described EBP as a standardised systematic way of doing things, in order to guide practice. A Best-Practice guideline, on the other hand, was understood to be guidelines that are universally accepted, and which work well to benefit the patient.

### **3.5.3.1 Sub-theme 3.1: HCPs understood EBP to be research-based showing what is proven and tested**

The healthcare professionals stated that they understood EBP to be research-based evidence that is used in practice. The participants also indicated that EBP guides them in doing the right thing at all times. Generally, EBP was understood as research that produces evidence relevant to the practices; and it was also described as what people have done successfully that has been shown to work in practice. The following quotes from HCPs depict their understanding of EBP:

*“EBP is where you have evidence you have something substantial to show that what you are doing is relevant. For example, I am sure after this research you will know whether what we are doing is really working or not; but you have the evidence that this thing that you are doing is really making it; so you have to have evidence. It is not just saying it; but you need something substantial to show that what I am doing I am making it right” (P18:9).*

*“EBP is what has been proven to work, what people have done successfully.....hmmm continuously let me use the word, something that has been done continuously and has been found to work – either through research, or through practice; it has been found to work and we use that to apply or use it in our work; and because it has been successful and we often use it successfully.... Continuously saying that it works” (P17:5).*

*“... whatever practice we have, of course we have things that people do, studies all over, research all over the place and every now and then something comes up, we here it all over ...but whatever we are doing, we can reproduce it anywhere and it can be used anywhere, there is evidence to support that it works. Evidence-based that means they have done research to back it and in practice too it is been done and it is working ...it should be backed by research and it should be practicable; and you can produce it anywhere and anybody can use it and know that yes it is working as it should” (P16:11).*

In this regard, the participants’ understanding of EBP appears to be similar to that of Satterfield, Spring, Brownson, Mullen, Newhouse, Walker and Whitlock (2009:370), who stated that evidence-based practice was projected to develop and promote clear

and realistic processes for decision-making that de-emphasize intuition and unsystematic clinical experience, while emphasizing the importance of incorporating the best-research findings into clinical care.

### **3.5.3.2 Sub-theme 3.2: HCPs understood EBP to be a standardised, systematic way of doing things**

Healthcare professionals further expressed their understanding of evidence-based practice as a standardized, systematic way of doing things and underpinning good practice. The HCPs also indicated that EBP is a policy or document that stipulates what should be done in practice; and how it should be done.

*“So, it is like that one is like lay down procedure that you will follow to help you deal with your practice...EBP that one I think it is a policy or document that state how we should go about maybe if it is counselling what we need to know about it so is like a written down document or policy telling you how to do any practice or any intervention or something” (P20: 6).*

*“...for me is work done elsewhere have shown good results you pick them up apply to your daily practice that will be evidence” (P24:4).*

The participants' understanding of EBP only focused on one aspect of EBP, which was practice-based on research; but the other aspect of evidence-based practice, which was the patient's needs and values was absent from their description. According to Grove *et al.* (2015:3), evidence-based practice evolves from the integration of the best research evidence with clinical expertise and the patient's needs. It appears as if the participants were not familiar with the concept; and this concurs with the findings of Becker, Midoun and Spirito (2014:1), who stated that participants in their study had little familiarity with the concept of evidence-based practice.

### **3.5.3.3 Sub-theme 3.3: HCPs indicated that BPGs are guidelines that work well, are universally accepted, and will benefit patients**

Healthcare professionals shared their understanding of BPGs; and they indicated that BPGs are guidelines that work well, and are universally accepted by healthcare professionals; and they benefit patients, when applied in practice. The HCPs

experienced BPGs to be necessary for directing practice; because they help practitioners to be more efficient and effective in whatever they do. The HCPs also indicated that BPGs could be used as a road map or tool by everyone in the healthcare services to guide their practices; so that the best care is being rendered to the patients. They described it as follows:

*“BPG can be a tool for health workers, or any other sector, it can be a tool for anyone to conform to that tool. It helps; so that you can be more efficient effective and productive; so that everybody would have a common platform. Everybody knows I am supposed to do this; and this kind of way not what I want ...A best-practice guideline is very necessary for any form of work that one does” (P18:10).*

*“And they also serve as guide or road map in offering care; so it is not all practices that are good. We come to identify the ones that are beneficial, ones that are good; and now the one that will support us and support the clients; we adopt it, then it will form part of our guidelines for practice” (P27:4).*

*“BPG is, I will say that it is what we have accepted universally to be good, to be appropriate, to benefit the patients that we will have, or give to them; so best-practice is what we see that is accepted universally to be good for the patient; that is what we use” (P17:5).*

The findings of this study are congruent with those of the New Zealand Guidelines Group (2001:4), who also described BPGs as tools used by healthcare professionals to assist them in clinical decision-making; so that healthcare for consumers could be improved. In view of the above discussion, it may be concluded that the healthcare practitioners appear to have a fairly good understanding of BPGs.

#### **3.5.3.4 Summary of theme 3**

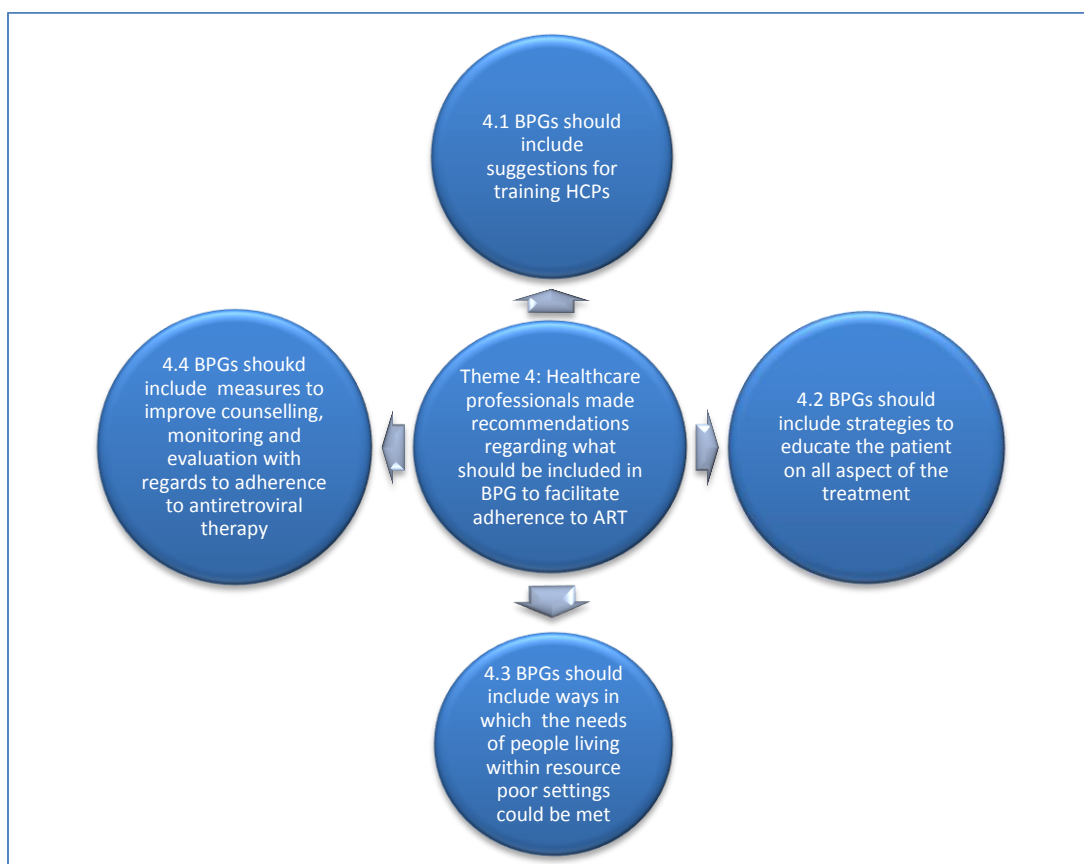
Three sub-themes emerged from theme three, which highlighted the HCPs' understanding of evidence-based practice and best-practice guidelines. The significant description of EBP emphasized included research-based evidence, showing what is proven and tested; standardized systematic way of doing things to guide practice and Sub-theme 3.3 emphasised HCPs' understanding of BPGs.

Significant among their description was that guidelines that work well are universally accepted; and they would be beneficial to the patients. They failed to mention that BPGs were developed by using the best available research evidence.

### 3.5.4 Theme 4: Healthcare professionals made recommendations on what should be included in BPG to facilitate adherence to ART

Healthcare professionals recommended various aspects to be included in a best-practice guideline that would facilitate the patient's adherence to the ART. These recommendations include training of HCPs, the availability of resources to facilitate adherence to ART, holistically meeting the needs of the patients living in resource-poor settings and the improvement of counselling, monitoring and evaluation with regard to adherence to ART.

A diagrammatic presentation of theme 4 with its respective sub-themes is presented in Figure 3.4 below:



**Figure 3.4: Recommendations made by Healthcare professionals regarding what should be included in BPG to facilitate adherence to ART**



### **3.5.4.1 Sub-theme 4.1: BPGs should include suggestions for training HCPs**

The participants accentuated the need for the BPG to facilitate ART adherence, and to include suggestions for training HCPs. They emphasized that HCPs need training on how to be empathetic and appreciative of the patient, and on how to relate properly to the patient, in order to provide efficient and supportive care. They stressed that all the information that the patient needs to know about the anti-retroviral medication should be in a BPG for facilitating adherence to ART. The participants also expressed the need for HCPs to receive training on how to relate to the patients.

*“...Providers should understand, should be empathetic that when it comes to taking a medication for the rest of your life, it is not as easily said; and then when you understand that, you need to relate it to the client; but nevertheless, when it comes to drug adherence that the information, which the client needs to know concerning the medication or the genuine issues about it should be made known (P27:6).*

*“...We, the health providers [have] our relationship with the client; so it is maybe more training for the personnel on how to relate with the clients because we have to understand them the psychological view maybe they [HCP] should have more training to be able to interact better with the clients, to be able to empathize with them and encourage them; so I think that should be inside more training for the practitioners and more dedication too...” (P16:14).*

*“I also think that training also doing refresher courses for service providers is also a way of improving on their productivity and their efficiency and all that...(P18:11).*

In order for the healthcare professional to be able to provide the patient on ART with the needed information on the condition and the medication, s/he needs to be trained. Breitenauer, Mmeje, Njoroje, Darbes, Leddy and Brown (2015:4) maintain that one means of improving patients' access to HIV service is the provision of education about HIV prevention. In order to facilitate the satisfaction of the patient and his/her retention in care, there should be better understanding and communication between the patient and the healthcare professional (Borgart, Chetty, Giddy, Sypek, Sticklor, Walensky, Losina, Katz & Basset , 2013:852). Delobelle, Rawlinson, Ntuli, Malatsi, Decock and

Depoorter (2009:1069) maintained that there is an urgent need for accelerated HIV/AIDS training of healthcare workers in developing countries, in order to maintain quality patient care.

**3.5.4.2 Sub-theme 4.2: BPGs should include strategies to educate the patient on all aspects of the treatment.**

The recommendations made by the health-care professionals in this study on strategies to educate the patient on all aspects of the treatment, outline the need to educate the patient with the needed information on HIV infection, the importance and the effect of the anti-retroviral medication, the expected side-effects, the nutritional requirements and how to live a safe lifestyle. The strategies should create opportunities for the patients to ask questions for clarification. They also recommended that the BPG must include strategies on what to do in circumstances where the ART needs to be changed.

*“So eat before you take your drug, do not take alcohol, do not smoke and all that, do protective sex, then the importance of those things that you are telling him or her and then in case you do not do it the outcome of that basically that is what we tell them verbally. We have some small ART teaching guidelines; and it also contains information of the side-effects; so you tell them all that; in case they have the side-effects what they should do and all that and you always create the room for questions; and in case the patient does not have any questions same day on any visit that s/he thinks s/he needs clarification in any area, s/he is welcome to any of the counselling rooms to do so” (P25:5).*

*“The side-effect of the medication, the differentiation between HIV and AIDS, there should be a real differentiation for the person to know that HIV and AIDS are not the same thing, then something on immunological failure or treatment failure why is this person... if this person is not adhering to therapy; and there is a failure why this person’s [drug is being changed] or it to be changed to this drug” (P28:4).*

Having education on ART is more likely to result in increased adherence, compared to the basic education (Bam, Rajbhandari, Karmacharya & Dixit, 2015:10). A higher

priority needs to be placed on the patient's education; and hence, healthcare providers need to set time aside and educate the patients at every visit and answer all the questions posed to them by the patients (Terblanche & Stellenberg, 2014:7). According to Kip, Ehlers and Wal (2009:155), health provider's health-education efforts should address a patient's susceptibility to HIV/AIDS, the consequences of being HIV positive, AIDS-defining illnesses and the potential side-effects of ART, as well as the actions to be taken.

Furthermore, the importance of the CD4 count and the viral load, the negative effects of alcohol and traditional medicine on ART, and the importance of taking the correct number of all the prescribed pills every day at a specified time should be emphasised. Health providers should also provide health education that is appropriate to the patient's level of education.

#### **3.5.4.3 Sub-theme 4.3. The BPG should include ways, in which the needs of people living in resource-poor settings could be met**

Healthcare professionals recommended various aspects to be included in the BPG for facilitating ART adherence with regard to how the needs of people living in resource-poor settings could be met, in order to expedite ART adherence by patients. The recommendations made by the HCPs included the clear spelling out of procedures that need to be followed before a patient is started on ART, what needs to be done when the patient does not adhere to the treatment, and how to encourage those who are adhering to the treatment to continue. They also stressed the need to communicate in a language that would be best understood by the patient, in order to facilitate comprehension.

Another aspect that was suggested for inclusion in the best-practice guideline to facilitate patients' adherence to ART was the involvement of the family to provide much-needed support. This was expressed as a means of potentially reducing the stigma associated with the condition. It was recommended that there should be proper training of traditional and spiritual healers on an appropriate referral system.

Furthermore, training is required on the benefits of ART, which could serve to encourage traditional and spiritual healers to refer patients timeously, and not to delay

the essential treatment. Proper documentation was also recommended as an important factor to meet holistically the needs of the patient. These were their views:

*“...a lot concerning the HCPs, like taking the pain to go through the guidelines systematically with the client because some of the clients do not understand the language we use...When it come to the client, we should make sure that they have actually understood what we are talking about; and then we should not rush the client” (P29:8).*

*“...now looking at our health-seeking behaviour of the African, almost about 90% of all black men, ...would have consulted a herbal practitioner, or would have gone to maybe a chemist shop ... maybe seek some form of help before they come to us; now how are we going to rope all these people in? How are we going to train all these people; so that they will then get them referred to...we need to look at how best we will be able to incorporate the extended family; so that the support base will be what, much better; so that when it comes to the prevention of HIV it will be easier for us... then the issue of stigma may reduce, may be erased” (P17:8 & 9).*

*“So we will have to befriend our clients and our non-verbal communication should be that the person will see that we are here for him. Then we do a lot of documentations too; and I will put that in the guidelines that whatever interaction has taken place, you need to document; because I may not be here tomorrow and the client is here; so, my colleague should be able to tell that the last interaction this was the issue; and find out whether maybe the method I proposed to solve it has been solved already; so we capture a lot of records as well” (P21:10).*

The findings of this study described in the above quotations appear to conform to the findings of Roura, Nsigaye, Nhandi, Wamoyi, Busza, Urassa, Todd and Zaba (2010:9), who maintain that it is perceived that HIV/AIDS is a punishment from God for sinful behaviour; it has a spiritual cause; and hence, it must be treated through spiritual means. A study on improving clinical attendance and adherence to anti-retroviral therapy through a treatment-supported intervention by Kunutsor, Walley, Muchuro, Katabira, Balidawa, Namagala and Ikoona (2011:1800 & 1801) maintained that having

a treatment supporter impacts positively on ART adherence. The authors concluded that the treatment-supporter strategy is a practical, cost-effective and feasible method for enhancing adherence and improving clinical attendance.

#### **3.5.4.4 Sub-theme 4.4: BPGs should include measures to improve counselling, monitoring and evaluation with regard to the adherence to anti-retroviral therapy**

Healthcare professionals suggested that there should be proper structuring of counselling sessions to give the patient enough time to decide on the initiation of the treatment. Further, there should be proper monitoring and evaluation of the patient with laboratory tests to assess the progress, as well as any adverse effects of the drugs that are likely to influence their adherence to the therapy.

*“...the counselling I just think that if we should space it a little bit ... They also need to go and think about what they have been told ...so that the counselling goes down well with them...” (P19:9).*

*“I think with the counselling; I think it should be stated that the counselling you shouldn't do once, and then put a client on medication; it should be done at least three times for the person to really understand what he or she is going to take like the medication for a long time; and then the monitoring issues should be there; so that the person can support the client in taking the medication; and then the lab issue doing the lab every six months we should spell it out that you do this to help to know whether there are any side-effects, or not” (P20:7).*

A study on a patient communication tool to enhance ART adherence counselling in low and highly resourced settings by Finocchario-Kesler, Catley, Thomson, Bradley-Ewing, Berkley-Patton and Goggin (2012:168) maintains that the systematic explanation on the need for adherence, using the adherence tool, helped the participants to apply the advice to their own regimen. This was found to increase significantly patients' knowledge of medication timing and the avoidance of resistance.

### **3.5.5 Summary of theme 4**

Four sub-themes emerged in theme four, which highlighted the recommendations made by HCPs regarding what should be included in a BPG. The significant recommendations emphasized included training of HCPs to provide care and support to the patient on ART and the strategies to be included in the BPG, in order to ensure the availability of resources to facilitate adherence to ART. Furthermore, the theme emphasized the inclusion in the BPG of how the needs of people living in resource-poor settings could be met and the suggestions of HCPs to include measures to improve counselling, as well as monitoring and evaluating with regard to adherence to ART in the BPG.

## **3.6 SUMMARY OF CHAPTER THREE**

The focus of this chapter has been on the discussion of the findings that emerged from the data collection and the analysis of the semi-structured individual interviews with HCPs and patients on ART. This concluded the first phase of the research process. The results that were obtained after the patients had shared their experiences following being diagnosed and living with HIV, the experiences of HCPs relating to their patients taking ART, followed by their understanding of EBP and BPG, and finally their recommendations for the content of a BPG for facilitating adherence to ART, were all compared with the literature as a means of validating the results.

## **CHAPTER FOUR**

### **INTEGRATIVE LITERATURE REVIEW REPORT**

#### **4.1 INTRODUCTION**

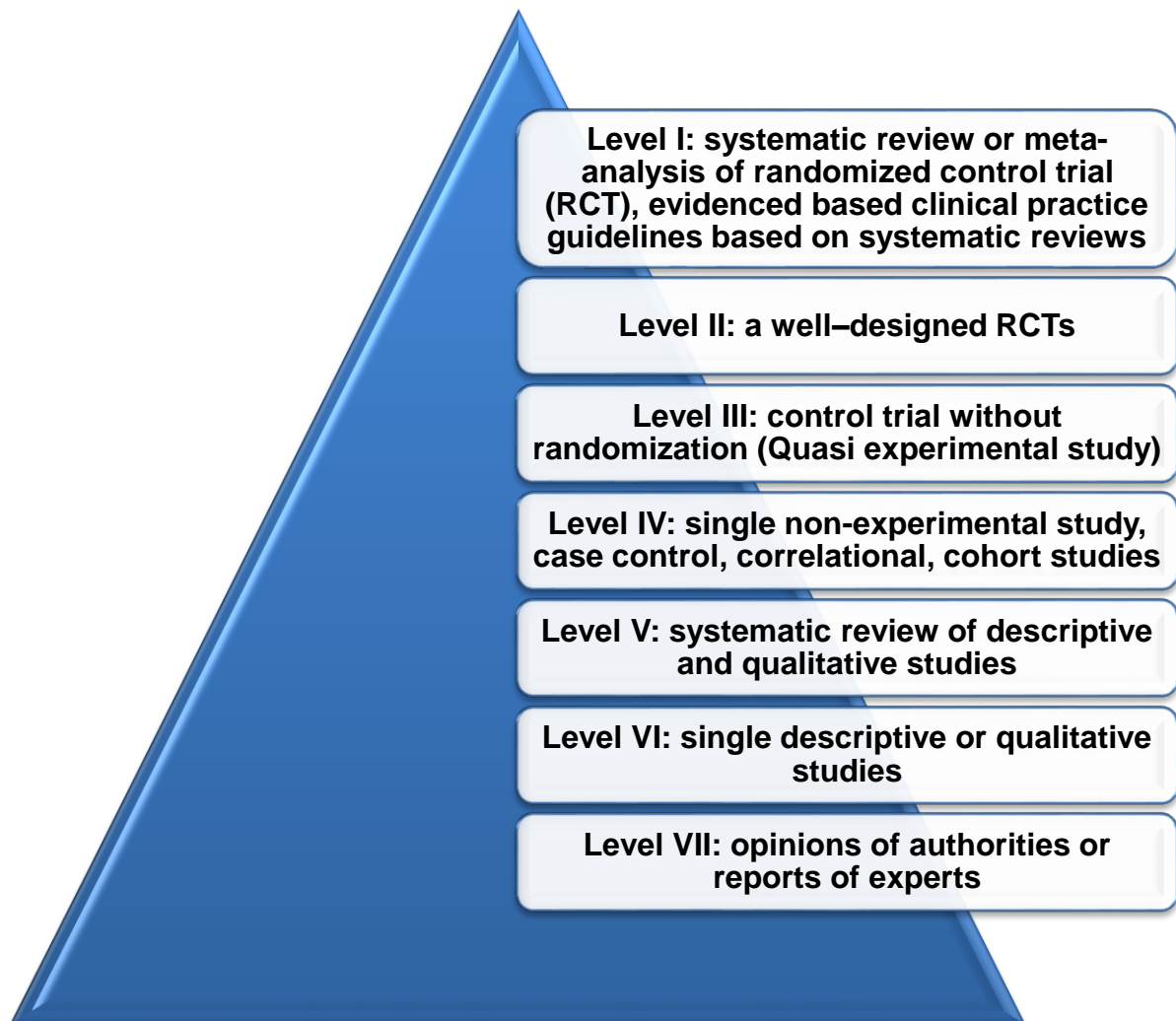
The previous chapter provided a thick description of the empirical findings from the semi-structured interviews conducted with patients on ART and with healthcare professionals who provide care and support to persons on ART. During the analysis of the data in the previous phase of the research study, a literature control was conducted by the researcher to contextualize the identified themes in the existing literature. The literature control also assisted in the interpretation and the validation of the findings. Chapter Three concluded Phase 1 of the research study. This chapter commences Phase 2 of the research study. The focus of this chapter, therefore, is on the integrative literature review that was conducted to establish the available evidence on adherence to ART.

#### **4.2 CLARIFYING INTEGRATIVE LITERATURE REVIEW**

The integrative literature review method is the broadest type of research-review method that allows for the simultaneous inclusion of experimental and non-experimental research, in order to gain a better comprehension of the phenomenon being studied. This type of review method also allows for the combination of data from the theoretical, as well as from the empirical literature (Whittemore & Knaf1 2005: 547). During the integrative literature review, a search was conducted for existing guidelines, using the five steps of the integrative review process, as described by Whittemore and Knaf1 (2005:545). These five steps include problem identification, literature search, data evaluation, data analysis and data presentation.

The hierarchy of the levels of evidence, as described by LoBiondo-Wood and Haber (2014:15) in Figure 4.1 below, were applied in conducting the integrative literature review. The evidence of the hierarchy for rating levels of evidence associated with study designs ranges from systematic reviews, or the meta-analysis of randomized control trials, or evidence-based clinical practice guidelines based on systematic reviews constituting the highest level of evidence (level 1) to the opinions of

authorities, or reports of experts constituting the lowest level of evidence (level VII). However, this study included only Level I evidence.



**Figure: 4.1: Evidence of hierarchy for rating levels of evidence associated with study design (LoBiondo-Wood & Haber, 2014:15)**

According to Figure 4.1 above, evidence-based practice guidelines form part of Level I evidence, which is the highest level of evidence. The process through which the integrative literature review was conducted is discussed in the following section.

### **4.3 LITERATURE SEARCH PROCESS**

The steps of the integrative-review process described by Whittemore and Knaf (2005:548) were used to search for existing guidelines on adherence to ART. These



steps, as mentioned earlier, are: 1) Problem identification; 2) literature search; 3) data evaluation; 4) data analysis; and 5) data presentation.

### **Step One: Problem Identification**

The focus of this step is the identification of the research problem to be addressed by the review. Anecdotal evidence reflects that patients do not always adhere to ART as expected of them, thus there is a need to develop a best-practice guideline for facilitating adherence to ART. The PICO acronym was used to formulate the review question, which served as a guide in the search for the relevant literature. The PICOT was not used; because the T, which represents the timeframe of the intervention, was not appropriate for the review question. The PICO acronym was used as follows to search for the relevant literature:

P (Population): HIV positive adult patients

I (Intervention): Antiretroviral therapy

C (Context): Public hospitals

O (Outcome): Facilitated adherence

The review question that was formulated and used to conduct the integrative literature review was:

*What is the best available evidence that facilitates antiretroviral therapy adherence amongst HIV positive adult patients in public hospitals?*

### **Step Two: Literature Search**

This step comprised the search for all the relevant level I evidence (EBP guidelines based on systematic reviews) related to adherence to antiretroviral therapy. The librarian for the Faculty of Health Sciences at the Nelson Mandela Metropolitan University was consulted to assist in the search for any relevant literature. The search for the relevant literature was conducted using search engines, such as PubMed, Google Scholar, (CINAHL, ERIC, Academic search complete, E-journals, Psycinfo and MEDLINE) via EBSCOHOST, EMERALD INSIGHT, JSTOR, SCIENCE DIRECT and FINDPLUS. Guidelines were also accessed from the databases of the Canadian Medical Association InfoBase clinical practice database, national guidelines

clearinghouse, Writer's Guidelines database, as well as the National Institute for Health and Clinical Excellence (NICE).

All databases, including electronic journals, were searched using the key words and key phrases, such as evidence-based practice, best-practice guidelines, HIV/AIDS, antiretroviral therapy, adherence to ART, healthcare professionals' experience on ART, lived-experience of persons on ART, ART-adherence guidelines, adherence-facilitating guidelines, ("evidenced based" or clinical practice or best-practice) and guidelines, \*or protocol\*and adherence to antiretroviral therapy and public or government and hospitals or healthcare institutions were used for the search.

Grey literature, including unpublished theses, was included in the literature search. The key words and the phrases used in searching the various databases are indicated in Annexure L.

- **Selection of evidence**

The selected evidence was based on inclusion and exclusion criteria. The inclusion criteria assisted in including the relevant literature in order to answer the PICO review question.

- **Inclusion criteria**

The inclusion criteria were used to guide the selection of studies to be included in this review. The inclusion criteria were the type of evidence, the language of publication, types of participants and the date of publication.

- **Type of evidence**

According to the hierarchy of evidence, only level I evidence was included in the study. Guidelines that focused on ART, adherence and treatment guidelines for ART and adult patients were included in the review.

- **Language of publication**

Primarily, it was planned to include publications from all languages; however, after exploring the cost of translating of each article, it was decided to include only studies published in English.

- **Type of participants**

All the guidelines on adherence to antiretroviral therapy that were developed for adults seeking healthcare services in a hospital were included in the integrative review.

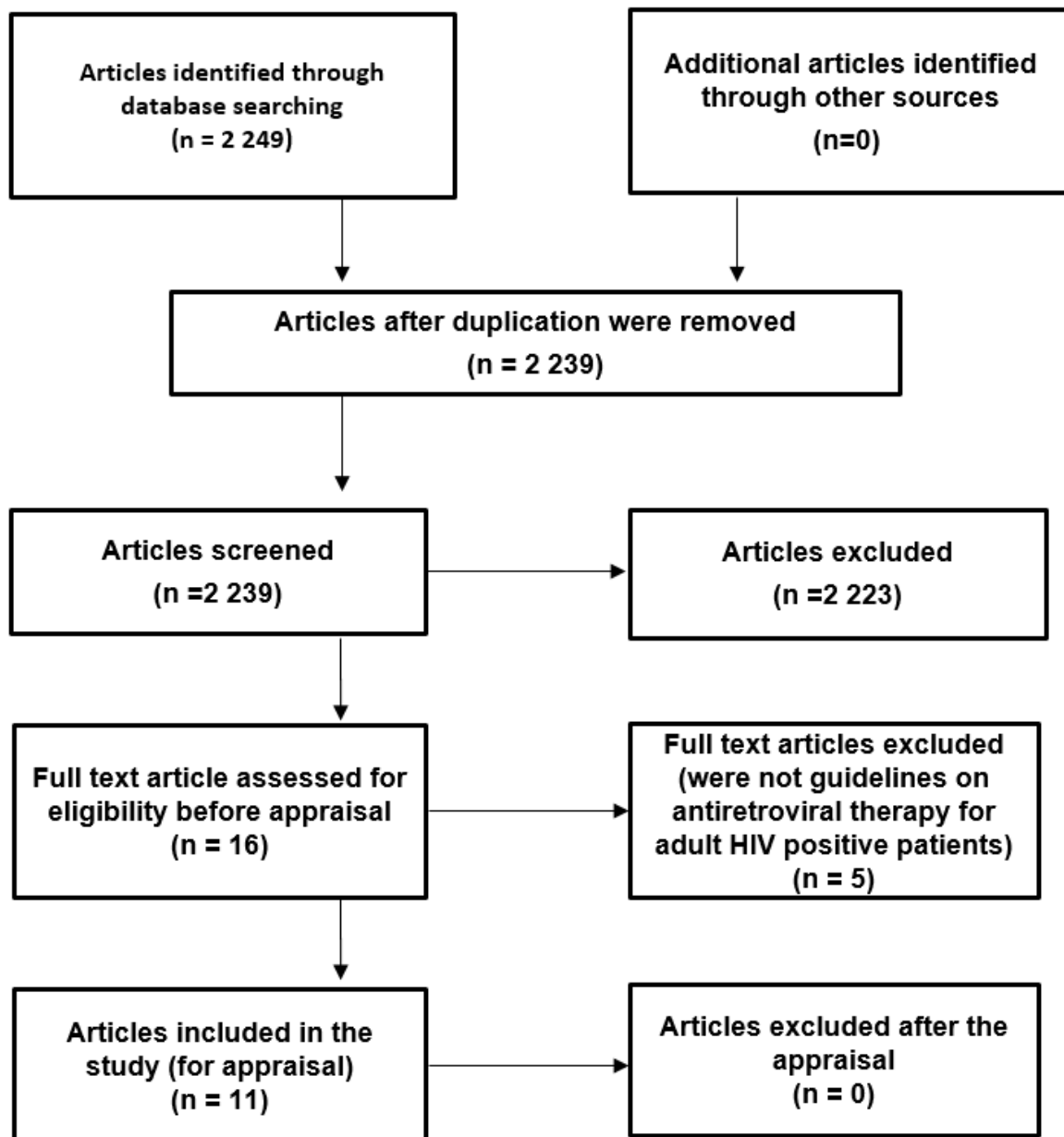
- **Date of publication**

All the guidelines published from 1996 to 2016 were included in the review; since the first highly active ART was introduced in 1996.

- **Exclusion criteria**

All the literature that did not focus on adherence to antiretroviral therapy, was not developed for adults, and was not published in English, were excluded from the integrative literature review.

Figure 4.2 below is a summary of the literature-review process that was developed from the PRISMA (2009) flow diagram. This comprises the identification section in which the total number of articles identified are indicated, the screening section, the eligibility section and the articles included in the review section (Moher, Liberati, Tetzlaff Altman & the PRISMA Group, 2009:3).



**Figure 4.2: Flow-chart of the literature review process developed from PRISMA flow diagram (2009:3)**

After all the databases had been searched, a total of 2 249 articles were found. These articles were reduced to 2 239 by removing duplications. The abstracts of the 2 239 articles were screened, paying attention to the title and the objectives. After the initial screening, 2 223 articles were excluded because they were not relevant to the purpose of the literature search, which was to search for all relevant evidence-based best-practice guidelines applicable to the adherence of antiretroviral therapy. Sixteen articles on guidelines on ART were found; these were further scrutinised to exclude

the articles that did not address issues on adherence to ART, as well as those that were developed for children rather than adults. At the end of the process, 5 guidelines were excluded (see annexure M) and 11 guidelines were included for the critical appraisal, using the AGREE II instrument, as described in Chapter Two.

### **Step Three: Data Evaluation**

The focus of step three was to critically appraise all the literature (guidelines) selected for inclusion in the study. The decision to critically appraise an existing guideline is to ascertain whether an existing clinical best-practice guideline is of sufficiently high quality to be adapted (Polit & Beck, 2014:35). To ensure that the existing guidelines are clear, comprehensive and congruent with the best existing evidence, an independent reviewer – a holder of a Doctor of Philosophy degree in research and a content expert in nursing – reviewed and appraised the guidelines simultaneously with the researcher.

The AGREE II instrument was used to appraise the guidelines as this is the required tool for guideline appraisal and has broad support (Polit & Beck, 2014:35). The AGREE II instrument was developed in order to address the issues of guideline quality and validity and is a tool that assesses the methodological rigour and transparency with which a guideline is developed. The AGREE II instrument aims to provide a framework to assess the quality of guidelines; to provide a methodological strategy for the development of guidelines, to inform what information is available and how the information ought to be reported in guidelines. It is the result of a refined original AGREE instrument (Brouwers *et al.*, 2010:1).

The AGREE II instrument is a 23-item tool that consists of six quality domains. Each domain captures a unique dimension of guideline quality and is been designed to assess guidelines developed by local, regional, national or international groups, or by an affiliated government organization. The AGREE II instrument can be used by healthcare providers, guideline developers, policy-makers and educators (Brouwers *et al.*, 2010:4). Details of the various domains of the AGREE II were described earlier in the methodology chapter (Chapter Two) of this study.

During the appraisal of the guidelines, a score of 1 was given when the rating concept was poorly represented or when there was no relevant information on the item being rated. A score of seven was given when there was an exceptionally good quality of reporting on the item, as well as when the full criteria and consideration articulated in the AGREE II was met. Scores of 2-6 were assigned when the reporting on the AGREE II item did not meet the full criteria. A minimum total score that an appraised guideline using the AGREE II instrument could have is 23 that is 1 for each of the 23 items; while the maximum total score is 161 – that is when a score of 7 is given for all 23 items. A percentage was calculated by using the scores obtained from the appraisal as the numerator; and the maximum score of 161 as the denominator, and then multiplying it by 100. Below is a summary of the appraisal scores, as well as the average score from the two reviewers for the 11 guidelines that were appraised.

**Table 4.1: Summary of the Appraised Guidelines**

|   | <b>Title of guideline</b>   | <b>Total scores by reviewer 1 (researcher) in percentages</b> | <b>Total scores by reviewer 2 (independent Reviewer) in percentages</b> | <b>Average score</b> |
|---|---|---|---|----------------------|
| 1 | Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV. (Thompson et al. 2012)   | 84  | 77  | 80.5                 |
| 2 | Scaling up antiretroviral therapy in resourced limited setting (WHO, 2006)  | 73  | 68  | 70.5                 |
| 3 | British HIV association guidelines for treatment of HIV-infected adults with ART (Pozniak et al. 2001)                                | 74  | 68  | 71                   |
| 4 | National HIV/AIDS secretariat health sector Response Group. National Antiretroviral Treatment Guidelines. Sierra Leone (MOHSSL, 2006) | 52  | 51  | 51.5                 |
| 5 | Antiretroviral therapy guidelines for HIV-infected adults and adolescents (DOAC/NACO/MOHEW/GOI, 2013)                                 | 59  | 51  | 55                   |

|    | <b>Title of guideline</b>  | <b>Total scores by reviewer 1 (researcher) in percentages</b> | <b>Total scores by reviewer 2 (independent Reviewer) in percentages</b> | <b>Average score</b> |
|----|--|---|---|----------------------|
| 6  | Guidelines for antiretroviral therapy in Ghana ( NHASCP/MOH/GHS 2010)  | 57  | 51  | 54                   |
| 7  | Guidelines for use of antiretroviral agents in HIV-1 infected adults and adolescents (PAGAA, 2014)   | 78  | 84  | 81                   |
| 8  | British HIV Association (BHIVA)/ British Association for sexual health and HIV (BASHH) guidelines on provision of adherence support to individuals receiving antiretroviral therapy (Poppa <i>et al.</i> , 2004) | 74  | 69  | 71.5                 |
| 9  | Guidelines for using antiretroviral agents among HIV-infected adults and adolescents. (Dybul, <i>et al.</i> , 2002)  | 55  | 50  | 52.5                 |
| 10 | Primary guidelines for the management of persons infected with HIV: 2013 update by HIV medicine association of the infectious Diseases Society (Aberg <i>et al.</i> , 2014)                                      | 79  | 69  | 74                   |
| 11 | British HIV Association guidelines for the routine investigation and monitoring of adult HIV-1-infected individuals (Asboe, <i>et al.</i> , 2012)  | 65  | 61  | 63                   |

An inclusion criterion of a score of 50% or more was used after consensus was reached between the independent reviewer and the researcher. A total of eleven guidelines were appraised by both the researcher and the independent reviewer and, after the appraisal. A minimum score of 50% and a maximum score of 84% were obtained with an average minimum and maximum obtained scores of 51.5 and 81, respectively. A discussion ensued between the independent reviewer and the

researcher in areas where there were vast differences between the scores. The review of the guidelines was again independently conducted; and consensus was reached between the researcher and independent reviewer. A discussion on the cut-off point for inclusion also ensued between the independent reviewer and the researcher. A figure of 50% and above was agreed on; hence, all the eleven appraised guidelines were included in the integrative review.

#### **Step Four: Data Analysis**

The data-analysis stage is where the data were reduced by analysing the data, according to topics and subtopics, and then extracting the data. The data were displayed in the form of a table stating the title, year of publication, the authors, and the main recommendations; these enhanced the visualization of patterns and relationships within and across the data. The depicted data from the eleven appraised guidelines were examined in order to identify any emerging themes. The extracted data from the guidelines were analysed using thematic analysis.

Thematic analysis is a qualitative method of identifying, analysing and reporting patterns or themes, using a given dataset. It minimally organises and describes the dataset in detail (Braun & Clarke, 2006:79). Thematic analysis was employed in order to extract the needed data from the appraised guidelines. Similar variables were grouped and contrasted and a comparison between the data was carried out. This assisted in building a logical chain of evidence. The data were grouped into subgroups and each subgroup was analysed and important elements from each were analysed. Because of the heterogeneity found in the literature, it was decided that thematic analysis was the appropriate method to use.

#### **Step Five: Data Presentation**

This is the stage at which the conclusion of the review process is documented.

### **4.4 RESULTS AND DISCUSSION OF THE INTEGRATIVE REVIEW**

This section discusses the results of the integrative review, based on the thematic analysis of the identified guidelines related to ART adherence.



#### 4.4.1 Description of Evidence

After all the databases were searched, 16 guidelines on ART were found. After excluding five guidelines the remaining 11 guidelines were included for the critical appraisal using the AGREE II instrument. After the appraisal, all eleven appraised guidelines were used for the integrative literature review. Table 4.2 below shows the characteristics of the eleven appraised guidelines.

**Table 4.2: Characteristics of Appraised Guidelines**

| No. | Guidelines  | For whom it was developed           | Context              | Target group  |
|-----|---|-------------------------------------|----------------------|---|
| 1   | Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV.<br>(Thompson <i>et al.</i> , 2012) | People living with HIV              | Washington           | Care providers, patients, policy-makers. Organizations and health systems involved with implementing HIV care and treatment |
| 2   | Scaling up antiretroviral therapy in a resourced-limited setting (WHO, 2006)  | HIV-infected patients               | Developing countries | Clinicians in resourced-limited setting   |
| 3   | British HIV association guidelines for treatment of HIV infected adults with ART (Pozniak <i>et al.</i> , 2001)                                 | HIV-infected adults                 | United kingdom       | Physicians caring for patients infected with HIV  |
| 4   | National HIV/AIDS secretariat health sector Response Group. National Antiretroviral Treatment Guidelines. Sierra Leone (MOHSSL, 2006)           | HIV-infected patients               | Sierra Leone         | Health workers providing treatment  |
| 5   | Antiretroviral therapy guidelines for HIV infected adults and adolescent (DOAC/NACO/MOHEW/GOI, 2013)  | HIV-infected adults and adolescents | India                | Physicians, counsellors, nurses, pharmacists, peer educators, NGO workers   |

| NO. | Guidelines  | For whom it was developed           | Context  | Target group                              |
|-----|---|-------------------------------------|----------|---|
| 6   | Guidelines for antiretroviral therapy in Ghana (NHASCP/MOH/GHS 2010)  | HIV-infected patients               | Ghana    | Healthcare workers                        |
| 7   | Guidelines for use of antiretroviral agents in HIV-1 infected adults and adolescents (PAGAA, 2014)  | HIV-infected adults and adolescents | USA      | HIV-care practitioners                    |
| 8   | British HIV Association (BHIVA)/ British Association for sexual health and HIV (BASHH) guidelines on provision of adherence support to individuals receiving antiretroviral therapy (Poppa, <i>et al.</i> , 2004) | HIV patients                        | Britain  | Healthcare providers                      |
| 9   | Guidelines for using antiretroviral agents among HIV-infected adults and adolescents (Dybul, <i>et al.</i> , 2002)  | HIV-infected adolescents            | Maryland | Clinicians and other healthcare providers |
| 10  | Primary guidelines for the management of persons infected with HIV: 2013 update by HIV medicine association of the infectious Diseases Society (Aberg <i>et al.</i> , 2014)                                       | HIV-infected patients               | America  | Healthcare providers                      |
| 11  | British HIV Association guidelines for the routine investigation and monitoring of adult HIV-1-infected individuals (Asboe <i>et al.</i> , 2012)  | HIV-infected patients               | Britain  | Healthcare providers                      |

#### 4.4.2 Results

The integrative review of the eleven guidelines was carried out based on the identified themes and their respective recommendations taken from guidelines and based on systematic reviews. Three major themes were identified as: Interventions to improve/promote ART adherence; Monitoring of ART adherence; Challenges to ART adherence.

#### **4.4.2.1 Interventions to promote/improve ART adherence**

Eight out of the eleven guidelines analysed addressed issues on interventions to promote/improve adherence. According to the Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV by the International Association of Physicians in AIDS Care (IAPAC), interventions to promote adherence to ART are strategies aimed at improving the outcome of clients receiving ART (Thompson *et al.*, 2012). Interventions to improve adherence focus on the role that the person receiving the ART is expected to play, continuous monitoring and assessment of the person on the ART.

It also entails providing the client with the needed information and the required skills for them to have a better comprehension of the therapy, as well as interventions that address health systems and delivery issues. Different grading systems were used in the various pieces of literature found. Interventions to promote/improve adherence to ART were synthesized from the recommendations in the appraised guidelines. These are discussed in the following sections: a) Adherence tools for patients; b) Education and counselling intervention; c) Health-service delivery interventions; and d) ART strategies.

- **Adherence tools for patients**

Five of the eight guidelines that addressed issues on interventions to promote/improve ART adherence included adherence tools for patients. The findings from the data synthesised from the guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV developed by IAPAC indicated that many people commonly use self-managed adherence tools, including pill boxes, medication planners or calendars, and these have been associated with improved adherence. The use of dose-time reminder alarms and the use of short-message services have demonstrated improvement in adherence. The guideline, however, recommended the use of reminder devices, as well as the use of communication technology e.g. with interactive components (Grade IB), as well as the use of specific adherence-related tools during education and counselling (Grade IA) (Thompson, *et al.*, 2012: 820).

Similarly, the guidelines for antiretroviral therapy in Ghana by the National HIV/AIDS/STI control program, the Ministry of Health and the Ghana Health Service (NHASCP/MOH/GHS) recommended the use of drug timetables, adherence monitors and pillboxes (NHASCP/MOH/GHS, 2010: 64-65). The guidelines on scaling up antiretroviral therapy in resource-limited settings by the World Health Organization recommended the use of pillboxes and blister packs (WHO, 2004:45). Similar to the above recommendations, the guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents by the Health and Human Service (HHS) Panel on Antiretroviral Guidelines for Adults and Adolescents (PAGAA), recommended the use of pill organizers and medication reminders, together with aids such as alarm clocks, pager and calendars to enhance adherence (Dybul, Fauci, Bartlett, Kaplan & Pau, 2002:k-2).

Similarly, the guidelines on the provision of adherence support for individuals receiving antiretroviral therapy by the British HIV Association (BHIVA)/British Association for Sexual Health and HIV (BASHH), recommended that medication-alert containers should be provided, as appropriate (Poppa, Davidson, Deutsch, Godfrey, Fisher, Head, Horne & Sherr, 2004:51).

According to the data synthesized, there are suggestions from five of the eight guidelines that addressed issues on adherence tools for patients. Tools with the tendency to remind the patients on the timings of the ART would be beneficial. Also, a communication technique that aims to remind patients, as well as the use of pill boxes, blister packs and a drug timetable can be of great benefit in promoting adherence of ART by the patients. Based on the synthesised information derived from the data analysis, the following suggestions with regard to adherence tools for patients were noted:

- Persons on ART should use reminder devices, such as dose-time reminders, alarm clocks, programmable wrist-watches, pager and a calendar, as tools to enhance their adherence to the therapy.
- The use of communication techniques, such as a short text-message service, text-message software, telephone, or postcard, as well as a pill diary and chart, can be helpful.

- Use of pillboxes, drug timetables or medication containers and blister packs must be encouraged.
- The use of specific adherence-related tools during education and counselling must be encouraged.

- **Education and counselling interventions**

Six guidelines addressed education and counselling interventions as ways of improving/promoting ART adherence. The correct education of the patients before the initiation of ART is considered vital for the success of an adherence strategy (WHO, 2005:44). The guidelines on scaling up antiretroviral therapy in resource-limited settings by the World Health Organization and the National Antiretroviral Treatment Guidelines by the Ministry of Health and Sanitation in Sierra Leone (MOHSSL) recommended that the education that the client receives before the initiation of the ART should address basic information about HIV and its manifestation, the benefits and side-effects of ARV medications, how the medications should be taken, as well as the importance of not missing any dose. During the education process, peer counselling and the use of visual materials were recommended (WHO, 2005:44; MOHSSL, 2006:49 ).

The guidelines on the provision of adherence support to individuals receiving antiretroviral therapy by the BHIVA/BASHH recommended that every HIV treatment centre should have a written adherence strategy in place, which should be audited regularly within the context of a growing knowledge base. Providers must ensure that patients have sufficient understanding of HIV pathogenesis, the rationale for anti-HIV therapy, the relationship between adherence and resistance, the requirements of their regimen and its potential side-effects. The support of voluntary sector resources should be enlisted and verbal information should be supported by written information. Interventions offered by treatment centres should involve multidisciplinary input. HIV professionals require continuing education in adherence issues, including professional development and skills-based training (Poppa, *et al.*, 2004:51).

The guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV developed by the IAPAC recommended that there should be individual one-on-one ART education and one or more adherence-

counselling approaches should be employed in providing adherence support. Multidisciplinary education and counselling intervention approaches (Grade IIIC), as well as peer support, were also recommended (Grade IIIC) (Thompson, *et al.*, 2012:821).

The guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents by the HHSPAGAA recommended that healthcare providers should provide all patients with a basic level of adherence-related information and support. Before writing the first prescription(s) for patients initiating or reinitiating ART, the healthcare provider should assess the patient's adherence readiness. Healthcare providers should evaluate patients' knowledge about HIV disease, its treatment, and prevention; they should provide basic information about ART, the viral load and CD4 count, as well as the expected outcome of ART based on these parameters, the importance of strict adherence to ART and the consequences of non-adherence.

In addition, healthcare providers should assess patients' motivation to successfully adhere to ART and identify and support any facilitating factors; and address any potential barriers to adherence. Finally, healthcare providers should ensure that patients have the necessary medication, as well as the skills to follow the prescribed regimen (Dybul, *et al.*, 2014:k-3).

The Antiretroviral therapy guideline for HIV-infected adults and adolescents by the Department of AIDS Control Program (DACP), National AIDS Control Program (NACP), Ministry of Health

and Family Welfare (MOHFW) and the Government of India (GOI) recommends that an individual treatment plan should be developed, fitting ART into the patient's lifestyle/daily event (DACP/NACP/MOHFW/GOI, 2013:64). Based on the synthesized information derived from the data analysis, the following suggestions with regard to education and counselling intervention were noted:

- There should be correct education and counselling of the patient before initiating ART;
- The use of visual aids must be encouraged, to assist in better explanation of the basic concepts of as well as the benefits of ART;

- More than one counselling session should be employed to assist in better preparation of the patients;
- Peer-counselling should be encouraged; there should be one-on-one ART education;
- There should be more than one adherence-counselling session on different days and the patient's understanding of the received knowledge should be assessed before initiation of the ART;
- The patient should be educated on basic information about ART, viral load and CD4 cell count;
- There should be assessment of the patient's adherence readiness and evaluation of the patient's knowledge about HIV-disease treatment and prevention;
- Patients must be counselled by the doctor, the pharmacist, the nurse/trained counsellor, the dietician and the psychologist before ART is initiated;
- At every visit to the hospital, the patients must go through all the stages of counselling and their understanding on HIV and its manifestation, the benefits of taking the ARV, the possible side-effects, how the medication should be taken, what to do when a dose is missed, the importance of adhering strictly to the prescribed dosage and the relationship between adherence and resistance must be assessed and documented;
- All verbal information given to the patient on the ART must be supported by written information.

- **Health system and service-delivery interventions**

Four of the eight guidelines analysed addressed issues on health-service delivery interventions. The guidelines analysed focused on interventions that targeted factors believed to be related to adherence that are also associated with systems of care or service delivery, such as transport to clinic, food supplements, staffing and service modification, as well as systems of care that influence social determinants such as the HIV-associated stigma.

Findings from the data synthesised from the guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV developed by

IAPAC recommended that the nurse or community-counsellor-based care has an adherence record similar to those of a doctor or clinic counsellor-based care; hence this should be encouraged, especially in under-resourced settings (Grade IIB). It was also recommended that a medication-management service (distinct services, or a group of services that optimized therapeutic outcomes for individual patients) should be integrated into pharmacy systems (Grade IIIC) (Thompson *et al.*, 2012:821).

Primary Care Guidelines for the Management of Persons Infected with HIV by the HIV Medicine Association of the Infectious Disease Society of America recommended that HIV care sites should utilise a multidisciplinary model but they should identify a primary provider for each patient, and support the development of a trusting long-term patient-provider relationship (Aberg, Gallant, Ghanem, Emmanuel, Zingman & Horberg, 2014:29). The guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents by the HHSPAGAA recommended that establishing a trusting patient-provider relationship over time and maintaining good communication would help to improve adherence and long-term outcomes (Dybul, *et al.*, 2014: k-3). The guidelines on the provision of adherence support to individuals receiving antiretroviral therapy by the BHIVA/BASHH recommended that HIV professionals receive continuing education in adherence issues, including professional development and skill-based training (Popper, *et al.* 2004:51).

Based on the synthesised information derived from the data analysis, the following suggestions on health-service delivery interventions were noted:

- There should be proper training of nurses in the community to provide home-based adherence counselling since this can assist in resolving challenges with transport to the healthcare facility for service, thereby improving adherence.
- Medication management services should be integrated into the pharmacy system.
- There should be correct and ongoing training of healthcare professionals on adherence issues.
- There should be an established trusting relationship between the patient and the healthcare providers; and the client would also benefit from an assigned primary provider, who would work with healthcare professionals in other disciplines, to provide the needed care and support to the patients.



- **ART-adherence strategies**

Three of the eight guidelines analysed addressed issues on ART-adherence strategies. The guidelines for Improving Entry into and Retention in Care and Antiretroviral Adherence for Persons with HIV developed by the IAPAC recommended that, among the regimens of similar efficacy and tolerability, one-daily regimen is recommended for treatment-naive patients (HIV-positive patients, who have never taken any ART for their infection) beginning ART (Grade IIB). Switching treatment-experienced patients receiving complex or poorly tolerated regimen to a once-daily regimen was recommended, given a regimen with equivalent efficacy (Grade IIIB). Furthermore, among the regimens of equal efficacy and safety, fixed-dose combinations are recommended to decrease the pill burden (Grade IIIB) (Thompson, *et al.*, 2012:820).

The guidelines on the provision of adherence support to individuals receiving antiretroviral therapy by BHIVA/BASHH recommended that the extent to which lifestyle factors, such as eating, sleeping and working patterns, may impede adherence to a proposed regime must be evaluated. Individual preferences in regimen characteristics, including formulation and pill size, should be assessed instead of being assumed. Regimens that are dosed once or twice daily and which do not require fasting or dietary modification, and which have a lower pill burden are likely to enable higher adherence and should be prescribed where appropriate, in accordance with the preference of the patient.

It was also recommended that the patients should always see the pill that may be prescribed for them prior to regimen selection. In order to identify possible adherence barriers, ART may be substituted with placebos, in order to assist in identifying the actual barriers. Also, the potential for drug interactions should be assessed prior to starting therapy (Poppa, *et al.*, 2004:53-54).

Similarly, the guidelines on the use of antiretroviral agents in HIV-1-infected adults and adolescents by the HHSPAGAA recommended that the patient should be involved in ARV selection by reviewing regimen potency, potential side-effects, dosing frequency, pill burden, storage requirements and the consequences of non-adherence. The daily activities of the patient should also be assessed; and the regimen should be tailored

to a predictable and routine daily event. The use of a fixed dose combined formulation should be considered and assessment should be made on the effect of cost/co-payment for drugs on medication and adherence (Dybul, *et al.*, 2014:k-5).

Based on the synthesised information derived from the data analysis, the following suggestions on ART-adherence strategies were noted:

- Among the regimens of similar efficacy and tolerability, a once-daily regimen is recommended for treatment-naive patients beginning treatment;
- Treatment-experienced patients receiving complex or a poorly tolerated regimen should be switched to a once-daily regimen of equivalent efficacy;
- Among regimens of equal efficacy and safety, fixed-dose combinations are suggested in order to decrease the pill burden;
- The extent to which lifestyle factors, such as eating, sleeping and working patterns, could impede adherence to a proposed regime must be evaluated thoroughly;
- Individual preferences of regimen characteristics, including formulation and pill size, should be assessed instead of being assumed;
- Regimens, that are dosed once or twice daily, that do not require fasting or dietary modification, and that have a lower pill burden are likely to enable higher adherence and should be prescribed where appropriate, in accordance with the preference of the patient;
- In order to identify possible adherence barriers, the ART may be replaced by placebos;
- The potential for drug interactions should be assessed prior to starting therapy

#### **4.4.2.2 Monitoring ART adherence**

Seven of the eleven guidelines analysed addressed issues of adherence monitoring (adherence assessment/measurement). Adherence monitoring is very important as it assists in the assessment of the effect of interventions; it also informs the providers of the need to implement interventions (Thompson, *et al.*, 2012:819). Monitoring adherence to ART is a measure for maintaining support for adherence, after ART has been initiated. This will be discussed under methods for measuring adherence.

- **Methods for measuring ART adherence**

The guidelines for Improving Entry into and Retention in Care and Antiretroviral Adherence for Persons with HIV developed by the IAPAC indicate that it is necessary to monitor adherence since it assists in the assessment of the effectiveness of interventions and it also informs the healthcare provider of the need to implement an intervention. Adherence-measurement methods include self-reporting, pharmacy-refilling data, electronic drug monitors, pill counting and drug concentrations from biological samples. It is, however, recommended that self-reported adherence should be obtained routinely from all patients (Grade IIA); and pharmacy-refill data were also recommended for adherence monitoring whenever medication refills are not automatically sent to patients (Grade IIB) (Thompson, *et al.*, 2012:819).

As with the recommendation made by IAPACP, guidelines for the treatment of HIV-infected adults with antiretroviral therapy by the British HIV Association (BHIV) indicate that adherence is measured by patient self-reporting, pill counting, an electronic device fitted to the pill container (e.g. Medication Event Monitoring System Cap (MEMSCap). This records the date and time whenever a patient opens a vial, the physician's report and drug-level monitoring (Pozniak, Gazzard Babiker, Churchill, Collins, Deutsch, Fisher, Johnson, Khoo, Loveday, Main, Matthews, Moyle, Nelson, Peters, Phillips, Pillay, Poppa, Taylor, Williams & Youle, 2001:287).

The guidelines on scaling up antiretroviral therapy in resource-limited settings by the World Health Organization indicate that it is important to maintain support for adherence after the initiation of ART. They recommend that there should be an adherence assessment whenever there is a visit to the healthcare facility (WHO 2004:44). The guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents by the HHSPAGAA indicate that the patient's self-reporting is a useful tool for assessing adherence, in addition to pharmacy records and pill counts. They recommend that, in order to determine whether additional adherence or retention-intervention measurements are warranted, assessment should be carried out at each clinical encounter and it should be the responsibility of the entire healthcare team (Dybul, *et al.*, 2014:k-2).

Guidelines for the routine investigation and monitoring of adult HIV-1-infected individuals by the British HIV Association recommend what the healthcare providers should do in order to help the patient report his/her non-adherence. The following were recommended: Explanations should be given on why a question is being asked, asking questions without implying blame, assuring the patient that there is no right or wrong answer, using open-ended questions, using words familiar to the patient and using cues to prompt recall. These questions posed by the healthcare professional would assist in the measurement of the patient's non-adherence to the ART (Asboe, Aitken, Boffito, Booth, Cane, Fakoya, Geretti, Kelleher, Mackie, Muir, Murphy, Orkin, Post, Rooney, Sabin, Sherr, Smit, Tong, Ustianowski, Valappil, Walsh, Williams & Yirrell, 2012:8).

The guidelines on the provision of adherence support to individuals receiving antiretroviral therapy by the BHIVA/BASHH recommend that every patient who is on prescribed antiretroviral therapy should have their adherence measured and recorded at routine clinic visits. They indicate that the preferred method is a standardized self-completed questionnaire, which invites either 14-day or 1-month recall of adherence. The viral load rebound should always prompt healthcare providers to discuss adherence behaviour with the patient and to assess the patient's understanding of how their regimen should be taken. Furthermore, the use of open-ended questions, acknowledging that low adherence is common is recommended and are more likely to elicit full responses from the patients (Poppa, *et al.*, 2004:55).

The National Antiretroviral Treatment Guidelines by the MOHSSL recommended that, after the initiation of therapy, it is essential to maintain support for adherence. This should involve adherence assessments whenever there is a visit to a health centre. They also recommended that each patient who enters a treatment programme should complete a personal-adherence plan. The adherence plan should include the identification of a companion, or a treatment supporter, who would assist the patient to adhere to his/her drugs. The companion would be charged with checking the client on a daily basis to observe and document at least one of the doses being taken. In order for this strategy to succeed, each companion should receive an orientation to ARV (MOHSSL, 2006:49).

Based on the synthesised information derived from the data analysis, the following suggestions on methods of measuring ART adherence were noted:

- Self-reported adherence should be obtained routinely and pharmacy-refill data must be kept accurately.
- Adherence in patients should be measured by pill counting, an electronic device fitted to the pill container (e.g. MEMSCap), a physician's report and drug-level monitoring in the blood.
- There should be adherence measurement whenever there is a visit to the healthcare facility.
- Adherence measurement should be carried out at each clinical encounter, and this should be the responsibility of the entire healthcare team.
- Healthcare professionals should employ the following, in order to help the patient report his/her non-adherence: Giving explanations on why a question is being asked, asking questions without implying blame, assuring the patient that there is no right or wrong answer, using open-ended questions, using words familiar to the patient and using cues to prompt a recall.
- A standardized self-completed questionnaire, which invites either 14-day or 1-month recall of adherence, should be used to measure the patient's adherence to ART.
- Viral-load rebounding should always prompt healthcare providers to discuss adherence behaviour with the patient, and to assess the patient's understanding of how their regimen should be adhered to.
- Patients who enter a treatment programme should complete a personal-adherence plan. The adherence plan should include the identification of a companion who would assist the patient to adhere to his/her drug regimen. The companion would be charged with checking the client on a daily basis, to observe and document at least one of the doses being taken. In order for this strategy to succeed, each companion should receive an orientation to ARV treatment.

#### **4.4.2.3 Challenges to ART adherence**

Three of the eleven guidelines analysed, addressed issues on challenges to ART adherence. How the challenges would be addressed, in order to facilitate patients' adherence to ART were recommended.

- **Addressing the challenges to ART adherence**

According to the guidelines for the treatment of HIV-infected adults with antiretroviral therapy of the British HIV Association (BHIVA), the most common causes of missed doses reported by patients themselves are forgetfulness and drug toxicity. It was recommended that memory aids should be provided to establish and maintain a pill-taking routine, as well as the management of the side-effects. Furthermore, regimes that dose once or twice a day should facilitate better adherence than those dosed more frequently. Patients' perceptions of their therapy are influential; hence belief in one's capacity to follow the regimen must be encouraged (Pozniak, *et al.*, 2001:287).

The guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents by the HHSPAGAA indicate that non-adherence from the patient's perspective is often a consequence of one or more behavioural barriers, such as depression, other mental illness, neuro-cognitive impairment, low health literacy, low levels of social support, stressful life events, high levels of alcohol consumption and active substance use, homelessness, poverty, non-disclosure of HIV sero status, denial, stigma and inconsistent access to medications. However, they recommend that motivational interviewing should be used; and high levels of adherence should be recognised with incentives and rewards (Dybul, *et al.*, 2014:k-1).

The guidelines for antiretroviral therapy in Ghana by the National HIV/AIDS/STI Control Program, the Ministry of Health and the Ghana Health Service (NHASCP/MOH/GHS) indicate that the main reasons for non-adherence to therapy are forgetfulness, the number and timing of doses, the number and size of pills (the pill burden), food restrictions, perceived or actual side-effects and missed appointments for drug refills. The guideline, however, recommends the use of drug time-tables, adherence monitors, pill boxes and ongoing adherence counselling (NHASCP/MOH/GHS 2010: 64-65).

Based on the synthesised information derived from the data analysis, the following suggestions for addressing the challenges to ART adherence were noted:

- Memory aids should be provided to establish and maintain a pill-taking routine, as well as the management of the side-effects.
- Regimens that dose once or twice a day may facilitate better adherence than those dosed less frequently.
- Patients' perceptions of their therapy are influential; hence, belief in one's capacity to follow the regimen must be encouraged.
- Motivational interviewing should be used – and also high levels of adherence should be rewarded with incentives and rewards.
- The use of drug timetables, adherence monitors, pill boxes and ongoing adherence counselling should be encouraged.

#### **4.5 SUMMARY OF THE INTEGRATIVE REVIEW ON EVIDENCE-BASED GUIDELINES ON ADHERENCE TO ART**

The evidence found in the appraised guidelines reviewed related to adherence to ART. This chapter synthesised the available literature in the form of guidelines, based on systematic reviews about adherence to ART, using an integrative literature review approach by Whitemore and Knafl (2005:548). The steps employed in the search for the guidelines were as follows: a) The PICO acronym was utilised in the formulation of the review question after the research problem had been identified; b) the review question was used as a guide in searching for evidence; c) the evidence, which comprised guidelines on ART adherence, were evaluated and critically appraised, using the AGREE II tool; d) the data were extracted and analysed from the guidelines; (e) the data were presented in the form of recommendations to facilitate adherence to ART.

The following data were extracted and synthesized from the critically appraised guidelines. Practices that facilitate adherence to antiretroviral therapy amongst HIV patients are:

- Interventions to improve/promote ART adherence. These include adherence tools for patients, education and counselling interventions, health-service delivery interventions and ART strategies.
- Monitoring of ART adherence. This includes methods of measuring ART adherence.
- Challenges to ART adherence. This includes strategies in addressing the challenges to ART adherence.

#### **4.6 SYNTHESIS OF QUALITATIVE FINDINGS AND THE INTEGRATIVE REVIEW FINDINGS**

In Phase One of this research, the data were collected from patients on anti-retroviral therapy and healthcare professionals providing ART treatment, care and support services to HIV-positive patients. The data collected from patients related to their experiences on receiving ART at public hospitals, and on their adherence to the therapy. The data collected from healthcare professionals related to their experiences with regard to the care, support and guidance given to patients on ART, their understanding of evidence-based practice and best-practice guidelines, as well as their recommendations for developing a best-practice guideline for facilitating adherence to ART for persons attending public hospitals in Ghana.

The qualitative findings were analysed and synthesized, together with the findings from the integrative reviews of evidence-based guidelines in Phase Two, in order to develop recommendations for a best-practice guideline for facilitating adherence to ART in Phase Three. From phases One and Two it is evident that the qualitative findings correlate with some aspects of the recommendations made in the best practice guidelines that were reviewed as part of the evidence for the integrative literature review. The following conclusions are therefore drawn and recommendations are made for the development of a best practice guideline on adherence to ART under interventions to promote/improve ART adherence, monitoring adherence and challenges to ART adherence.

Table 4.4 on next page describes the synthesis of Phase One and Phase Two that underpinned Phase Three.



**Table 4.4: Synthesis of Phase One and Phase Two for Underpinning Phase Three**

| Phase 1: Summary of the qualitative findings related to adherence to ART  | Phase 2: Summary of integrative review of guidelines related to adherence to ART  | Phase 3: Synthesis of Phase 1 and Phase 2 (recommendations for best-practice guidelines for adherence to ART)   |
|---|---|---|
| <p><b>Participants cited diverse challenges with regard to adherence to treatment:</b><br/>           Limited knowledge on condition and treatment.<br/>           Forgetting to take the treatment.<br/>           Travelling without the drugs or running out of the drug.<br/>           Financial difficulties.</p> <p><b>HCPs expressed a range of experience related to their patients taking ART</b><br/>           HCPs recognised the need to provide effective counselling monitoring, and support for patients taking ART.</p> <p><b>HCPs made recommendations regarding what should be included in a BPG:</b></p> <ul style="list-style-type: none"> <li>• Suggestions for training HCPs</li> <li>• Strategies to ensure the availability of resources to facilitate adherence to ART</li> <li>• How the needs of people living in resource-poor settings could be met</li> </ul> | <p><b>Interventions to Promote/Improve ART Adherence</b></p> <ul style="list-style-type: none"> <li>• Adherence tools for patients</li> <li>• Education and counselling interventions</li> <li>• Health services delivery interventions</li> <li>• ART adherence strategies</li> </ul> <p><b>Monitoring ART adherence</b></p> <ul style="list-style-type: none"> <li>• Methods of measuring ART adherence</li> </ul> <p><b>Challenges to ART adherence</b></p> <ul style="list-style-type: none"> <li>• Addressing challenges to ART adherence</li> </ul> | <p><b>Intervention to promote/improve ART adherence</b></p> <ul style="list-style-type: none"> <li>✓ Adherence tools for patient</li> <li>✓ Education and counselling interventions</li> <li>✓ Health service delivery intervention</li> <li>✓ ART adherence strategy</li> <li>✓ How the needs of people living within resource poor setting could be met</li> </ul> <p><b>Monitoring adherence</b></p> <ul style="list-style-type: none"> <li>- Methods of measuring ART adherence</li> </ul> <p><b>Challenges to ART adherence</b></p> <ul style="list-style-type: none"> <li>- Limited knowledge on condition and treatment.</li> <li>- Forgetting to take the treatment.</li> <li>- Travelling without the drugs or running out of the drug.</li> <li>- Financial difficulties.</li> </ul> <ul style="list-style-type: none"> <li>• Addressing the challenges to ART adherence</li> </ul> |

#### **4.7 CHAPTER SUMMARY**

The findings of the integrative review of the evidence-based guidelines related to adherence to antiretroviral therapy have been provided in this chapter. A best-practice guideline was developed from the findings of this chapter together with the findings of the empirical research conducted in Phase One of this study. This will be presented in Chapter Five of this study.

## **CHAPTER FIVE**

### **DEVELOPMENT OF A BEST-PRACTICE GUIDELINE**

#### **5.1 INTRODUCTION**

Chapter One of the study provided an overview of the research study. Chapters Two and Three concluded Phase One of the study comprising an in-depth discussion of the research design and methods and the qualitative data analysis and discussion for the empirical study. Chapter Four concluded Phase Two of the study which focused on the integrative literature review process and report of best-practice guideline for facilitating adherence to antiretroviral therapy. Phase Three of the study, which is the development of a Best-practice Guideline for facilitating adherence to ART, will be the focus of this chapter. The following will be discussed in this chapter:

- The steps followed in the guideline development process
- Feedback from expert panel and guideline summary

#### **5.2 THE STEPS FOLLOWED IN THE GUIDELINE DEVELOPMENT PROCESS**

Chapter Two of this study described the process of developing the best-practice guideline. On completion of the data analysis of semi-structured individual interviews (Phase One) and the literature review of the best-practice guidelines on adherence to ART (Phase Two), a draft best-practice guideline for facilitating adherence to antiretroviral therapy for persons receiving treatment at public hospitals in Ghana was developed.

Best-practice Guidelines are “systematically developed statements to assist practitioners’ and consumers’ decision about appropriate health care for specific circumstances, taking into account evidence for effectiveness and competing claims and forms a fundamental basis for planning” (New Zealand Guidelines group 2001:5). According to Grove, Gray and Burns (2013:415), evidence-based practice involves the integration of best research evidence with clinical expertise and patients’ values and needs in the delivery of health care which is quality safe and cost-effective. Best research evidence is therefore produced by the conduct and synthesis of numerous high quality studies in a selected health related areas.

This research study integrated the research evidence obtained from the synthesis of best-practice guidelines on adherence to ART (Phase Two) with the experiences of patients on ART and healthcare professionals on patients' adherence to ART (Phase One). The AGREE II appraisal instrument was used as a guide in the development of this guideline. The instrument provides a standard framework for the development and implementation of best-practice guidelines. It consists of a checklist with 23 key items that have been organized within six domains and provides a methodological strategy for the development of guidelines including what and how information ought to be reported in the guideline. It can be used as part of an overall quality mandate aimed to improve health care (Brouwers, *et al.*, 2010:1&10). A description of the AGREE II instrument was provided in Chapter Two of this study and a copy is provided in annexure R.

The reader is introduced to the guideline which begins with the introduction of the guideline indicating the definition of the scope and purpose of the draft guideline. This entails the objectives, the review question and the definition of the target population. This is followed by the second part of the guideline which addresses stakeholders' involvement, and the third part which discusses the integrative review findings and the best-practice recommendations based on these findings. The other domains of AGREE II which are the rigour of development and clarity of presentation were applied and discussed. The last domain, the editorial independence, was concerned with the formulation of recommendations not being unduly biased with competing interest and was also discussed in the guideline.

The fifth domain in the AGREE II instrument, the domain of applicability that addresses the potential barriers and the possible cost implications in applying the recommendations was not applicable, owing to the scope of this research study.

### **5.3 FEEDBACK FROM EXPERT PANEL AND GUIDELINE SUMMARY**

This section of the study presents the comments from the expert panel reviewers. The final guideline is attached as Annexure S. The expert panel members as described in Chapter Two were contacted to confirm their availability to participate in the study. Each panel member gave his or her consent confirming their voluntary participation in the study. In instances where face-to-face sessions were not possible, telephonic

communication or electronic mail was used. The draft best-practice guideline named: “A best-practice guideline for facilitating adherence to anti-retroviral therapy for persons attending public hospitals in Ghana” was submitted through the electronic mail or in hard copy to the selected panel members for review.

The researcher issued a shortened version of the review sheet (Annexure O) based on the AGREE II appraisal instrument to the reviewers in order to enable them assess the guideline. The expert panel members were asked to complete the AGREE II review sheet and to make comments and/or their recommendations. Discussion sessions were held after receiving written feedback from each reviewer and this was done through electronic mail or telephonic communication in cases where personal sessions were not feasible. The feedback from each reviewer was then considered in preparing the final best-practice guideline.

### **5.3.1 Comments from expert panel**

The comments and or recommendations from the six reviewers are presented in accordance with the headings used in the AGREE II review sheet. The final guideline was adapted based on the comments from the reviewers. The formula in the AGREE II instrument was used to calculate the score as rated by the reviewers for each domain. A detailed explanation on how the domain score was done is given in the first domain, subsequently only the percentages obtained for each domain is stated.

#### **5.3.1.1 *Scope and purpose of the clinical guideline***

The items on the first domain were the overall objective of the guideline, the health question and the population to whom the guideline is meant to apply. The expert panel reviewers either strongly disagreed scoring 1 or strongly agreed scoring 7 on whether or not the overall objective(s) of the guideline is (are) specifically described, the health question(s) covered by the guideline is specifically described and the population is specifically described. One of the reviewers commented that the age or gender of the target population should be indicated and also explicitly state whether pregnant women are included or not. This was discussed under heading 5.4.2.2.3.. The guideline was therefore amended accordingly. The remaining five reviewers either

agreed or strongly agreed to the scope and purpose of the guideline. The calculation of the domain score for the first domain was as follows:

|              | ITEM 1    | ITEM 2    | ITEM 3    | TOTAL      |
|--------------|-----------|-----------|-----------|------------|
| Reviewer 1   | 6         | 6         | 5         | 17         |
| Reviewer 2   | 7         | 7         | 7         | 21         |
| Reviewer 3   | 7         | 7         | 7         | 21         |
| Reviewer 4   | 7         | 7         | 7         | 21         |
| Reviewer 5   | 7         | 7         | 7         | 21         |
| Reviewer 6   | 7         | 6         | 7         | 20         |
| <b>Total</b> | <b>41</b> | <b>40</b> | <b>40</b> | <b>121</b> |

**Maximum possible score=7x3 items x 6 reviewers=126**

**Minimum possible score= 1x3 items x 6 reviewers=18**

The scaled domain percentage score will be:

$$\frac{\text{Obtained score} - \text{minimum possible score}}{\text{Maximum possible score} - \text{minimum possible score}} \times 100$$

$$\frac{121-18}{126-18} \times 100 = 103/108 \times 100 = 95.4\%$$

The higher the obtained score rating per domain, the greater the consensus related to the domain assessed thus validating the content of the best-practice guideline. The score is reliable and therefore this section does not need adaption

### **5.3.1.2 Stakeholder involvement**

One of the reviewers commented that the views of the target population and their preference and perspective must be stated clearly. This is discussed under heading 5.4.2.3. The study sought the views of the patients as well as those of the healthcare professionals. Based on the comments, the guideline was amended and adapted. The

overall domain score for this section, as calculated and indicated above was 90.7%, thus indicating that this section was reliable.

#### **5.3.1.3 Rigour of development**

Two of the reviewers commented that the strength and the limitations of the body of evidence were not clearly stated. Based on these comments, the guideline was amended and adapted. The overall domain score for this section was calculated as indicated above and was found to be 90.2% therefore this section was considered reliable.

#### **5.3.1.4 Clarity and presentation**

This section of the clinical guideline was well accepted by all the members of the panel by agreeing or strongly agreeing that the recommendations are specific and unambiguous and the recommendations are easily identifiable. The overall domain score for this section was 86.1%. No amendments were made to this section of the guideline.

#### **5.3.1.5 Editorial independence**

The last domain discussed in this guideline is the editorial independence where any possible conflict of interest and independence of the recommendations was stated. This section was well accepted by the members of the review panel and the overall domain score for this section was 97.2%, thus indicating that this section was reliable.

#### **5.3.1.6 Other comments**

The general comments made by the members of the review panel are as follows:

##### **Reviewer one:**

- Overall guideline assessment: Overall quality rating score of 6, and recommended the guideline for use with modification
- Regarding the target population, state if certain age or gender will be included. What about pregnant women? Will they be excluded or included?
- The strength and limitations of the body of evidence are not clear

**Reviewer two:**

- Overall guideline assessment: Overall quality rating score of 7, and recommended the guideline for use.
- State the time of the guideline development and its publication.
- HIV management is a fast revolving discipline. Many advances take place over a short period and recommendations must be adapted accordingly.
- The review date of the guideline should be also stated when published, for example the guideline must be reviewed in the next two years.

*Researcher's note:* the guideline forms part of a thesis and hence the procedure to regularly update the guideline is not within the scope of the study. It is however recommended that if this guideline is accepted for practice, it should be reviewed every two years.

**Reviewer three:**

- Overall guideline assessment: Overall quality rating of 6, and recommended the guideline for use with modification.
- Clearly state that you considered the weakness of the evidenced used as well as their recommendations.

**Reviewer four:**

- Overall guideline assessment: Overall quality rating of 6, and recommended the guideline for use.
- The guideline clearly delineates an evidence-based guideline that contributes to facilitating adherence to anti-retroviral therapy for individuals attending public hospitals.
- The research addresses timely issues in healthcare delivery. Implementation of its findings will make sustainable improvements into solving barriers to treatment adherence among individuals receiving ART.



**Reviewer five:**

- Overall guideline assessment: Overall quality rating of 6, and recommended the guideline for use with modification.
- Indicate the views and preferences of the target population.

*Researcher note:* The view of the target population was sought and included in the recommendations. These are discussed under heading 5.4.2.5.

**Reviewer six:**

- Overall guideline assessment: Overall quality rating 5, and recommended the guideline for use with modification. The acronym HIV/AIDS should be used as recommended by South African Nursing Council as HIV and AIDS.

**5.3.2 Guideline summary**

A summary of the best-practice guideline to facilitate adherence to ART is provided in the following section. A copy of the final guideline is attached as annexure S.

**5.3.2.1 Guideline title**

A best-practice guideline for facilitating adherence to Anti-retroviral therapy for persons attending public hospitals in Ghana.

**5.3.2.2 Scope and purpose**

This section discussed the objectives of the guideline, the integrative review question (health question) and the intended population to whom the guideline is meant to apply.

**5.3.2.2.1 Guideline objective**

The objective of this best-practice guideline is to provide recommendations based on best available evidence in order to assist the facilitation of adherence in persons receiving ART in public hospitals in Ghana.

#### **5.3.2.2.2 Review question**

The integrative review question that was formulated in order to search for relevant literature pertaining to adherence to ART was: “What is the best available evidence that facilitates antiretroviral therapy adherence amongst HIV positive adult patients in the public hospitals?” The review question was accepted by all the reviewers.

#### **5.3.2.2.3 Target group**

The best-practice guideline is intended for use amongst healthcare professionals in order to assist facilitation of adherence in persons (either a male or female adult, including pregnant adult women) receiving ART in public hospitals in Ghana.

#### **5.3.2.3 Stakeholders involvement**

The guideline was developed by the researcher and the research study promoters, rather than by a recommended guideline development group, and this was due to the scope of this research. An expert panel was however consulted to review and comment on the guideline content and construction. The panel consisted of experienced clinicians and professionals who are experts on the content and have knowledge on guideline development. The expert panel comprised of two medical specialists, one selected based on his expertise in care of patients on ART at a public hospital in Ghana, while the other medical specialist was selected based on his expertise in research, evidence- based practice and guideline development. The panel also consisted of two professional nurses with a PhD in Nursing. Both are involved in the development of guidelines and are lecturers. One is in a public university in South Africa and the other in a private university in Ghana. Among the panel were HIV and AIDS content specialists and an educationalist from a private nursing college with experience in the development of best-practice guidelines.

The views of the healthcare professionals and persons on ART obtained during Phase One of the study were taken into account during the development of this guideline. Owing to the scope of this research study, the guideline was not pilot tested among the healthcare professionals who constituted the target group. However as part of a follow up study, it is recommended that the guideline be implemented and reviewed.

#### **5.3.2.4 Rigour of development**

The librarian at the Faculty of Health Sciences at the Nelson Mandela Metropolitan University assisted in a search for relevant literature in citation databases such as PubMed, Google Scholar, (CINAHL, ERIC, Academic search complete, E-journals, Psycinfo, MEDLINE) via EBSCOHOST, EMERALD INSIGHT, JSTOR, SCIENCE DIRECT and FINDPLUS. Search items used for ascertaining literature pertaining to guidelines on adherence to antiretroviral therapy were, for instance, “adherence to ART,” “ART adherence guidelines” and “adherence facilitating guidelines”. The search consulted the Guidelines databases of the Canadian Medical Association InfoBase clinical practice database, National guidelines clearinghouse, Writer’s guidelines database and National Institute for Health and Clinical Excellence (NICE).

Inclusion criteria for studies considered in the integrative review comprised all guidelines that focused on ART, adherence and treatment guidelines for ART, and adult patients. To ensure a comprehensive search, all guidelines that were published from 1996 to 2016 were included in the integrative review. Guidelines that were not published in English, all guidelines that did not focus on adherence to anti-retroviral therapy and were not developed for adults were excluded. The initial search for evidence identified 16 possible guidelines for inclusion in the integrative review. After eliminating guidelines (n=5) that did not adhere to the inclusion criteria of the review, 11 guidelines were included in the critical appraisal process.

Following the process that was done independently by two reviewers, these guidelines were appraised by using the Appraisal of Guidelines for Research and Evaluation Instrument (AGREE II). The data from the eleven guidelines were displayed, critically appraised and synthesised. No meta-analysis was performed due to the type of evidence found and the heterogeneity of the various guidelines. The extracted data from the guidelines were analysed using thematic analysis.

#### **5.3.2.5 Clarity and presentation of recommendations**

This section presents the recommendations based on the evidence found and appraised.

### **5.3.2.5.1 Interventions to Promote/Improve ART Adherence**

These interventions were developed based on the synthesis and triangulation of Phases One and Two. Interventions to improve adherence focuses on the role that the person receiving the ART is expected to play, continuous monitoring and assessment of the person on the ART, provision of the client with the needed information and the required skills for them to have a better comprehension of the therapy and the interventions that address health systems and service delivery issues.

The following recommendations based on the synthesized evidence from the integrative literature review and the qualitative data were made with regards to interventions to promote/ improve ART adherence

#### **5.3.2.5.1.1 Adherence tools for patients**

It is recommended that:

- Persons on ART should use reminder devices such as dose time reminders, alarm clocks, programmable wrist watches, pagers and a calendar as tools to enhance their adherence to the therapy.
- Use of communication techniques such as short text-message service, text message software, telephone or post card and pill diary and chart can be helpful.
- Use of pill boxes, drug time tables or medication containers and blister packs must be encouraged.
- Use of specific adherence related tool during education and counselling must be encouraged.

No changes were made to this section as it was well accepted by the reviewers.

#### **5.3.2.5.1.2. Education and counselling interventions**

With regards to educational and counselling interventions to promote/improve ART adherence, the following recommendations are made based on the synthesized evidence from the integrative literature review and the qualitative data:

- There should be correct education and counselling of the patient before initiating ART.
- The use of visual aids must be encouraged to assist in better explanation of the basic concepts as well as the benefits of ART.
- More than one counselling session should be encouraged to assist in better preparation of the patients.
- The counselling should be performed by a qualified health professional.
- Peer counselling should be encouraged and there should be one-on-one ART education.
- There should be more than one adherence counselling on different days and the patient's understanding of the received knowledge should be assessed before initiation of ART.
- The patient should be educated on basic information about ART, viral load and CD4 cell count and the expected outcome of ART based on these parameters, the importance of strict adherence to ART, and the consequences of non-adherence.
- Healthcare providers should provide all patients with a basic level of adherence-related information and support.
- The patient should be counselled on how to live a protective lifestyle.
- An individual treatment plan should be developed, fitting ART into the patient's lifestyle/daily event and identifying treatment reminders.
- There should be an assessment of the patient's adherence readiness and evaluation of the patient's knowledge about HIV disease, treatment and prevention.
- Patient must be counselled by the doctor, the pharmacist, the nurse, trained counsellor, the dietician and the psychologist before ART is initiated.
- At every visit to the hospital the patients must go through all the stages of counselling and their understanding on HIV and its manifestation, the benefits of taking the ARV, the possible side effects, how the medication should be taken, what to do when a dose is missed, the importance of adhering strictly to the prescribed dosage, the importance of good nutrition, the relationship between adherence and resistance must be assessed and documented.

- All verbal information given to the patient on the ART must be supported by written information.

No changes were made to this section as it was well accepted by the reviewers.

#### **5.3.2.5.1.3 Health systems and services delivery interventions**

The following health systems and service delivery interventions that aim to promote/improve adherence to ART were recommended based on the synthesized evidence from the integrative literature review and the qualitative data.

- There should be proper training of nurses within the community to provide home based adherence counselling and this can assist in resolving challenges with transportation to the healthcare facility for service, hence improving adherence.
- The medication management service should be integrated into the pharmacy system.
- There should be correct and continuous training of healthcare professionals on adherence issues including professional development and skills based training.
- There should be an established trusting relationship and maintenance of good communication between the patient and the healthcare professionals.
- Patient should be assigned to a primary provider who will work with other healthcare professionals in other disciplines to provide the needed care and support to the patient.

No changes were made to this section as it was well accepted by the reviewers.

#### **5.3.2.5.1.4 ART adherence strategies**

With regard to ART adherence strategies, the following recommendations are made:

- Among the regimens of similar efficacy and tolerability, the one-daily regimen is recommended for treatment-naive patients beginning treatment.
- Treatment-experienced patients receiving complex or poorly tolerated regimen should be switched to the once daily regimen with equivalent efficacy.
- Among regimens of equal efficacy and safety, fixed-dose combinations are suggested to decrease the pill burden.

- The extent to which lifestyle factors such as eating, sleeping and working patterns may impede adherence to a proposed regime must be evaluated.
- Individual preference regarding regimen characteristics, including formulation and pill size should be assessed instead of being assumed.
- Regimens that are dosed once or twice daily and that do not require fasting or dietary modification, and that have a lower pill burden are likely to enable higher adherence and should be prescribed where appropriate in accordance with the preference of the patient.
- In order to identify possible adherence barriers, ART may be substituted with placebos.
- Potential for drug interactions should be assessed prior to starting therapy.

No changes were made to this section as it was well accepted by the reviewers.

#### **5.3.2.5.1.5 Ways in which the needs of people living within resource poor settings could be met**

The following recommendations based on the synthesized qualitative data from healthcare professionals were made:

- Local languages that patients are comfortable with should be used in order to facilitate patients' comprehension.
- Support from the nuclear and extended family must be encouraged
- Traditional and spiritual healers should be trained regarding appropriate and early referral of patients from their camps to recognised health facilities.
- Traditional and spiritual healers should be trained on the importance and the benefits of ART in the life of the patients.

No changes were made to this section as it was well accepted by the reviewers.

#### **5.3.2.5.2 Monitoring adherence**

Adherence monitoring assists in the assessment of the effect of interventions and also informs providers of the need to implement interventions (Thompson et al. 2012:819).

Monitoring adherence to ART is a measure of maintaining support for adherence after ART has been initiated.

#### **5.3.2.5.2.1 Methods of measuring ART adherence**

With regard to the methods of measuring ART adherence, the following recommendations are made based on the synthesized evidence from the integrative literature review and the qualitative data:

- Self-reported adherence should be obtained routinely and pharmacy refill data must be accurately kept.
- Adherence in patients should be measured by pill count, electronic devices fitted to pill containers (e.g. MEMSCap), physician reports and drug level monitoring in the blood.
- Adherence measurement should occur whenever there is a visit to the health care facility.
- Adherence measurement should be carried out at each clinical encounter and should be the responsibility of the entire health care team.
- Healthcare professionals should employ the following in order to help the patient report non-adherence: giving explanations on why a question is being asked, asking questions without implying blame, assuring the patient there is no right or wrong answer, using open ended questions, using words familiar to the patient and using cues to prompt recall.
- A standardized self-completed questionnaire which invites either 14-day or 1-month recall of adherence should be used to measure patient's adherence to ART.
- Viral load rebound should always prompt health care providers to discuss adherence behaviour with the patient and to assess the patient's understanding of how the regimen should be taken.
- A patient who enters a treatment programme should complete a personal adherence plan. The adherence plan should include the identification of a companion (treatment supporter) who will assist the patient to adhere to his/her drugs. The companion will be charged with checking the client on a daily basis



to observe and document at least one of the doses being taken. In order for this strategy to succeed, each companion should receive orientation to ART.

- There should be continuous involvement of relatives and /or community support personnel

No changes were made to this section as it was accepted by the reviewers.

### **5.3.2.5.3 Challenges to ART adherence**

Identified challenges to ART adherence from the qualitative findings include, limited knowledge of the patients on the ART, forgetting to take the drug, travelling and leaving the drug behind and financial difficulties. Recommendations are made on how the challenges should be addressed in order to facilitate patient's adherence to ART.

#### **5.3.2.5.3.1 Addressing challenges to ART adherence**

With regard to addressing challenges to ART adherence, the following recommendations are made based on the synthesized evidence from the integrative literature review and the qualitative data:

- Memory aids should be provided to establish and maintain a pill taking routine, as well as the management of side effects.
- Regimens that dosed once or twice a day may facilitate better adherence than those dosed more frequently.
- Patients' perceptions of their therapy are influential, hence belief in one's capacity to follow the regimen must be encouraged.
- Motivational interviewing should be used and also high levels of adherence should be recognised with incentives and rewards (if possible).
- Use of drug time-tables, adherence monitors, pill boxes and continued adherence counselling should be encouraged.
- The patient should be reassured about side-effects and an alternate regimen should be discussed if side-effects are intolerable.

No changes were made to this section as it was well accepted by the reviewers.

### **5.3.2.6 *Editorial independence***

The responses from the HCPs and the patients on ART as well as the integrative literature review results formed the basis for the development of this best-practice guideline. The three promoters of the research study assisted in the outset and design of the guideline. This guideline is editorially independent and no conflict of interest is applicable to the development of this guideline.

## **5.4 SUMMARY OF THE CHAPTER**

Chapter five described the development of a draft best-practice guideline and concluded Phase Three of the study. The best-practice guideline was submitted to an expert review panel for comments. The final best-practice guideline was prepared after the review process. The final comprehensive guideline is included as annexure S. The conclusion of the research study which discusses the limitations and the recommendations related to the study is described in the next and final chapter.

## **CHAPTER SIX**

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

#### **6.1 INTRODUCTION**

The purpose of this study was to develop a best-practice guideline that was based on qualitative evidence and level one guidelines. Chapter One of this study provided an overview of the study and highlighted the research problem, purpose and objectives. Chapter Two provided an in-depth description of the research methodology, while Chapter Three described the process, data analysis and research findings of Phase One of the study. The integrative literature review process and findings were described in Chapter Four of this study, the process of best-practice guideline development was described and the final best-practice guideline was presented. This chapter addresses the summary, conclusion, the application of the paradigmatic perspective, limitations and recommendations made with regard to this research study.

#### **6.2 SUMMARY AND CONCLUSION OF THE STUDY**

This section provides a brief summary of the three phases used to conduct this study in order to achieve the research purpose and objectives. The research purpose was to develop a best-practice guideline for facilitating adherence to ART by persons receiving treatment at public hospitals in Ghana, based on the qualitative research findings and the integrative literature review related to adherence to ART.

The objectives of the research study were:

- To explore and describe the experiences of healthcare professionals with regard to the care, support and guidance they give to persons on anti-retroviral therapy.
- To explore and describe the lived-experience of persons receiving anti-retroviral therapy at public hospitals, on their adherence to the therapy.
- To explore and describe healthcare professionals' understanding of Evidence-Based Practice and Best-Practice Guidelines.

- To explore, describe, appraise, extract and synthesize the existing literature to guide the development of best-practice guideline that would facilitate adherence to ART by persons receiving treatment at public hospitals in Ghana.
- To develop a best-practice guideline for facilitating adherence to ART, to be used by healthcare professionals.

A summary of the three phases used in the study will be provided below:

Phase One of the study comprised the empirical research phase. A qualitative, explorative, descriptive design was used to conduct this phase of the study. The sampling population comprised 15 healthcare professionals providing care to patients on ART and 15 patients receiving anti-retroviral therapy at public hospitals in Ghana. Purposive sampling was used to select the research sample of 30 participants. In-depth interviews were conducted with healthcare professionals to explore and describe their experiences with regard to the care, support and guidance given to persons on anti-retroviral therapy and with patients to explore and describe the lived-experiences of persons receiving anti-retroviral therapy at public hospitals on their adherence to the therapy.

Tesch's method of coding was used during the analysis of the research data. An independent coder assisted with the data analysis. Strategies to ensure trustworthiness and a high ethical standard of research were implemented throughout the study. The main findings of the research included patients' experience of various emotions after been diagnosed with HIV infection. These included the experience of shock, disbelief, surprise and fear of death. Other findings included patients' experience of stigmatization and discrimination because of their HIV status as well as the experience of side effects of the ART such as dizziness. The patients also experienced diverse challenges with regards to their adherence to the ART. It was also found that healthcare professionals identified factors that influenced patients' adherence to ART such as non-disclosure of their HIV status, pill burden, improved health on ART, socioeconomic factors, travelling and forgetting to take the treatment, denial of their positive HIV status and blaming the cause of the HIV infection on spiritual factors. The HCPs also recognized the need to provide effective counselling,

monitoring and support for patients taking ART although the HCPs did not base their healthcare practice on evidence.

In view of the above discussion it can therefore be concluded that the first two research objectives listed above were achieved.

Phase Two of the research was conducted to operationalise the fourth objective which was: to explore, describe, appraise, extract and synthesize the existing literature to guide the development of best-practice guideline that would facilitate adherence to ART by persons receiving treatment at public hospitals in Ghana. This objective was achieved by doing an integrative literature review on adherence to ART. Eleven guidelines were critically appraised using the AGREE II instrument. An independent reviewer assisted in appraising the guidelines and data were extracted and synthesized. The following are among the practices that facilitate adherence to anti-retroviral therapy amongst HIV patients:

- Interventions to improve/promote ART adherence. These include adherence tools for patients, education and counselling interventions, health-service delivery interventions and ART strategies.
- Monitoring of ART adherence. This includes methods of measuring ART adherence.
- Challenges to ART adherence. These include strategies in addressing the challenges to ART adherence.

In view of the above discussion it can therefore be concluded that the third objective listed above was achieved.

Phase Three was based on the evidence generated from Phase One and the integrative review findings from Phase Two and a best-practice guideline was formulated. The aim of the guideline was to provide healthcare professionals in public hospitals in Ghana with the best recommendations to facilitate adherence of patients to ART. The draft guideline was submitted to an expert panel for review. The reviewers used the adopted AGREE II tool to review the guideline. The recommendations and comments made by the expert panel were utilized to finalize the guideline.

In view of the above discussion it can therefore be concluded that the fourth objective listed above was achieved.

In conclusion it can be stated that the data analysed from Phase One of the study clearly revealed that various factors influenced patients' adherence to ART. No best-practice guideline existed for facilitating patients' adherence to ART in public hospitals in Ghana thus making the development of the best-practice guideline a unique contribution to the body of research and knowledge.

### **6.3 PARADIGMATIC PERSPECTIVE**

The research was based on the JBI model. This model describes the four main components of the evidence-based health care process that include health care evidence generation, evidence synthesis, evidence transfer and evidence utilization. The following components were applied in this research study in line with the JBI model of evidence based health care. Not all the components of this process were applied in the research since the implementation of the best-practice guideline is beyond the scope of this study.

#### **Healthcare Evidence Generation**

The model asserts that evidence may derive from experience, expertise, inference, deduction, or the results of rigorous inquiry, but it recognizes that "the results of well-designed research studies grounded in any methodological position are seen to be more credible as evidence ... than anecdotes or personal opinion" (Pearson, *et al.*, 2012:2). In this study evidence was generated from a qualitative approach using semi-structured interviews. The experiences of healthcare professionals about their experiences in providing care, support and guidance to persons on ART, and their understanding of evidence-based practice and best-practice guidelines were explored. In addition, the experience of patients receiving ART in relation to their adherence to the therapy was explored. The collected and analysed data allowed for evidence generation from the patients and healthcare professionals on adherence to anti-retroviral therapy. Further evidence was generated by means of performing the integrative review on adherence to ART.

## **Evidence Synthesis**

Evidence synthesis is the evaluation or analysis of research evidence and opinions on a specific topic to aid in decision-making in healthcare (Pearson, *et al.*, 2012:2). In this study, the data collected and analysed from the interviews were used in conjunction with an integrative literature review. The data collected from the two phases was triangulated in order to develop a Best-practice Guideline for facilitating adherence to ART. The Best-practice Guideline for facilitating adherence was submitted to a panel of experts for review. Feedback from the reviewers was considered in order to prepare the final best-practice guideline for facilitating adherence to ART for public hospitals in Ghana.

## **Evidence Transfer**

This component of the model relates to the act of transferring evidence (knowledge) to individual health professionals, health facilities, and health systems globally by means of journals, other publications, guidelines, electronic media, education and training, and decision-support systems. Evidence transfer is seen to involve more than merely disseminating or distributing information and it should include the careful development of strategies that identify target audiences such as clinicians, managers, policy-makers and consumers, as well as methods to package and transfer information that are understood and used in decision-making (Pearson *et al.*, 2012:3). The final Best-practice Guideline (BPG) will enhance health care practice related to patients' adherence to ART. It will be distributed to public and private hospitals in Ghana. There will be a presentation on how to implement the BPG at the various hospitals to train the HCPs. The BPG will also be published in a recognised international journal to give other HCPs access to it.

## **Evidence Utilization**

This relates to the implementation of evidence in practice, as is evidenced by practice and/or system change. It identifies the following elements: Evaluating the impact of the utilization of evidence on the health system; the process of care and health outcomes; practice change; and the acquisition of evidence through system/organizational change (Pearson, *et al.*, 2012:3-4). For the scope of this

research study, a best-practice guideline was developed by the researcher which was reviewed by an expert panel comprising of various members of multi-disciplinary team. The team used a structured validated review sheet (AGREE II) hence making the recommendations for practice valid. For the scope of this study, the guideline will not be implemented but it can be recommended that it can be implemented and the impact of the guideline measured.

#### **6.4 LIMITATIONS**

The following limitations were identified during the research:

- The low number of doctors working at the ART clinics limited their fair representation among the healthcare professionals
- The busy schedule of HCPs prevented most of them from participating in the study during the data collection stage although they showed interest.
- The length of time spent in acquiring ethical clearance at the Nelson Mandela Metropolitan University and Korle Bu Teaching Hospital because of the involvement of HIV patients, who are a vulnerable population, delayed the progress of the research study.
- Only English articles were included hence all non-English articles were excluded due to the translation cost. These excluded articles might have enriched the findings of the study.

#### **6.5 RECOMMENDATIONS**

The recommendations made from the research study will be discussed under those for nursing research, nursing education and nursing practice.

##### **6.5.1 Recommendations for Nursing Research**

- The analysed data revealed the non-existence of best-practice guideline on adherence to ART that guide the practice of the HCPs. It is therefore recommended that there should be further research to explore the effect of the absence of these best-practice guidelines on practice.
- From the data analysis it was clear that discrimination and stigmatization contributed to patients' non-adherence to ART. It is recommended that further



research should be conducted on the extent of discrimination and stigmatization on the success of attaining optimal adherence to ART.

- Further research is required to explore HCPs' knowledge on the concepts related to evidence based practice and the use of evidence in making clinical decisions.
- Once the best-practice guideline is implemented, further research will be required to evaluate its use and impact on facilitating adherence to ART.
- Further research will also be required on the extent of compliance to the guideline by HCPs.

### **6.5.2 Recommendations for Education**

- It is recommended that healthcare professionals providing care, support and guidance to patients on ART should be well trained on adherence counselling and current issues on HIV and AIDS.
- It is recommended that more emphasis should be placed on adherence counselling based on evidence.
- Health care professionals should base their decisions on best available evidence and not on their previous experiences. Short learning programmes on evidence based practice can be developed and presented for HCPs.
- It is recommended that healthcare professionals should be trained on how to use evidence based practice guidelines.
- It is recommended that patients receiving ART should be provided with an education material that will assist in their adherence to the therapy.

### **6.5.3 Recommendations for Practice**

- The guideline can be implemented in all the ART clinics in Ghana. It is recommended that the guideline be incorporated into the ART booklet used by HCPs at the ART clinics.
- It is recommended that there should be educational sessions and workshops to enhance patient education in order for the patients on ART to be constantly reminded of the information on the condition and the medication.
- It is recommended that the use of the best-practice guideline be piloted amongst healthcare professionals working in one public hospital and one

private hospital because the implementation of the BPG did not form part of this study.

- It is recommended that the Ghana AIDS Commission and the Ghana Health Service should develop a strategy for the implementation of the developed best-practice

## **6.6 SUMMARY OF THE CHAPTER**

This chapter focused on providing a summary of the whole research process and highlighting the main findings. Conclusions were drawn about the study and a description provided with regard to how the research paradigm underpinned this study. The limitations were highlighted and recommendations were made with regard to nursing practice, nursing education and nursing research.

It can be concluded that this research study has succeeded in the development of a best-practice guideline, which can be utilized by HCPs to assist the facilitation of patients' adherence to ART. This will assist the HCPs to make use of current and best evidence in making decisions on how to assist with the facilitation of their patients' adherence to ART. The findings from the research revealed the non-availability of best-practice guideline on adherence to ART in Ghana. This research study has therefore made an exceptional contribution to the body of knowledge, research and practice by the development of a best-practice guideline based on best available evidence on adherence to ART.

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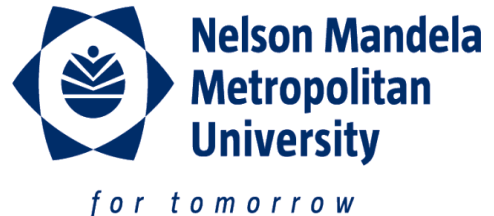
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**ANNEXURE A: INFORMATION AND INFORMED CONSENT FORM FOR  
HEALTHCARE PROFESSIONALS**



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• Port Elizabeth • 6031 • South Africa • [www.nmmu.ac.za](http://www.nmmu.ac.za)

**INFORMATION AND INFORMED CONSENT FORM  
FOR HEALTHCARE PROFESSIONALS**

My name is Mrs Joana Agyemen-Yeboah and I am a Doctor of Philosophy in Nursing student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth. The research I wish to conduct for my Doctoral thesis is entitled: *A best-practice guideline for facilitating adherence to Anti-retroviral therapy (ART) by persons receiving treatment at public hospitals in Ghana.*

The aim of this research study is to explore and describe the experiences of healthcare professionals providing care, support and guidance to persons on ART. The data will be collected by means of individual interviews. The information will be used to develop a Best-practice Guideline for facilitating adherence to ART. There are no risks involved to the participants during this study. The benefits of participation in this study will contribute to the development of a Best-Practice Guideline for facilitating adherence to ART by persons receiving treatment at public hospitals in Ghana. The participants' identity will not be revealed in any discussion, description or scientific publications by the investigator. Participation is voluntary; and the decision whether or not to participate will in no way affect the employment.

**INFORMED CONSENT**

I hereby voluntarily consent to participate in the research study: A Best-Practice Guideline for facilitating adherence to anti-retroviral therapy by persons receiving treatment at public hospitals in Ghana.

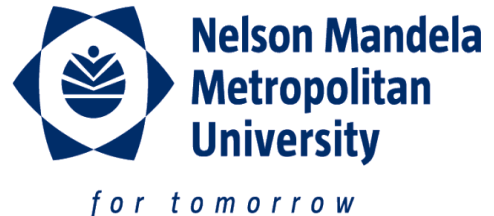
Signed

at.....on.....

Signature of participant: .....

## ANNEXURE B: INFORMATION AND INFORMED CONSENT FORM FOR PERSONS ON ART

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za



### INFORMATION AND INFORMED CONSENT FORM FOR PERSONS ON ART

My name is Mrs Joana Agyemen-Yeboah and I am a Doctor of Philosophy in Nursing student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth. The research I wish to conduct for my Doctoral thesis is entitled: A best-practice guideline for facilitating adherence to Anti-retroviral therapy (ART) by persons receiving treatment at public hospitals in Ghana.

The aim of this research study is to explore and describe the experiences of persons living with Human Immunodeficiency Virus /Acquired Immune Deficiency Syndrome (HIV/AIDS) on ART. The data will be collected by means of individual interviews. The information will be used to develop a Best-practice Guideline for facilitating adherence to ART. There are no risks involved to the participant during this study. The benefits of participation in this study will contribute to the development of a Best-Practice Guideline for facilitating adherence to ART by persons receiving treatment at public hospitals in Ghana. The participants' identity will not be revealed in any discussion, description or scientific publications by the investigator. Participation is voluntary; and the decision whether or not to participate will in no way affect your lifestyle.

### INFORMED CONSENT

I hereby voluntarily consent to participate in the research study: A Best-practice Guideline for facilitating adherence to antiretroviral therapy by persons receiving treatment at public hospitals in Ghana.

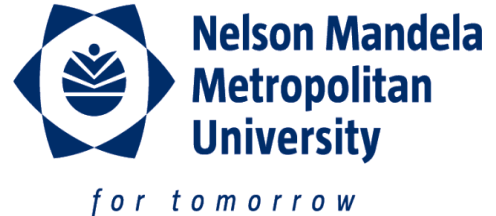
Signed

at.....on.....

Signature of participant: .....

**ANNEXURE C: PERMISSION TO CONDUCT A RESEARCH STUDY AT KOR-LE  
BU TEACHING HOSPITAL**

• PO Box 77000 • Nelson Mandela Metropolitan University  
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9<sup>th</sup> December 2014

Director of Medical Service  
Korle-Bu Teaching Hospital  
Accra

Dear Sir/Madam

**PERMISSION TO CONDUCT A RESEARCH STUDY AT KOR-LE BU TEACHING  
HOSPITAL**

My name is Joana Agyeman-Yeboah; and I am a Doctor of Philosophy in nursing student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth, South Africa. I am conducting research in the Korle-Bu Teaching hospital, Ridge hospital and 37 Military Hospital in Accra. The focus of the research is to develop a Best-Practice Guideline to facilitate adherence to Anti-retroviral therapy by persons receiving treatment at public hospitals in Ghana. The study will be conducted under the supervision of my promoters, Prof. E. J. Ricks, Dr M. Williams and Dr P. Jordan.

The participants will be healthcare professionals (Doctors, nurses, pharmacists and trained counsellors) providing care to persons on anti-retroviral therapy. Also the participants will include persons who receive their antiretroviral therapy from your institution. The information obtained will be used to develop a Best-practice Guideline

that will facilitate adherence to antiretroviral therapy by persons receiving treatment at public hospitals in Ghana.

I wish to interview healthcare professionals at your institution, such as doctors, nurses, pharmacists, and trained counsellors, as well as persons receiving ART in your institution. The data will be collected by conducting a semi-structured interview with each participant. Each interview will last approximately 30-60 minutes. The questions that the healthcare professionals will be asked are:

- Tell me about your experience in providing ART;
- What is your understanding of evidence-based practice?
- What is your understanding of best-practice guidelines?
- What policies and guidelines direct your practice?
- What do you think should be included in a best-practice guideline that would assist you to facilitate your patients' adherence to ART?

The questions that the persons receiving ART will be asked are:

- How have you experienced receiving your ART from the staff at a public hospital?
- Explain to me how it is for you to manage your ART on a daily basis?
- What do you think could further assist you to learn how to manage your disease on a long-term basis?

The participants will not be coerced; and they may withdraw from participating in the study at any time. The information gathered will be managed confidentially. Quotes from interviews may be used in the research report or in an academic article. However, the actual names of the participants will be replaced with pseudonyms. There are no direct benefits for the participants; but the guidelines/recommendations developed from the study will be of benefit to persons on ART.

I am hereby seeking your consent to conduct research in your institution. I have attached a copy of my proposal, which includes copies of the consent forms to be used in the research process, as well as copies of the approval letters, which I received from the NMMU's Research Ethics Committee (Human).

Upon completion of the study, I undertake to provide your institution with a bound copy of the full research report. If you require any further information, please do not hesitate to contact me:

- Cell: +233-244292275/+233-266748337
- E-mail: joanaagyemanyeboah@outlook.com

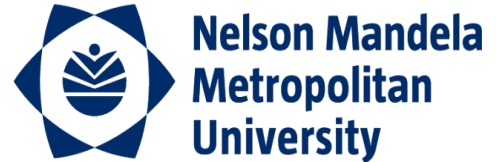
Thank you for your consideration.

Yours sincerely,

**Joana Agyeman-Yeboah**  
**Researcher**

## ANNEXURE D: PERMISSION TO CONDUCT A RESEARCH STUDY AT RIDGE HOSPITAL

• PO Box 77000 • Nelson Mandela Metropolitan University  
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*for tomorrow*

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9<sup>th</sup> December 2014

Director of Medical Service  
Ridge hospital  
Accra

Dear Sir/ Madam

### PERMISSION TO CONDUCT A RESEARCH STUDY AT RIDGE HOSPITAL

My name is Joana Agyeman-Yeboah and I am a Doctor of Philosophy in nursing student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth, South Africa. I am conducting research in Ridge hospital, Korle-Bu Teaching Hospital and 37 Military Hospital in Accra. The focus of the research is to develop a Best-practice Guideline to facilitate adherence to anti-retroviral therapy by persons receiving treatment at public hospitals in Ghana. The study will be conducted under the supervision of my promoters, Prof E. J. Ricks, Dr M Williams and Dr P. Jordan.

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The questions that the persons receiving ART will be asked are:

- How have you experienced receiving your ART from the staff at a public hospital?
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Participants will not be coerced and they may withdraw from participating in the study at any time. The information gathered will be managed confidentially. Quotes from interviews may be used in the research report or in an academic article. However, the actual names of the participants will be replaced with pseudonyms. There are no direct benefits for the participants but the guidelines/recommendations developed from the study will be of benefit to persons on ART

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- E-mail: [joanaagyemanyeboah@outlook.com](mailto:joanaagyemanyeboah@outlook.com)

Thank you for your consideration.

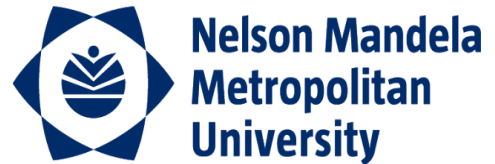
Yours sincerely,

**Joana Agyeman-Yeboah**  
**Researcher**



**ANNEXURE E: PERMISSION TO CONDUCT A RESEARCH STUDY AT 37  
MILITARY HOSPITAL**

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • [www.nmmu.ac.za](http://www.nmmu.ac.za)



*for tomorrow*

J.Agyeman-Yeboah  
P.O.Box CT 1775  
Cantonment-Accra  
Ghana  
0244292275/0266748337  
joanaagyemanyeboah@outlook.com  
9<sup>th</sup> December 2014

The Director of Medical Services  
Ghana Armed Forces Medical Service  
Burma Camp  
Accra

Dear Sir,

**PERMISSION TO CONDUCT A RESEARCH STUDY AT 37 MILITARY HOSPITAL**

My name is Joana Agyeman-Yeboah and I am a Doctor of Philosophy in nursing student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth, South Africa. I am conducting research in 37 Military hospital, Korle-Bu Teaching hospital and Ridge hospital in Accra. The focus of the research is to develop a Best-practice Guideline to facilitate adherence to Anti-retroviral therapy by persons receiving treatment at public hospitals in Ghana. The study will be conducted under the supervision of my promoters, Prof E. J. Ricks, Dr M. Williams and Dr P. Jordan.

The participants will be healthcare professional (Doctors, Nurses, Pharmacists and trained counsellors) providing care to persons on anti-retroviral therapy. Also the participants will include persons who receive their antiretroviral therapy from your institution. The information obtained will be used to develop a Best-practice Guideline that will optimize adherence to antiretroviral therapy by persons receiving treatment at public hospitals in Ghana.

I wish to interview healthcare professionals at your institution, such as doctors, nurses, pharmacist, and trained counsellors, as well as persons receiving ART in your institution. The data will be collected by conducting a semi-structured interview with each participant. Each interview will last approximately 30-60 minutes. The questions that the healthcare professionals will be asked are:

- Tell me about your experience in providing ART;
- What is your understanding of evidence-based practice?
- What is your understanding of best-practice guidelines?
- What policies and guidelines direct your practice?
- What do you think should be included in a best-practice guideline that would assist you to facilitate your patients' adherence to ART?

The questions that the persons receiving ART will be asked are:

- How have you experienced receiving your ART from the staff at a public hospital?
- Explain to me how it is for you to manage your ART on a daily basis?
- What do you think could further assist you to learn how to manage your disease on a long-term basis?

Participants will not be coerced and they may withdraw from participating in the study at any time. The information gathered will be managed confidentially. Quotes from interviews may be used in the research report or in an academic article. However, the actual names of the participants will be replaced with pseudonyms. There are no direct benefits for the participants but the guidelines/recommendations developed from the study will be of benefit to persons on ART

I am hereby seeking your consent to conduct research in your institution. I have attached a copy of my proposal, which includes copies of the consent forms to be used in the research process, as well as copies of the approval letters which I received from the NMMU's Research Ethics Committee (Human).

Upon completion of the study, I undertake to provide your institution with a bound copy of the full research report. If you require any further information, please do not hesitate to contact me:

- **Cell:** 00233-244292275 / 00233-266748337
- **Email:** joanaasante@yahoo.co.uk

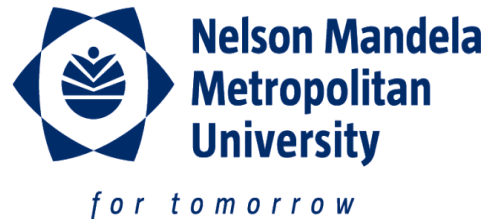
Thank you for your consideration.

Yours sincerely,

**Joana Agyeman-Yeboah**  
**Researcher**

## ANNEXURE F: REQUEST FOR PERMISSION TO INTERVIEW PARTICIPANT

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • [www.nmmu.ac.za](http://www.nmmu.ac.za)



23<sup>th</sup> October 2014

Dear Sir/Madam

### **RE: REQUEST FOR PERMISSION TO INTERVIEW PARTICIPANT**

My name is Mrs Joana Agyeman-Yeboah and I am a Doctor of Philosophy in Nursing student at the Nelson Mandela Metropolitan University (NMMU) in Port Elizabeth. The research I wish to conduct for my Doctoral thesis is entitled: *Best-practice guidelines for facilitating adherence to antiretroviral therapy for persons attending public hospitals in Ghana*. The project is being conducted under the supervision of Professor Esmeralda Jennifer Ricks, Dr Margaret Williams and Dr. Portia Jordan at the Department of Nursing Science at the NMMU.

I am hereby seeking your consent to interview healthcare professionals (doctors, nurses, pharmacist and trained counsellors) and persons receiving ART at your institution. The goal of the study is to explore and describe both the experiences of healthcare professionals providing care, support and guidance to persons on ART and the experiences of persons living with HIV/A on ART. The information will be used to develop best-practice guidelines that will contribute to optimizing adherence to the ART by persons receiving treatment at public hospitals in Ghana. The data will be collected by individual interview and each interview will last approximately 30-60 minutes.

There are no direct benefits for the participants, but the guidelines that will be developed from the study contribute to optimizing adherence to ART and this will be of benefit to all persons receiving ART.

Upon completion of the study, I undertake to provide your institution with a bound copy of the full research report. If you require any further information, please do not hesitate to contact me:

**Cell no:** 0244292275

**Email:**joanaagyemanyeboah@outlook.com

Thank you for your time and consideration in this matter.

Yours sincerely,

Mrs J. Agyeman-Yeboah

## ANNEXURE G: ETHICAL CLEARANCE FROM NMMU



**Nelson Mandela  
Metropolitan  
University**

*for tomorrow*

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

**Chairperson: Research Ethics Committee (Human)**  
Tel: +27 (0)41 504-2235

Ref: [H14-HEA-NUR-029 /Approval]

Contact person: Mrs U Spies

15 April 2015

Prof E Ricks  
Faculty: Health Sciences  
Department: Nursing Science  
J Block – 02 - 03  
North Campus

Dear Prof Ricks

### **A BEST PRACTICE GUIDELINE FOR FACILITATING ADHERENCE TO ANTIRETROVIRAL THERAPY FOR PERSONS ATTENDING PUBLIC HOSPITALS IN GHANA**

PRP: Prof E Ricks  
PI: Ms J Agyeman-Yeboah

Your above-entitled application for ethics approval served at Research Ethics Committee (Human).

We take pleasure in informing you that the application was approved by the Committee.

The ethics clearance reference number is **H14-HEA-NUR-029** and is valid for three years. Please inform the REC-H, via your faculty representative, if any changes (particularly in the methodology) occur during this time. An annual affirmation to the effect that the protocols in use are still those for which approval was granted, will be required from you. You will be reminded timeously of this responsibility, and will receive the necessary documentation well in advance of any deadline.

We wish you well with the project. Please inform your co-investigators of the outcome, and convey our best wishes.

Yours sincerely

A handwritten signature in cursive script that reads "CB Cilliers".

**Prof CB Cilliers**  
**Chairperson: Research Ethics Committee (Human)**

cc: Department of Research Capacity Development  
Faculty Officer: Health Sciences

## ANNEXURE H: ETHICAL CLEARANCE FROM MILITARY HOSPITAL



### **Institutional Review Board**

37 Military Hospital  
Neghelli Barracks  
ACCRA

Tel: 0302-775958

Email: [irb37milhosp@hotmail.com](mailto:irb37milhosp@hotmail.com)

27<sup>th</sup> February 2015

**Our Ref: IRB/37MH/083/15**

### **ETHICAL CLEARANCE**

**37MH-IRB IPN 024/2015**

On 17<sup>th</sup> February 2015 the 37 Military Hospital (37MH) Institutional Review Board (IRB) at a full Board meeting reviewed and approved your amended protocol.

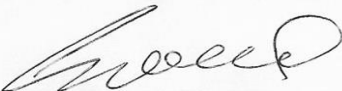
**TITLE OF PROTOCOL: A Best Practice Guideline for Facilitating Adherence to Antiretroviral Therapy For Persons Attending Public Hospital in Ghana**

**PRINCIPAL INVESTIGATOR: Joana Agyeman -Yeboah**

Please note that a final review report must be submitted to the Board at the completion of the study.

Please report all serious adverse events related to this study to 37MH-IRB within seven (7) days verbally and fourteen (14) days in writing.

This certificate is valid till 17<sup>th</sup> February 2016.

  
**DR EDWARD ASUMANU**  
(37MH-IRB, Vice Chairperson)

**37 MILITARY HOSPITAL  
INSTTTUTIONAL REVIEW BOARD**

**DATE** 27<sup>th</sup> Feb 2015

Cc: Brig Gen (Dr) Ralph Ametepi  
Commander, 37 Military Hospital

# ANNEXURE I: ETHICAL CLEARANCE FROM GHANA HEALTH SERVICE

## GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

*In case of reply the  
number and date of this  
Letter should be quoted.*

*My Ref. :GHS-ERC: 3  
Your Ref. No.*



Research & Development Division  
Ghana Health Service  
P. O. Box MB 190  
Accra  
Tel: +233-302-681109  
Fax + 233-302-685424  
Email: Hannah.Frimpong@ghsmai.org

3<sup>rd</sup> July, 2015

Joana Agyeman-Yeboah  
P. O. Box CT 1775  
Cantoments – Accra  
Ghana

### **ETHICS APPROVAL - ID NO: GHS-ERC: 13/05/15**

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol titled:

#### **“A Best Practice Guideline for Facilitating Adherence to Anti Retroviral Therapy for Persons Attending Public Hospitals in Ghana”**

This approval requires that you inform the Ethics Review Committee (ERC) when the study begins and provide Mid-term reports of the study to the Ethics Review Committee (ERC) for continuous review. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Please note that any modification without ERC approval is rendered invalid.

You are also required to report all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.

You are requested to submit a final report on the study to assure the ERC that the project was implemented as per approved protocol. You are also to inform the ERC and your sponsor before any publication of the research findings.

Please note that this approval is given for a period of 12 months, beginning July 3<sup>rd</sup> 2015 to 2<sup>nd</sup> July 2015.

However, you are required to request for renewal of your study if it lasts for more than 12 months.

Please always quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....

DR. CYNTHIA BANNERMAN  
(GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra



**ANNEXURE J: GRANTED PERMISSION LETTER FROM KOR-LE BU TEACHING  
HOSPITAL**

**DIRECTOR OF MEDICAL AFFAIRS  
KORLE BU TEACHING HOSPITAL**

---

16<sup>th</sup> June, 2015

THE HEAD  
DEPT OF INTERNAL MEDICINE  
KORLE BU

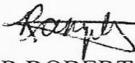
**LETTER OF INTRODUCTION**  
**MADAM JOANA AGYEMAN-YEBOAH**

This is to introduce to you the above named Student from Nelson Mandela Metropolitan University, Faculty of Health Sciences.

She has expressed the desire to carry out a research in your Department entitled “**A best practice guideline for facilitating adherence to antiretroviral therapy for persons attending Public Hospital in Ghana**”.

Please accord her the needed assistance.

Thank you.

  
DR ROBERTA LAMPTEY  
DEPUTY DIRECTOR OF MEDICAL AFFAIRS  
FOR: DIRECTOR OF MEDICAL AFFAIRS

**ANNEXURE K: GRANTED PERMISSION LETTER FROM 37 MILITARY  
HOSPITAL**

RESTRICTED



Department of Medical Services  
General Headquarters  
Ghana Armed Forces  
Burma Camp  
ACCRA

Accra: 777397

Email: [gafmeddept@gmail.com](mailto:gafmeddept@gmail.com)/  
[ghqmed@yahoo.com](mailto:ghqmed@yahoo.com)

GHQ/9109/A/MED

08 Apr 15

37 MIL HOSP

**REQUEST FOR PERMISSION TO CONDUCT  
RESEARCH AT THE 37 MILITARY HOSPITAL  
JOANA AGYEMAN-YEBOAH – PHD STUDENT**

1. I am to convey approval for the above-named PHD student of the Nelson Mandela Metropolitan University, Port Elizabeth, South Africa, to conduct a doctoral research on the topic “A best practice guideline for facilitating adherence to antiretroviral therapy for persons attending public hospitals in Ghana” at the 37 Mil Hosp.
2. On completion, the student is required to submit a copy of her work to this Department for retention. I am to request you to accord her the necessary assistance to facilitate her work.
3. Respectfully submitted, please.

**EC SAKA**  
Col  
for Director-General

RESTRICTED

**ANNEXURE L: SEARCH TERMS: ADHERENCE TO ANTIRETROVIRAL  
THERAPY**

| <b>DATA BASE</b> | <b>SEARCH STRATEGY</b>   |
|------------------|--|
| Find plus        | <ul style="list-style-type: none"> <li>• Adherence facilitating guidelines and antiretroviral*</li> <li>• Antiretroviral adherence guidelines</li> <li>• Evidence based practice</li> <li>• Best-practice guidelines</li> </ul>  |
| EBSCOHOST        | <ul style="list-style-type: none"> <li>• Adherence facilitating guideline and antiretroviral therapy</li> <li>• “Evidence based” or clinical practice or best-practice</li> <li>• Guidelines or protocol and adherence to antiretroviral therapy and public or government not private</li> </ul> |
| Science Direct   | <ul style="list-style-type: none"> <li>• Guidelines on adherence and antiretroviral therapy</li> </ul>   |
| Biomed central   | <ul style="list-style-type: none"> <li>• ARV adherence</li> <li>• “Antiretroviral adherence guidelines” all words</li> </ul>   |
| PubMed           | <ul style="list-style-type: none"> <li>• Healthcare professionals experiences with patients on ART</li> <li>• Lived experiences of patients on ART</li> <li>• Guidelines on ART</li> <li>• ART adherence guidelines</li> </ul>   |
| Google scholar   | <ul style="list-style-type: none"> <li>• Guidelines on adherence to ART</li> <li>• Antiretroviral therapy guidelines</li> <li>• Protocol on adherence to ART</li> <li>• Practice guidelines on adherence to ART</li> </ul>   |
| Emerald insight  | <ul style="list-style-type: none"> <li>• ART adherence guidelines</li> <li>• HIV/AIDS treatment guidelines</li> </ul>  |

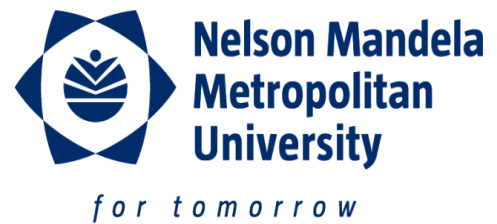
| DATA BASE  | SEARCH STRATEGY  |
|--|--|
| JSTOR  | <ul style="list-style-type: none"> <li>• Adherence and guidelines</li> <li>• ART adherence and guidelines</li> <li>• Guidelines and adherence</li> </ul> |
| Canadian Medical Association InfoBase clinical practice database | <ul style="list-style-type: none"> <li>• “antiretroviral therapy guidelines</li> <li>• ART guidelines</li> </ul>   |
| National guidelines clearinghouse                                | <ul style="list-style-type: none"> <li>• HIV/AIDS treatment</li> <li>• Adherence to ART</li> </ul>   |
| Writer’s guidelines database                                     | <ul style="list-style-type: none"> <li>• Antiretroviral therapy</li> <li>• Guidelines on adherence to ART</li> </ul>                                     |
| National Institute for health and clinical Excellence (NICE)     | <ul style="list-style-type: none"> <li>• Adherence facilitating guidelines</li> <li>• Adherence to antiretroviral therapy guidelines</li> </ul>          |

## ANNEXURE M: CHARACTERISTICS OF EXCLUDED GUIDELINES

| No. | Guidelines   | Reasons for Exclusion  |
|-----|--|--|
| 1   | Bloch, M., Hoy, J., Cunningham, N., Roth, N., Andrianopoulos, N., Rayner, C., Carr, A. 2010. Adherence to HIV treatment guidelines for initiation of antiretroviral therapy in Australia. <i>Journal of the International AIDS Society</i> 13( 4) 172<br><a href="http://www.jiasociety.org/content/13/S4/P172">http://www.jiasociety.org/content/13/S4/P172</a> | Not a guideline on adherence to antiretroviral therapy                                     |
| 2   | British Columbia Guidelines for The Care Of HIV Positive Pregnant Women and Interventions to Reduce Perinatal Transmission (2013). 1-107<br><a href="http://www.BC_HIV_in_pregnancy_guidelines">Hppt/www.BC_HIV_in_pregnancy_guidelines</a> . Accessed 18/3/15   | Did not address adherence to the ART   |
| 3   | Hirschall G., Harries A.D., Easterbrook, P.J., Doherty, M. C., Ball, A. 2013. The next generation of the World Health Organization's global antiretroviral guidance. <i>J Int AIDS Soc</i> 16: 18757.  | Guidelines on ART but not on adherence to ART  |
| 4   | Petersen, T.S., Andersen, S.E., Gerstoft, J., Thorsteinsson, K., Larsen, C.S., Pedersen, G. Pedersen, C. & Obel, N. 2011. Adherence to national guidelines for initiation of antiretroviral regimens in HIV patients: a Danish nationwide study. <i>British Journal of Clinical Pharmacology</i> . 72(1) 116-124.  | Not a guideline but a study on adherence to a guideline.                                   |
| 5   | Who, 2010. Antiretroviral therapy for HIV infection in Adults And Adolescents Recommendations for a public health approach. WHO Library Cataloguing-in-Publication data. <a href="http://www.who.int.HIV">hppt/ www.who.int.HIV</a> . Accessed march 2015  | Guideline on antiretroviral therapy but did not address issues on adherence to the therapy |

## ANNEXURE N: LETTER TO EXPERT PANEL

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • [www.nmmu.ac.za](http://www.nmmu.ac.za)



Faculty of Health Sciences  
School of Clinical care Sciences  
Department of Nursing Science  
Tel: +233-244292275  
E-mail: [s214230872@live.nmmu.ac.za](mailto:s214230872@live.nmmu.ac.za)/  
[joanaagyemanyeboah@outlook.com](mailto:joanaagyemanyeboah@outlook.com)  
17<sup>th</sup> November 2016

Dear Sir/Madam,

I am currently engaged in a research study related to the development of an Evidence Based Best-practice Guideline for facilitating adherence to Anti-retroviral therapy for persons attending public hospitals in Ghana. A draft guideline on adherence to Antiretroviral therapy is in the process of being developed and is based on an integrative literature review of evidence-based guidelines and the opinions of healthcare professionals.

You are being requested to participate as part of an expert panel to independently review the guideline developed during the research study. I anticipate that a draft guideline will be completed at the first week in December, 2016. To participate, it will be required of you to complete the provided, attached guideline review form and give comments where necessary. The evidence-based guideline is based on the AGREE II clinical appraisal tool (See attachment). Therefore it is important to note that the format of the guideline comprises of the evidence found and recommendations for practice.

Anonymity as a participant will be ensured, if required. You are under no obligation to participate in this research study. However, your valuable input will be appreciated and will be used in finalizing the guideline. Please would you complete the attached consent form indicating your willingness to participate in the review panel? Upon

receipt of your consent, the guideline will be sent to you for review. Please note that I value your input, and you had been recommended for your expertise in this regard by Professor Ricks in consensus with Prof Jordan and Dr. Williams. Should you have any queries please do not hesitate to contact me or my promoters, Prof. E.J. Ricks, Prof. P.J. Jordan and Dr M. Williams

Yours sincerely,

JOANA AGYEMAN-YEBOAH  
RESEARCHER

**CONSENT TO PARTICIPATE IN THE EXPERT PANEL**

I \_\_\_\_\_


Hereby agree to participate in the expert panel for the assessment of the draft evidence-based guidelines on Adherence to Antiretroviral Therapy.

Signature-----

Date-----

**ANNEXURE O: REVIEW SHEET FOR EVIDENCE-BASED BEST-PRACTICE  
GUIDELINES (ADAPTED FROM THE AGREE II INSTRUMENT)**

**Please tick the most relevant responses in the block as indicated below**

|  |   |   |   |   |   |   |   |
|--|---|---|---|---|---|---|---|
| Citation information   | Evidenced-based best-practice guidelines for facilitating adherence to Anti-retroviral therapy for persons attending public hospitals.<br>J. Agyeman-Yeboah, E.J. Ricks, M. Williams and P.J. Jordan, School of Clinical Care Science, Department of Nursing Science, NMMU, 2016      |   |   |   |   |   |   |
| Description of context   | The evidence-based best-practice guideline was developed for healthcare professionals who render care to adult HIV patients on ART in Public hospitals. The guideline was based on the data derived from the integrative review and the findings from the qualitative study conducted |   |   |   |   |   |   |
| <b>DOMAIN 1: SCOPE AND PURPOSE</b>   | Strongly disagree  Strongly agree  |   |   |   |   |   |   |
| <b>Score</b>   | 1   | 2 | 3 | 4 | 5 | 6 | 7 |
| 1.The overall objective(s) of the guideline is (are) specifically described                                  |   |   |   |   |   |   |   |
| 2. The health question (s) covered by the guideline is (are) specifically described                          |   |   |   |   |   |   |   |
| 3. the population ( patients, public etc.) to whom the guideline is meant to apply is specifically described |   |   |   |   |   |   |   |
| <b>DOMAIN 2: STAKEHOLDER INVOLVEMENT</b>   |   |   |   |   |   |   |   |
| 4. The guideline development group includes individuals from all relevant professional groups                |   |   |   |   |   |   |   |
| 5. The views and preferences of the target population (patients, public, etc.) have been sought              |   |   |   |   |   |   |   |
| 6. The target users of the guideline are clearly defined   |   |   |   |   |   |   |   |
| <b>DOMAIN 3: RIGOUR OF DEVELOPMENT</b>   |   |   |   |   |   |   |   |
| 7. Systematic methods were used to search for evidence   |   |   |   |   |   |   |   |
| 8. The criteria for selecting the evidence are clearly described   |   |   |   |   |   |   |   |
| 9. The strengths and limitations of the body of evidence are clearly described                               |   |   |   |   |   |   |   |
| 10. The methods of formulating the recommendations are clearly described                                     |   |   |   |   |   |   |   |
| 11. There is an explicit link between the recommendations and the supporting evidence                        |   |   |   |   |   |   |   |
| 12. The guideline has been externally reviewed by experts prior to its publication                           |   |   |   |   |   |   |   |



|  |  |  |  |  |  |  |  |
|--|--|--|--|--|--|--|--|
| <b>DOMAIN 4: CLARITY OF PRESENTATION</b>   |  |  |  |  |  |  |  |
| 13. The recommendations are specific and unambiguous.                                |  |  |  |  |  |  |  |
| 14. Key recommendations are easily identifiable                                      |  |  |  |  |  |  |  |
| <b>DOMAIN 5: EDITORIAL INDEPENDENCE</b>  |  |  |  |  |  |  |  |
| 15. The views of the funding bodies have not influenced the content of the guideline |  |  |  |  |  |  |  |

**Overall guideline assessment**

**1. Rate the overall quality of this guideline**

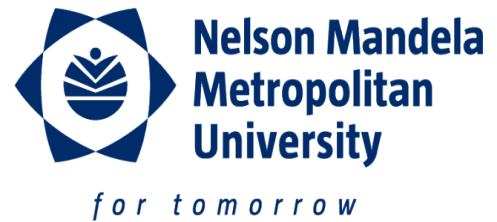
|                              |   |   |   |   |   |                               |
|------------------------------|---|---|---|---|---|-------------------------------|
| 1<br>Lowest possible quality | 2 | 3 | 4 | 5 | 6 | 7<br>Highest possible quality |
|------------------------------|---|---|---|---|---|-------------------------------|

**2. I will recommend this guideline for use**

|                              |  |
|------------------------------|--|
| <b>Yes</b>                   |  |
| <b>Yes with modification</b> |  |
| <b>No</b>                    |  |
| <b>Notes:</b>                |  |
|                              |  |

## ANNEXURE P: LETTER TO INDEPENDENT CODER

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • [www.nmmu.ac.za](http://www.nmmu.ac.za)



J.Agyeman-Yeboah  
P.O. Box CT 1775  
Cantonment-Accra  
Ghana  
0244292275/0266748337  
Joanaagyemanyeboah  
@outlook.com

Dear Dr Williams,

Thank you for agreeing to assist me with independent coding for my PhD study. The research I wish to conduct for my Doctoral thesis is entitled: A best-practice guideline for facilitating adherence to antiretroviral for persons attending public hospitals in Ghana.

The aim of this research study is to develop a best-practice guideline for facilitating adherence to ART based on the research findings related to adherence to ART. Data will be collected by means of individual interviews. Please use Tesch's eight steps on coding to code the interviews. I will be attaching the Tesch's data analysis method of identifying themes in the data, which allows a structured organisation of data to take place.

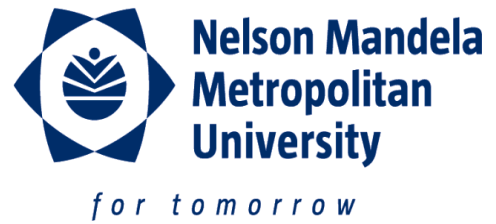
Should you have any queries please do not hesitate to contact me.

Yours sincerely,

JOANA AGYEMAN-YEBOAH  
RESEARCHER

## ANNEXURE Q: LETTER TO INDEPENDENT REVIEWER

• PO Box 77000 • Nelson Mandela Metropolitan University  
• Port Elizabeth • 6031 • South Africa • [www.nmmu.ac.za](http://www.nmmu.ac.za)



J.Agyeman-Yeboah  
P.O.Box CT 1775  
Cantonment-Accra  
Ghana  
0244292275/0266748337  
[joanaasante@yahoo.co.uk](mailto:joanaasante@yahoo.co.uk)  
15<sup>th</sup> April, 2016

Dear Dr Ten Ham,

Thank you for agreeing to assist me with the independent critical appraisal of the guidelines in my PhD study. The research I wish to conduct for my Doctoral thesis is entitled: A best-practice guideline for facilitating adherence to antiretroviral for persons attending public hospitals in Ghana.

The aim of this research study is to develop a best-practice guideline for facilitating adherence to ART by persons receiving treatment at public hospitals in Ghana, based on the research findings related to adherence to ART. I will be using the AGREE 11 instrument to appraise the guidelines. Please find a copy of the instrument attached. Should you have any queries please do not hesitate to contact me.

Yours sincerely,

JOANA AGYEMAN-YEBOAH  
RESEARCHER

**ANNEXURE R: COPY OF AGREE II GUIDELINE CRITICAL APPRAISAL  
INSTRUMENT**

|  |  |
|--|--|
| <b>DOMAIN 1: SCOPE &amp; PURPOSE<br/>SCORE</b>   |  |
| 1. The overall objective(s) of the guideline is (are) specifically described                                 |  |
| 2. The health question (s) covered by the guideline is (are) specifically described                          |  |
| 3. The population ( patients, public etc.) to whom the guideline is meant to apply is specifically described |  |
| <b>DOMAIN 2: STAKEHOLDER INVOLVEMENT<br/>SCORE</b>   |  |
| 4. The guideline development group includes individuals from all relevant professional groups.               |  |
| 5. The views and preferences of the target population (patients, public, etc.) have been sought              |  |
| 6. The target users of the guideline are clearly defined.  |  |
| <b>DOMAIN 3: RIGOUR OF DEVELOPMENT<br/>SCORE</b>   |  |
| 7. Systematic methods were used to search for evidence.  |  |
| 8. The criteria for selecting the evidence are clearly described.  |  |
| 9. The strengths and limitations of the body of evidence are clearly described.                              |  |
| 10. The methods of formulating the recommendations are clearly described.                                    |  |
| 11. The health benefits, side effects and risks have been considered in formulation the recommendations.     |  |
| 12. There is an explicit link between the recommendations and the supporting evidence.                       |  |
| 13. The guideline has been externally reviewed by experts prior to its publication                           |  |
| 14. A procedure for updating the guideline is provided   |  |

|  |  |
|--|--|
| <b>DOMAIN 4: CLARITY OF PRESENTATION<br/>SCORE</b>   |  |
| 15. The recommendations are specific and unambiguous.  |  |
| 16. Key different option for management of condition or health issues are clearly presented        |  |
| 17. Key recommendations are easily identifiable  |  |
| <b>DOMAIN 5: APPLICABILITY<br/>SCORE</b>   |  |
| 18. The guideline describes facilitators and barriers to its application.                          |  |
| 19. The guideline provide advice and /or tools on how the recommendations can be put into practice |  |
| 20. The potential resource implications of applying the recommendations have been considered       |  |
| 21. The guideline presents monitoring and /or auditing criteria                                    |  |
| <b>DOMAIN 6: EDITORIAL INDEPENDENCE<br/>SCORE</b>  |  |
| 22. The views of the funding body have not influenced the content of the guideline.                |  |
| 23. Competing interests of guideline development group members have been recorded and addressed.   |  |

## **ANNEXURE S: BEST-PRACTICE GUIDELINE FOR FACILITATING ADHERENCE TO ANTIRETROVIRAL THERAPY FOR PERSONS RECEIVING TREATMENT AT PUBLIC HOSPITALS IN GHANA**

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**Objective:** The objective of this best-practice guideline is to provide healthcare professionals in public hospitals in Ghana with best-practice recommendations for facilitating adherence to Antiretroviral Therapy (ART) among adult patients receiving ART at public hospitals.

**Design:** Based on the data derived from an integrative literature review and the qualitative findings gathered from the individual interviews with patients on ART and Healthcare Professionals (HCPs) providing ART services at public hospitals in Ghana, this best-practice guideline (BPG) was developed. Guideline databases which were searched were Canadian Medical Association InfoBase Clinical Practice database, National Guideline Clearinghouse, Writer's guidelines database and National Institute for Health and Clinical Excellence. The librarian for the Faculty of Health Sciences at the Nelson Mandela Metropolitan University was consulted to assist in the search for relevant literature. The search for relevant literature was conducted using search engines such as PubMed, Google Scholar, (CINAHL, ERIC, Academic search complete, E-journals, Psyc info, MEDLINE) via EBSCOHOST, EMERALD INSIGHT,

JSTOR, SCIENCE DIRECT and FINDPLUS. Critical appraisal and data extracting and synthesis were done on completion of the literature search process.

**Setting:** The best-practice guideline is intended for use by HCPs in order to assist facilitation of adherence in persons receiving ART at public hospitals in Ghana.

**Population:** The BPG aims to address adherence to ART in adult HIV positive patients at public hospitals.

**Results and Conclusion:** An integrative literature review was done on adherence to Antiretroviral Therapy. Based on the results of the integrative literature review and the qualitative findings gathered in the individual interviews with patients on ART and healthcare professionals, recommendations for adherence to ART were formulated and are categorized as follows: intervention to improve or promote ART adherence; monitoring of ART adherence and challenges to ART adherence.

**Keywords:** Adherence, Antiretroviral Therapy, Best-practice Guideline

## 1.1 INTRODUCTION

Adherence to ART is taking the exact medication at the right time and under the right condition (Ghana Health Service, 2010:62). Missing a single dose of ART can result in the development of resistance strains of HIV and thus reduces the efficiency of the treatment. Antiretroviral therapy must be commenced in a timely manner and patients must be supported to be retained in treatment programs and also receive support in adhering to the prescribed regime (UNAIDS, 2012:56).

A study conducted on the predictors of adherence to ART among HIV and AIDS patients in Ghana revealed that non-adherence to ART increased the risk of immunological failure; and regular follow-up was positively associated with the patient's adherence to ART. Effective counselling sessions on adherence for patients on ART are imperative for the realisation of the ART programmes in Ghana to be successful (Obirikorang, Selleh, Abledu, Fofie, 2013: 4).

Considering the importance of adherence to the successful initiation and implementation of Antiretroviral Therapy, it is imperative that healthcare practices

related to antiretroviral services must aim at facilitating patients' adherence to the ART and this must be in accordance to the latest and best-practice recommendations.

## **1.2 SCOPE AND PURPOSE**

The scope and purpose of the guideline encompasses the objectives, review question and target group.

### **1.2.1 Objectives of the Best-practice Guideline**

The objective of this best-practice guideline is to provide recommendations based on best available evidence in order to assist the facilitation of adherence in adult patients receiving ART in public hospitals in Ghana.

### **1.2.2 Review Question**

The integrative review question that was formulated in order to search for relevant literature pertaining to adherence to ART was: What is the best available evidence that facilitates antiretroviral therapy adherence amongst HIV positive adult patients in the public hospitals?

### **1.2.3 Target Group**

The evidence-based practice guideline is intended for use amongst healthcare professionals in order to assist facilitation of adherence in persons (could either be a male or female adult including pregnant adult women) receiving ART in public hospitals in Ghana. The guideline implementation and evaluation will not form part of this study but will be done post-doctoral.

## **1.3 STAKEHOLDERS INVOLVEMENT**

The draft guideline was submitted to an expert panel for review. The panel consisted of experienced clinicians and professionals who are experts on the content and have knowledge on guideline development. The expert panel comprised of two medical specialists, one was selected based on his expertise in care of patients on ART at a public hospital in Ghana, while the other medical specialist was selected based on his expertise in research, evidenced based practice and guideline development. The



panel also consisted of two professional nurses with a PhD in nursing; both are involved in the development of guidelines and are lecturers. One is in a Public University in South Africa and the other is in a private University in Ghana. Among the panel were HIV and AIDS content specialists and an educationalist from a private nursing college with experience in the development of best-practice guidelines.

The views of the healthcare professionals and persons on ART were taken into account during the development of this guideline. Owing to the scope of this research study, the guideline was not pilot tested among the healthcare professionals who constitute the target group. Implementation strategies thus have to be developed to enhance the use of this guideline in practice.

#### **1.4 RIGOUR OF DEVELOPMENT**

The librarian at the Faculty of Health Sciences at the Nelson Mandela Metropolitan University assisted in a search for relevant literature in citation databases such as PubMed, Google Scholar, (CINAHL, ERIC, Academic search complete, E-journals, Psycinfo, MEDLINE) via EBSCOHOST, EMERALD INSIGHT, JSTOR, SCIENCE DIRECT and FINDPLUS. Search items used for ascertaining literature pertaining to adherence to antiretroviral therapy were for instance, “adherence to ART, “ART adherence guidelines”, “adherence facilitating guidelines”.

Guidelines database which were searched were the Canadian Medical Association InfoBase clinical practice database, National guidelines clearinghouse, Writer’s guidelines database and National Institute for Health and Clinical Excellence (NICE).

Inclusion criteria for studies considered in the integrative review comprised all studies that focused on ART, adherence and treatment guidelines for ART, adult patients. Guidelines that were not published in English were excluded in the review. To ensure a comprehensive search, all guidelines that were published from 1996 to 2016 were included in the integrative review. All guidelines that did not focus on adherence to antiretroviral therapy and were not developed for adults were excluded. The initial search for evidence identified 16 possible guidelines for inclusion in the integrative review. After eliminating guidelines (n=5) that did not adhere to the inclusion criteria of the review, 11 guidelines were included in the critical appraisal process.

These guidelines were appraised by using the Appraisal of Guidelines for Research and Evaluation Instrument (AGREE II). The data was displayed in the form of a table. Displayed data from the eleven appraised guidelines were examined in order to identify emerging themes. Due to the type of evidence found and the heterogeneity of the various guidelines no meta-analysis was performed. The extracted data from the guidelines were analysed using thematic analysis. Owing to the scope of this research study, the guideline was developed by the researcher and not by a recommended guideline development group. However, a panel of experts with knowledge about content and guideline development was consulted to review and comment on the content and construction of the guideline.

## 1.5 RECOMMENDATIONS

The data relating to adherence to ART by patients attending public hospitals were categorized as illustrated in table 1 below.

**Table 1: Synthesized data from qualitative findings and guidelines found on adherence to ART**

| <b>Theme</b>                                      | <b>Subthemes</b>   |
|---|--|
| Interventions to improve or promote ART adherence | Adherence tools for patients.<br>Education and counselling intervention.<br>Health systems and service delivery interventions<br>ART adherence strategies<br>Ways in which the needs of people living within resource poor settings could be met |
| Monitoring of ART adherence                       | Methods of measuring ART adherence   |
| Challenges to ART adherence                       | Addressing the challenges to ART adherence   |

The data synthesized from the guidelines in the form of recommendations for facilitating adherence to ART were synthesized with the findings of the qualitative data regarding adherence to ART and are categorized as follows:

### **1.5.1 Interventions to Improve or promote ART adherence**

The following recommendations are made with regards to interventions to improve or promote adherence to ART in patients receiving treatment at public hospitals:

#### **1.5.1.1 Adherence tools for patients**

It is recommended that:

- Persons on ART should use reminder devices such as dose time reminders, alarm clock, programmable wrist watches, pager, and a calendar as tools to enhance their adherence to the therapy.
- Use of communication techniques such as short text-message service text message software, telephone or post card and pill diary and chart can be helpful.
- Use of pill boxes, drug time tables or medication containers and blister packs must be encouraged.
- Use of specific adherence related tool during education and counselling must be encouraged.

#### **Rationale**

Evidence derived from five guidelines confirmed that the use of adherence tools by patients improve their adherence to the ART. According to the Ghana National HIV/AIDS/STI Control Program, Ministry of Health and Ghana Health Service (NHASCP/MOH/GHS, 2010:64), one of the reasons for non-adherence has been given as forgetfulness. The frequency with which forgetfulness has been cited by HIV positive patients as a contributing factor to missed doses has necessitated the use of medication alerts in order to improve patients' adherence to ART (Poppa, Davidson, Deutsch, Godfrey, Fisher, Head, Horne, & Sherr, 2004: 50). Many people commonly use self-managed adherence tools including pill boxes, medication planners or calendars and these have been associated with improved adherence. It is common to combine an adherence tool with structural and behavioural interventions. Also, the use of dose-time reminder alarms, pager, drug time tables, adherence monitors and pill boxes as well as the use of short message services has demonstrated

improvement and enhancement in adherence to their medications (Thompson, Mugavero, Amico, Cargill, Chang, Gross, Orrell, Altice, Bangsberg, Bartlett, Beckwith, Dowshen, Gordon, Horn, Kumar, Scott, Stirratt, Remien, Simoni, & Nachega 2012: 820; NHASCP/MOH/GHS, 2010: 64-65 & Dybul, Fauci, Bartlett, Kaplan & Pau, 2004: k-3).

According to Oku, Owoaje, Ige and Oyo-ita (2013:6) the major reason cited by participants in their study for missing a dose of ART was operating a busy schedule and simply forgetting to take the medication. In the same vein, Hansana, Sanchaisuriya, Durham, Vanpharnom, Chaleunvong, Boonyaleepun and Schelpe (2013:8) also stated that forgetfulness was identified as a significant variable in predicting adherence. Similar to the above Musumaria, Feldmanb, Techasrivichiena, Woutersc, Ono-Kiharaa and Kiharaa (2013:1275) reported that forgetfulness was a common reason for skipping doses among participants in their study.

#### **1.5.1.2 Education and counselling intervention**

With regard to educational and counselling interventions to promote/improve ART adherence, the following recommendations are made:

- There should be correct education and counseling of the patient before initiating ART.
- The use of visual aids must be encouraged to assist in better explanation of the basic concepts as well as the benefits of ART.
- More than one counselling session should be encouraged to assist in better preparation of the patients.
- The counseling should be performed by a qualified health professional.
- Peer counselling should be encouraged and there should be one-on-one ART education.
- There should be more than one adherence counselling at different days and the patient's understanding on the received knowledge should be assessed before initiation of ART.
- The patient should be educated on basic information about ART, viral load and CD4 cell count and the expected outcome of ART based on these parameters,

the importance of strict adherence to ART, and the consequences of non-adherence.

- Healthcare providers should provide all patients with a basic level of adherence-related information and support.
- The patient should be counselled on how to live a protective lifestyle.
- An individual treatment plan should be developed, fitting ART into the patient's lifestyle/daily event and identifying treatment reminders.
- There should be assessment of the patient's adherence readiness and evaluation of the patient's knowledge about HIV disease treatment and prevention.
- Patient must be counselled by the doctor, the pharmacist, the nurse trained counsellor, the dietician and the psychologist before ART is initiated.
- At every visit to the hospital the patients must go through all the stages of counselling and their understanding on HIV and its manifestation, the benefits of taking the ARV, the possible side effects, how the medication should be taken, what to do when a dose is missed, the importance of adhering strictly to the prescribed dosage, the importance of good nutrition, the relationship between adherence and resistance must be assessed and documented.
- All verbal information given to the patient on the ART must be supported by written information.

## **Rationale**

Proper education of patients before the initiation of ART is considered vital for the success of an adherence strategy (WHO, 2005:44). The education that the patients receive before the initiation of the ART should address basic information about HIV and its manifestation, the benefits and side effects of ARV medications, how the medications should be taken and the importance of not missing any dose (WHO, 2005:44; MOHSSL 2006: 49 ). Every HIV treatment centre should have a written adherence strategy in place which should be audited regularly in the context of the growing knowledge base. Providers must ensure that patients have sufficient understanding of HIV pathogenesis; the rationale for anti-HIV therapy; the relationship between adherence and resistance; the requirements of their regimen, and its potential side effects, the support of voluntary sector resources should be enlisted,

and verbal information should be supported by written information (Poppa *et al.*, 2004: 51).

There should be individual one-on-one ART education and one or more adherence counselling approaches should be employed in providing adherence support. Multidisciplinary education and counselling intervention approaches as well as offering of peer support were also recommended (Thompson *et al.*, 2012: 821). Healthcare providers should provide all patients with a basic level of adherence-related information and support. Health care providers should evaluate patients' knowledge about HIV disease, treatment, and prevention and provide basic information about ART, viral load and CD4 count and the expected outcome of ART based on these parameters, the importance of strict adherence to ART, and the consequences of non-adherence (Dybul, *et al.*, 2014:k-3). An individual treatment plan should be developed, fitting ART into the patient's lifestyle/daily event and identifying treatment reminders (Department of AIDS Control Program (DACP) , National AIDS control program (NACP), Ministry of health and family welfare (MOHFW) and the government of India (GOI), 2013:64).

To validate the qualitative findings with regard to counselling and education intervention, Holtzman, Brady and Yehia (2015:449) stated that in order to retain clients who initiate ART in the treatment there must be the provision of general education and counselling. According to MacPherson, Munthali ,Ferguson, Armstrong, Kranzer, Ferrand and Ross (2015:1019), patients who received counselling on adherence to ART displayed greater improvement in ART adherence than those who did not receive counselling. Low perceived quality of information from care providers has been identified to be among the factors that remained significantly associated with subnormal adherence to ART (Do, Dunne, Kato, Pham & Nguyen 2013:5). Murray (2009:4) states that lack of understanding of treatment benefits are among the barriers to adherence. Similarly Muduka and Tobin-West (2015:159) reported that poor understanding of the effect of the drugs contributes to non-adherence to the treatment. In the same vein Shalihu (2014:971) stated that lack of understanding of the disease served as a barrier to adherence.

### **1.5.1.3 Health systems and services delivery intervention**

With regard to health systems and service delivery intervention, the following recommendations are made:

- There should be proper training of nurses within the community to provide home based adherence counselling and this can assist in resolving challenges with transportation to the healthcare facility for service, hence improving adherence.
- Medication management service should be integrated into the pharmacy system.
- There should be correct and continuous training of healthcare professionals on adherence issues including professional development and skill based training.
- There should be an established trusting relationship and maintenance of good communication between the patient and the healthcare professionals.
- Patient should be assigned to a primary provider who will work with other healthcare professionals in other disciplines to provide the needed care and support to the patients.

#### **Rationale**

Nurse or community-counsellors-based care is noted to have good adherence outcomes, hence should be encouraged, especially in under resourced settings. It was also recommended that distinct services or group of services that optimized therapeutic outcomes for individual patients known as medication management service should be integrated into pharmacy systems (Thompson, *et al.*, 2012: 821).

Primary Care Guidelines for the Management of Persons Infected With HIV by the HIV Medicine Association of the Infectious Disease Society of America recommended that HIV care sites should utilise a multidisciplinary model but identify a primary provider for each patient and support the development of a trusting long-term patient provider relationship ( Aberg, Gallant, Ghanem, Emmanuel, Zingman & Horberg, 2014:29) Establishing a trusting patient-provider relationship over time and maintaining good communication will help to improve adherence and long term outcomes (Dybul, *et al.*, 2014: k-3). The guidelines on the provision of adherence support to individuals receiving antiretroviral therapy by the recommended that HIV professionals require

continuing education in patient adherence issues including professional development and skill based training (Poppa, *et al.*, 2004:51).

To validate the qualitative findings with regard to training of healthcare providers, Breitenauer, Mmeje, Njoroge, Darbes, Leddy and Brown (2015:4) maintained that one means of improving patients' access to HIV service is the provision of education about HIV prevention. In order to facilitate the satisfaction of the patient and retention in care, there should be better understanding and communication between the patient and the healthcare professional (Borgart, Chetty, Giddy, Sypek, Sticklor, Walensky, Losina, Katz & Basset, 2013:852). Delobelle, Rawlinson, Ntuli, Malatsi, Decock and Depoorter (2009:1069) maintained that there is an urgent need for accelerated HIV/AIDS training of healthcare workers in developing countries in order to maintain quality patient care.

#### **1.5.1.4 ART adherence strategies**

With regard to ART adherence strategies, the following recommendations are made:

- Among the regimens of similar efficacy and tolerability, one-daily regimen is recommended for treatment-naive patients beginning treatment.
- Treatment-experienced patients receiving complex or poorly tolerable regimen should be switched to once daily regimen with equivalent efficacy.
- Among regimens of equal efficacy and safety, fixed-dose combinations are suggested to decrease pill burden.
- The extent to which lifestyle factors such as eating, sleeping and working patterns may impede adherence to a proposed regime must be evaluated.
- Individual preference regarding regimen characteristics, including formulation and pill size should be assessed instead of been assumed.
- Regimens which are dosed once or twice daily which do not require fasting or dietary modification, and which have lower pill burden are likely to enable higher adherence and should be prescribed where appropriate in accordance to the preference of the patient.
- In order to identify possible adherence barriers, ART may be substituted with placebos.
- Potential for drug interactions should be assessed prior to starting therapy.



## **Rationale**

The guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons With HIV developed by the (International Association of Physician in AIDS Care (IAPAC ) recommended that, among the regimens of similar efficacy and tolerability, one-daily regimen is recommended for treatment-naive patients ( HIV positive patients who have never taken any ART for their infection) beginning ART. Switching treatment-experienced patients receiving complex or poorly tolerable regimen to once daily regimen was recommended, given regimen with equivalent efficacy. Furthermore, among regimens of equal efficacy and safety, fixed-dose combinations are recommended to decrease pill burden (Thompson, *et al.*, 2012: 820).

The guidelines on the provision of adherence support to individuals receiving antiretroviral therapy by (BHIVA/BASHH) recommended that the extent to which lifestyle factors such as eating, sleeping and working patterns may impede adherence to a proposed regime must be evaluated. Individual preference regarding regimen characteristics, including formulation and pill size should be assessed instead of being assumed. Regimens which are dosed once or twice daily which do not require fasting or dietary modification, and which have lower pill burden are likely to enable higher adherence and should be prescribed where appropriate in accordance to the preference of the patient. It was also recommended that the patients should always see the pill that may be prescribed for them prior to regimen selection. In order to identify possible adherence barriers, ART may be substituted with placebos, in order to assist in identifying the actual barriers. Also potential for drug interactions should be assessed prior to starting therapy (Poppa *et al.*, 2004:53-54).

### **1.5.1.5 Ways in which the needs of people living within resource poor settings could be met**

Based on the findings of the qualitative interviews conducted in this study with patients on ART and health care professionals providing ART services, it is recommended that:

- Local languages that patients are comfortable with should be used in order to facilitate patients comprehension

- Support from the nuclear and extended family must be encouraged
- Traditional and spiritual healers should be trained regarding appropriate and early referral of patients from their camps to recognised health facilities.
- Traditional and spiritual healers should be trained on the importance and the benefits of ART in the life of the patients.

## **Rationale**

To validate the qualitative findings with regard to how the needs of people living within resource poor settings could be met, Roura, Nsigaye, Nhandi, Wamoyi, Busza, Urassa, Todd and Zaba (2010: 9) maintains that it is perceived that HIV/AIDS is a punishment from God for sinful behaviour; it has a spiritual cause and hence must be treated through spiritual means. A study on improving clinical attendance and adherence to antiretroviral therapy through a treatment supporter intervention by Kunutsor, Walley, Muchuro, Katabira, Balidawa, Namagala and Ikoona (2011:1800 & 1801) maintained that having a treatment supporter impacts positively on ART adherence. The authors concluded that the treatment supporter strategy is a practical, cost-effective and feasible method for enhancing adherence and improving clinical attendance.

### **1.5.2 Monitoring adherence**

Adherence monitoring assists in the assessment of the effect of interventions and also informs providers of the need to implement interventions (Thompson, *et al.*, 2012:819). Monitoring adherence to ART is a measure of maintaining support for adherence after ART has been initiated.

#### **1.5.2.1 Methods of measuring ART adherence**

With regard to the methods of measuring ART adherence, the following recommendations are made:

- Self-reported adherence should be obtained routinely and pharmacy refill data must be accurately kept.
- Adherence in patients should be measured by pill count, electronic device fitted to pill container (e.g. MEMSCap), physician report and drug level monitoring in the blood.

- There should be adherence measurement whenever there is a visit to the health care facility.
- Adherence measurement should be carried out at each clinical encounter and should be the responsibility of the entire health care team.
- Health care professionals should employ the following in order to help the patient report non-adherence: giving explanations on why a question is being asked, asking questions without implying blame, assuring the patient there is no right or wrong answer, using open ended questions using words familiar to the patient and using cues to prompt recall.
- A standardized self-completed questionnaire which invites either 14-day or 1-month recall of adherence should be used to measure patient's adherence to ART.
- Viral load rebound should always prompt health care providers to discuss adherence behaviour with the patient and to assess the patient's understanding of how their regimen should be taken.
- A patient that enters a treatment programme should complete a personal adherence plan. The adherence plan should include the identification of a companion (treatment supporter) that will assist the patient to adhere to his/her drugs. The companion will be charged with checking the client on a daily basis to observe and document at least one of the doses being taken. In order for this strategy to succeed, each companion should receive orientation to ART.
- There should be continuous involvement of relatives and /or community support personnel

## **Rationale**

Monitoring and assessment of adherence to ART is a measure of maintaining support for adherence after ART has been initiated. The guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV developed by the (IAPAC) indicated the necessity to monitor adherence as it assists in the assessment of the outcome of an interventions and also informs the healthcare provider of the need to implement intervention (Thompson, *et al.*, 2012:819) Methods of measuring adherence include self-reports, pharmacy refill data, electronic drug monitors, pill counts and drug concentrations from biological samples. The guideline

however recommended that self-reported adherence should be obtained routinely in all patients and pharmacy refill data (data on when and the amount of drugs issued out) was also recommended for adherence monitoring (Thompson, *et al.*, 2012:819). Adherence is measured by patient self –report, pill count, electronic device fitted to pill container, physician report and drug level monitoring (Pozniak, Gazzard Babiker, Churchill, Collins, Deutsch, Fisher, Johnson, Khoo, Loveday, Main, Matthews, Moyle, Nelson, Peters, Phillips, Pillay, Poppa, Taylor, Williams, & Youle 2001:287). It is important to maintain support for adherence after the initiation of ART and there should be adherence assessment whenever there is a visit to the health care facility. Also there should be continuous involvement of relatives and /or community support personnel (WHO, 2004:44).

Guidelines for the routine investigation and monitoring of adult HIV-1-infected individuals by the British HIV Association recommended what the healthcare providers should do in order to help the patient report non-adherence. The following was recommended: explanations should be given on why a question is being asked, asking questions without implying blame, assuring the patient that there is no right or wrong answer, using open ended questions, using words familiar to the patient and using cues to prompt recall (Asboe, Aitken, Boffito, Booth, Cane, Fakoya, Geretti, Kelleher, Mackie, Muir, Murphy, Orkin, Post, Rooney, Sabin, Sherr, Smit, Tong, Ustianowski, Valappil, Walsh, Williams & Yirrell 2012:8).

The guidelines on the provision of adherence support to individuals receiving antiretroviral therapy by the (BHIVA/BASHH) recommended that every patient who is prescribed antiretroviral therapy should have their adherence measured and recorded at routine clinic visits. They indicated that the preferred method is a standardized self-complete questionnaire, which invites either 14-day or 1-month recall of adherence. Also viral load rebound should always prompt health care providers to discuss adherence behaviour with the patient and to assess the patient's understanding of how their regimen should be taken. They also recommended the use of open questions which acknowledges that low adherence is common as it is more likely to elicit full response from patients (Poppa, *et al.*, 2004:55)

The National Antiretroviral Treatment Guidelines by the MOHSSL recommended that, after the initiation of therapy, it is essential to maintain support for adherence. This

should involve adherence assessments whenever there is a visit to a health centre, reinforcement of adherence principles to the patients by treatment supporters, and the continuous involvement of relatives, friends and/or community support personnel. They also recommended that each patient that enters a treatment programme should complete a personal adherence plan. The adherence plan should include the identification of companions that will assist patients to adhere to their drugs. The companions will be charged with checking the patients on a daily basis to observe and document at least one of the doses being taken. In order for this strategy to succeed, each companion should receive orientation to ARV (MOHSSL, 2006:49).

To validate the analysis of the qualitative data, Holtzman, Brady and Yehia Holtzman (2015:449) contended that there must be periodic monitoring of medication adherence among patients using patient self-report. Also pill counting was described as a measure of monitoring and ensuring medication adherence because pill counting involves counting the number of remaining doses with the patient so that one could detect whether the patient missed any doses.

### **1.5.3 Challenges to ART adherence**

Identified challenges to ART adherence from the qualitative findings include, limited knowledge of the patients on the ART, forgetting to take the drug, travelling and leaving the drug behind and financial difficulties. How the challenges should be addressed in order to facilitate patient's adherence to ART has been recommended.

#### **1.5.3.1 Addressing challenges to ART adherence**

With regard to addressing challenges to ART adherence, the following recommendations are made:

- Memory aids should be provided to establish and maintain a pill taking routine, as well as the management of side effects.
- Regimes that dosed once or twice a day may facilitate better adherence than those dosed more frequently.
- Patients' perceptions of their therapy are influential hence belief in one's capacity to follow the regime must be encouraged.

- Motivational interviewing should be used and also high levels of adherence should be recognised with incentive and reward (if possible).
- Use of drug time-tables, adherence monitors, pill boxes and continued adherence counselling should be encouraged.
- The patient should be reassured about side-effects and an alternate regimen should be discussed if side-effects are intolerable.

## **Rationale**

To validate the qualitative findings with regard to challenges to ART adherence, Senkomagoa, Guwatuddeb, Bredac, and Kaveh (2011:1250) maintained that the main reasons given for non-adherence was being away from the medication at the dose time or the time they were supposed to have taken the drugs. Patients tend not to carry their medications with them when they travel and hence see vacation travel as a vacation from medication as well (Taylor, Reyes, Levine, Khan, Gardun˜o. Donastorg, Hammer, Brudney, & Hirsch, 2014:291). According to Oku, *et al.* (2013:6) the major reason cited by participants in their study for missing a dose of ART was operating a busy schedule and simply forgetting to take the medication. Taylor, *et al.* (2014:291) cited the rising cost of transportation to ART clinic for clients who live quite a distance away from the clinic as a barrier to adherence to the treatment. Furthermore, Bezabhe, Chalmers, Bereznicki, Peterson, Bimirew and kassie (2014:7) stated that participants in their study missed pills and stopped collecting drugs from clinics when they could not afford to buy food.

According to the guidelines for the treatment of HIV-infected adults with antiretroviral therapy by British HIV Association (BHIVA), the most common causes of missed doses reported by patients themselves are forgetfulness and drug toxicity (Poppa, 2004:51). Also dietary restrictions may also have a negative impact on adherence. The guideline however recommended that the medications that are taken once or twice in a day may facilitate better adherence than those taken more frequently in a day. Patients must also be motivated to begin and continue the therapy and the impact of the therapy on the individual's lifestyle and psychological well-being must be addressed. It is also recommended that memory aids should be provided to establish

and maintain a pill taking routine and any underlying mental illness should be treated as well as the management of side effects (Pozniak, *et al.*, 2001:287)

The guidelines for the use of antiretroviral agent in HIV-1-infected adults and adolescents by the Health and Human Service (HHS) Panel on Antiretroviral Guidelines for Adults and Adolescents (PAGAA) indicated that non-adherence from the patients perspective is often a consequence of one or more behavioural barriers such as depression, other mental illness, neuro cognitive impairment, low health literacy, low levels of social support, stressful life events, high level of alcohol consumption and active substance use, homelessness, poverty, nondisclosure of HIV sero status, denial, stigma and inconsistent access to medications. The guideline however recommended that motivational interviewing should be used and also high levels of adherence should be recognised with incentive and reward. (Dybul, *et al.*, 2014:k-1)

The guidelines for antiretroviral therapy in Ghana by the National HIV/AIDS/STI Control Program, Ministry of Health and Ghana Health Service (NHASCP/MOH/GHS) indicated that the main reasons for non- adherence to therapy are forgetfulness, the number and timing of doses, number and size of pills (pill burden) food restrictions, perceived or actual side effects and missed appointments for drug refills. They however recommended that strategies used to overcome the problem of non-adherence, include use of drug time-tables, adherence monitors, pill boxes and continued adherence counselling. The patient should be reassured about side-effects and an alternate regimen should be discussed if side-effects are intolerable (NHASCP/MOH/GHS 2010: 64-65).

## **1.6 EDITORIAL INDEPENDENCE**

The responses from the patients on ARTs and the healthcare professionals who provide services to patients on ARTs formed the basis for the development of this evidence-based best-practice guideline. The promoter and co-promoters of this research study assisted in the conception and design of the guideline. The researcher received no funding and hence the guideline is editorially independent of any organization or institution. There is no conflict of interest in the development of the guideline.

## **1.7 CONCLUSION**

The best-practice guideline was developed from best available evidence on adherence to ART and it is expected that it would assist in the facilitating of adherence to ART. The views of the healthcare professionals on the content of the best-practice guideline gave a unique contribution to the development of the guideline. The guideline was however not piloted among the healthcare professionals who form the target group as this was not within the scope of the study.



## ANNEXURE T: EXTRACTED DATA FROM GUIDELINES

| TITLE OF GUIDELINE  | AUTHOR(S) AND YEAR OF PUBLICATION    | MAIN RECOMMENDATIONS   |
|---|--------------------------------------|--|
| <p>Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV.</p> | <p>Thompson <i>et al.</i> (2012)</p> | <p><b>A. MONITORING OF ADHERENCE</b></p> <ol style="list-style-type: none"> <li>1. Self-reported adherence should be obtained routinely in all patients</li> <li>2. Pharmacy refill data are recommended for adherence monitoring when medication refills are not automatically sent to patients</li> <li>3. Electronic Drug Monitors are not routinely recommended for clinical use</li> </ol> <p><b>B. INTERVENTIONS TO IMPROVE ART ADHERENCE</b></p> <p><b>BI. ART Strategies</b></p> <ol style="list-style-type: none"> <li>1. Among regimens of similar efficacy and tolerability, once-daily regimens are recommended for treatment-naive patients beginning ART.</li> <li>2. Switching treatment-experienced patients receiving complex or poorly tolerated regimens to once daily regimens is recommended, given regimens with equivalent efficacy</li> <li>3. Among regimens of equal efficacy and safety, fixed-dose combinations are recommended to decrease pill burden</li> </ol> <p><b>BII. Adherence Tools for Patients</b></p> <ol style="list-style-type: none"> <li>1. Reminder devices and use of communication technologies with an interactive component are Recommended</li> </ol> |

| TITLE OF GUIDELINE | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS   |
|--------------------|-----------------------------------|--|
|                    |                                   | <p>2, Education and counselling using specific adherence-related tools is recommended</p> <p><b>BIII. Education and Counselling Interventions</b></p> <ol style="list-style-type: none"> <li>1. Individual one-on-one ART education is recommended</li> <li>2. Providing one-on-one adherence support to patients through one or more adherence counselling approaches is recommended</li> <li>3. Group education and group counselling are recommended; however, the type of group format, content, and implementation cannot be specified on the basis of the currently available evidence</li> <li>4. Multidisciplinary education and counselling intervention approaches are recommended</li> <li>5. Offering peer support may be considered</li> </ol> <p><b>BIV Health System and Service Delivery Interventions</b></p> <ol style="list-style-type: none"> <li>1. Using nurse- or community counselor– based care has adherence and biological outcomes similar to those of doctor- or clinic counsellor– based care and is recommended in under resourced settings</li> <li>2. Integration of medication management services into pharmacy systems may be considered.</li> </ol> |

| TITLE OF GUIDELINE   | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS   |
|--|-----------------------------------|--|
| Scaling up antiretroviral therapy in resourced limited setting | WHO, 2006                         | <ul style="list-style-type: none"> <li>• The proper education of patients before the initiation of therapy is vital for the success of adherence strategies. Such education should cover basic information about HIV and its manifestations, the benefits and side-effects of ARV medications, how the medications should be taken and the importance of not missing any doses</li> <li>• Peer counsellors and visual materials can be particularly useful in this process.</li> <li>• Keys to success once treatment has begun include trying to minimize the number of pills, the frequency of dosing (no more than twice-daily regimens), avoidance of food precautions, fitting the ARVs into the patient's lifestyle, and the involvement of relatives, friends and/or community members in support of the patient's adherence.</li> <li>• After the initiation of therapy it is essential to maintain support for adherence. This should involve adherence assessments whenever there is a visit to a health centre, reinforcement of adherence principles to the patient by treatment supporters, and the continuous involvement of relatives, friends and/or community support personnel.</li> </ul> |

| TITLE OF GUIDELINE   | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS   |
|--|-----------------------------------|--|
| British HIV association guidelines for treatment of HIV-infected adults with ART | Pozniak, <i>et al.</i> (2001)     | <ul style="list-style-type: none"> <li>• Patients themselves report forgetfulness and drug toxicity as the most common causes of missed doses.</li> <li>• Dietary restrictions may also have a negative impact on adherence, and regimens that are dosed once or twice a day may facilitate better adherence than those dosed more frequently.</li> <li>• Interventions to support adherence should be multifaceted, responsive to the needs of the individual and an integral part of ongoing care that is offered to all patients.</li> <li>• In order to realize the benefits of expenditure on highly active ART, it is essential that these programmes receive adequate investment and dedicated, trained personnel.</li> <li>• Adherence is measured by patient self-report, pill counts, electronic devices fitted to pill containers (e.g. MEMScap), physician report and drug level monitoring. Though each method has potential flaws, patient self-reported adherence is convenient, reinforces 'ownership' of treatment use by the patient and has been validated as a predictor of virological response</li> </ul> <p>Promoting adherence: issues to consider</p> <ul style="list-style-type: none"> <li>• The motivation of the individual to begin and continue therapy</li> <li>• The individual's understanding of the importance of adherence and its relationship to drug resistance</li> </ul> |

| TITLE OF GUIDELINE  | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS   |
|---|-----------------------------------|--|
|   |                                   | <ul style="list-style-type: none"> <li>• The impact of therapy on the individual's lifestyle and psychological well being</li> <li>• The provision of memory aids (such as pill boxes, medication record cards), to establish and maintain a pill taking routine</li> <li>• Management of side effects</li> <li>• Treatment of any underlying mental health problems</li> <li>• The potential risks and benefits of therapy, both real and perceived, in the short and long term</li> <li>• The provision of written information to provide support outside the clinic setting, covering the regimen, potential side effects and the consequences of low adherence, plus information on procedures for out of hours advice and care</li> </ul> |
| <p>National HIV/AIDS secretariat health sector Response Group. National Antiretroviral Treatment Guidelines. Sierra Leone</p> | <p>MOHSSL (2006)</p>              | <ul style="list-style-type: none"> <li>• The proper education of patients before initiation of therapy is essential for the success of adherence strategies. Such education should cover basic information about HIV and its manifestations, the benefits and side effects of ARV medications, how the medication should be taken and the importance of not missing any doses.</li> <li>• After the initiation of therapy, it is essential to maintain support for adherence. This should involve adherence assessments whenever there is a visit to a health centre, reinforcement of adherence principles to the patients by treatment supporters,</li> </ul>  |

| TITLE OF GUIDELINE | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS   |
|--------------------|-----------------------------------|--|
|                    |                                   | <p>and the continuous involvement of relatives, friends and/or community support personnel.</p> <ul style="list-style-type: none"> <li>• It is recommended that each patient that enters a treatment programme should complete a personal adherence plan. The adherence plan should include the identification of a companion that will assist the patient to adhere to his/or drugs. The companion will be charged with checking the client on a daily basis to observe and document at least one of the doses being taken. In order for this strategy to succeed, each companion should receive orientation to ARV at least once.</li> </ul> <p><b>Failure of Regimen due to Poor Adherence</b></p> <ul style="list-style-type: none"> <li>• Each time a patient fails a drug regimen – the questions of adherence to the drug regimen must be raised and carefully enquired into.</li> <li>• If poor adherence is considered the underlying cause for treatment failure, then treatment should be stopped until the reasons for poor adherence have been addressed.</li> </ul> <p><b>Strategies to Improve Adherence</b></p> <ul style="list-style-type: none"> <li>• Establish trust with patient and family</li> <li>• Serve as Educator and source of Information</li> <li>• Provide ongoing support and monitoring</li> <li>• Utilise Health Team approach</li> </ul> |

| TITLE OF GUIDELINE  | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS  |
|---|-----------------------------------|---|
|   |                                   | <ul style="list-style-type: none"> <li>• Provide training to support antiretroviral therapy</li> <li>• Intensify management in periods of low adherence by more frequent visit.</li> </ul>  |
| Antiretroviral therapy guidelines for HIV-infected adults and adolescents | DOAC/NACO/MOHEW/GOI (2013)        | <ul style="list-style-type: none"> <li>• Adherence should be assessed and routinely reinforced by everyone in the clinical team (physicians, counsellors, nurses, pharmacists, peer educators, NGO workers, etc) at each of the patient's visits to the clinic.</li> <li>• Develop an individual treatment plan, fitting ART into the patient's lifestyle/daily events and identifying treatment reminders.</li> <li>• Assess patient's readiness for and commitment to ART.</li> <li>• If patients have difficulty in adhering to regular doses, reinforce adherence counselling.</li> <li>• List barriers to adherence and develop strategies to overcome these barriers.</li> <li>• Enlist community outreach teams and peer support groups of Persons Living with HIV/AIDS, as appropriate.</li> <li>• Help patients develop secondary support systems for themselves.</li> </ul> |

| TITLE OF GUIDELINE                             | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS  |
|--|-----------------------------------|---|
| Guidelines for antiretroviral therapy in Ghana | NHASCP/MOH/GHS 2010               | <p><b>Understanding Adherence</b></p> <p>Adherence is taking medications exactly as prescribed i.e. the right dose at the right time and under the right conditions. Missing just a single dose can lead to development of resistant strains of the virus and reduce the effectiveness of treatment.</p> <p>The main reasons for non-adherence to therapy are</p> <ul style="list-style-type: none"> <li>• Forgetfulness</li> <li>• The number and timing of doses</li> <li>• Number and size of pills (pill burden)</li> <li>• Food restrictions</li> <li>• Perceived or actual side effects.</li> <li>• Missed appointments for drug refills</li> </ul> <p>Strategies used to overcome the problem of non-adherence, include use of drug time-tables, adherence monitors, pill boxes and continued adherence counselling. The patient should be reassured about side-effects and an alternate regimen should be discussed if side-effects are intolerable</p> |



| TITLE OF GUIDELINE  | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS  |
|---|-----------------------------------|---|
| <p>Guidelines for use of antiretroviral agents in HIV-1 infected adults and adolescents</p> | <p>PAGAA,2014</p>                 | <p><b><i>Routine Monitoring of Adherence and Retention in Care</i></b></p> <ul style="list-style-type: none"> <li>• Patient self-report, the most frequently used method for evaluating medication adherence, remains a useful tool for assessing adherence over time. However, self-reports must be properly and carefully assessed as patients may overestimate adherence.</li> <li>• Other measures of adherence include pharmacy records and pill counts. Pharmacy records can be valuable when medications are obtained exclusively from a single source so that refills can be traced.</li> <li>• Pill counts are commonly used but can be altered by patients. Other methods of assessing adherence include the use of therapeutic drug monitoring and electronic measurement devices (e.g., MEMS bottle caps and dispensing systems). However, these methods are costly and are usually done primarily in research settings</li> </ul> <p><b><i>Interventions to Improve Adherence and Retention in Care</i></b></p> <ul style="list-style-type: none"> <li>• A continuum of ART adherence support services is necessary to meet individual patient needs. All health care team members, including physicians, physician assistants, nurse practitioners, nurse midwives, nurses, pharmacists, medication managers, and social workers</li> </ul> |

| TITLE OF GUIDELINE | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS  |
|--------------------|-----------------------------------|---|
|                    |                                   | <p>play integral roles in successful adherence.</p> <ul style="list-style-type: none"> <li>• Clinicians should provide all patients with a basic level of adherence-related information and support. Before writing the first prescription(s) for patients initiating or reinitiating ART, clinicians should assess the patient's adherence readiness.</li> <li>• Clinicians should evaluate patients' knowledge about HIV disease, treatment, and prevention and provide basic information about ART, viral load and CD4 count and the expected outcome of ART based on these parameters, the importance of strict adherence to ART, and the consequences of nonadherence.</li> <li>• Clinicians should assess patients' motivation to successfully adhere to ART and identify and support facilitating factors and address potential barriers to adherence.</li> <li>• Clinicians should be assured that patients have the necessary medication taking skills to follow the regimen as prescribed.</li> <li>• Given the wide array of treatment options, individualizing treatment with patient involvement in decision.</li> <li>• It is important to consider the patient's daily schedule; patient tolerance of pill number, size and frequency; and any issues affecting absorption (e.g., use of acid reducing therapy and food requirements). With the patient's input, a medication</li> </ul> |

| TITLE OF GUIDELINE   | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS  |
|--|-----------------------------------|---|
|  |                                   | <ul style="list-style-type: none"> <li>• Maintaining good communication will help to improve adherence and long-term outcomes. Medication taking can also be enhanced by the use of pill organizers and medication reminder aids (e.g., alarm clock, pager, and calendar).</li> <li>• To determine whether additional adherence or retention interventions are warranted, assessments should be done at each clinical encounter and should be the responsibility of the entire health care team.</li> <li>• Routine monitoring of HIV viral load, pharmacy records, and indicators that measure retention in care are useful to determine if more intense efforts are needed to improve adherence. Patients with a history of non-adherence to ART are at risk for poor adherence when re-starting therapy with the same or new drugs.</li> </ul> |
| <p>British HIV Association (BHIVA)/ British Association for sexual health and HIV (BASHH) guidelines on provision of adherence support to individuals receiving antiretroviral therapy</p> | <p>Poppa <i>et al.</i> 2004)</p>  | <ul style="list-style-type: none"> <li>• Engage individuals in discussion about their knowledge and understanding of the need for ART and their concerns about taking it. Regularly evaluate their concerns about anti-HIV therapy and address specific concerns and misconceptions promptly.</li> <li>• Evaluate the patient's motivation for and commitment to taking anti-HIV therapy prior to starting, and at regular intervals following initiation.</li> <li>• Mental health factors should be assessed regularly and significant mental health problems managed through appropriate referral to</li> </ul>  |

| TITLE OF GUIDELINE | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS   |
|--------------------|-----------------------------------|--|
|                    |                                   | <p>clinical psychology, psychiatry or other allied health professionals, prior to starting anti-HIV therapy.</p> <ul style="list-style-type: none"> <li>• Assess the extent to which the patient has the behavioural skills to adhere to therapy.</li> <li>• Every HIV treatment centre should have a written adherence strategy in place which should be audited regularly in the context of the growing knowledge base.</li> <li>• Providers must ensure that patients have sufficient understanding of HIV pathogenesis; the rationale for anti-HIV therapy; the relationship between adherence and resistance; the requirements of their regimen, and its potential side effects.</li> <li>• Medication alerts and containers should be provided as appropriate.</li> <li>• Regimens which are dosed once or twice daily, which do not require fasting or dietary modification, and which have lower pill burdens, are likely to enable higher adherence</li> <li>• Every patient prescribed antiretroviral therapy should have their adherence measured and recorded at routine clinic visits. The preferred method is a standardized self-complete questionnaire, which invites either 14-day or 1-month recall of adherence.</li> </ul> |

| TITLE OF GUIDELINE   | AUTHOR(S) AND YEAR OF PUBLICATION | MAIN RECOMMENDATIONS   |
|--|-----------------------------------|--|
| <p>Guidelines for using antiretroviral agents among HIV-infected adults and adolescents.</p> | <p>Dybul <i>et al.</i> (2002)</p> | <ul style="list-style-type: none"> <li>• Aids for measuring adherence ( example pill and count, pharmacy record)</li> <li>• Self-reporting should include a short term assessment of each dose that was taken during the recent past and a general inquiry regarding adherence since the last visit with explicit attention to the circumstance of missed doses and possible measure to prevent further missed doses</li> <li>• Patient education should include the goal of the therapy</li> <li>• Community-based management and peer educators can assist with adherence education and strategies for each patient</li> <li>• Regimens should be simplified as much as possible by reducing the number of pills and therapy frequency and by minimizing drug interactions and side effect.</li> </ul> |

| TITLE OF GUIDELINE   | AUTHOR(S) AND YEAR OF PUBLICATION  | MAIN RECOMMENDATIONS  |
|--|------------------------------------|---|
| <p>Primary guidelines for the management of persons infected with HIV: 2013 update by HIV medicine association of the infectious Diseases Society.</p> | <p>Aberg <i>et al.</i> (2014)</p>  | <ul style="list-style-type: none"> <li>• All HIV-infected patients should be provided timely access to routine and urgent primary medical care.</li> <li>• HIV care sites should make every effort to provide care in a way that is linguistically and culturally appropriate and competent.</li> <li>• HIV care sites should utilize a multidisciplinary model but identify a primary provider for each patient and support</li> <li>• The development of trusting long-term patient–provider relationships.</li> <li>• All patients should be evaluated for depression and substance abuse, and if present, a management plan that addresses these problems should be developed and implemented in collaboration with appropriate providers.</li> </ul> |
| <p>British HIV Association guidelines for the routine investigation and monitoring of adult HIV-1-infected individuals ( )</p>                         | <p>Asboe, <i>et al.</i> (2012)</p> | <ul style="list-style-type: none"> <li>• The beliefs of patients about their need for ART, and specific concerns they may have about it, should be explored before initiating treatment</li> <li>• Adherence to ART should be documented regularly.</li> <li>• It is good practice to periodically review, with patients, their current ART regimen, and its acceptability and tolerability (and alternatives if appropriate)</li> </ul>  |

## ANNEXURE U: LETTER FROM LANGUAGE EDITOR


24 Justin Road  
Broadwood  
Port Elizabeth 6070

### TO WHOM IT MAY CONCERN

I, Aileen Gail Klopper, declare that I have assessed and edited the thesis of JOANA AGYEMAN-YEBOAH, (Student Number: 214230872) entitled : **A Best-Practice Guideline for Facilitating Adherence to Antiretroviral Therapy for Persons Attending Public Hospitals in Ghana** submitted in complete fulfilment of the degree of Doctor of Philosophy in Nursing in the Faculty of Health Sciences at the Nelson Mandela Metropolitan University.

Any queries related to the editing of this thesis can be directed to me at 074 3209463.

Signed at Port Elizabeth on 21 January 2017.



Ms AG Klopper (MA HWM)  
Associate : Professional Editors Guild

**ANNEXURE V: CALCULATIONS OF THE DOMAIN SCORES FOR ALL THE FIVE DOMAINS**

**DOMAIN ONE**

|              | ITEM 1    | ITEM 2    | ITEM 3    | TOTAL      |
|--------------|-----------|-----------|-----------|------------|
| Reviewer 1   | 6         | 6         | 5         | 17         |
| Reviewer 2   | 7         | 7         | 7         | 21         |
| Reviewer 3   | 7         | 7         | 7         | 21         |
| Reviewer 4   | 7         | 7         | 7         | 21         |
| Reviewer 5   | 7         | 7         | 7         | 21         |
| Reviewer 6   | 7         | 6         | 7         | 20         |
| <b>Total</b> | <b>41</b> | <b>40</b> | <b>40</b> | <b>121</b> |

**Maximum possible score=7x3 items x 6 reviewers=126**

**Minimum possible score= 1x3 items x 6 reviewers=18**

The scaled domain percentage score will be:

$$\frac{\text{Obtained score} - \text{minimum possible score}}{\text{Maximum possible score} - \text{minimum possible score}} \times 100$$

$$\frac{121-18}{126-18} \times 100 = 103/108 \times 100 = 95.4\%$$



## DOMAIN TWO: STAKEHOLDER INVOLVEMENT

|            | ITEM 1 | ITEM 2 | ITEM 3 | TOTAL |
|------------|--------|--------|--------|-------|
| Reviewer 1 | 5      | 7      | 6      | 18    |
| Reviewer 2 | 7      | 7      | 7      | 21    |
| Reviewer 3 | 7      | 7      | 7      | 21    |
| Reviewer 4 | 6      | 7      | 7      | 20    |
| Reviewer 5 | 7      | 1      | 7      | 15    |
| Reviewer 6 | 7      | 7      | 7      | 21    |
| Total      | 39     | 36     | 41     | 116   |

**Maximum possible score=7x3 items x 6 reviewers=126**

**Minimum possible score= 1x3 items x 6 reviewers=18**

The scaled domain percentage score will be:

$$\frac{\text{Obtained score} - \text{minimum possible score}}{\text{Maximum possible score} - \text{minimum possible score}} \times 100$$

$$\frac{116-18}{126-18} \times 100 = 98/108 \times 100 = 90.7\%$$

### DOMAIN THREE: RIGOUR OF DEVELOPEMENT

|            | ITEM 1 | ITEM 2 | ITEM 3 | ITEM 4 | ITEM 5 | ITEM 6 | TOTAL |
|------------|--------|--------|--------|--------|--------|--------|-------|
| Reviewer 1 | 6      | 6      | 4      | 5      | 6      | 7      | 34    |
| Reviewer 2 | 7      | 7      | 7      | 7      | 7      | 7      | 42    |
| Reviewer 3 | 7      | 7      | 5      | 7      | 7      | 7      | 40    |
| Reviewer 4 | 7      | 7      | 7      | 7      | 7      | 7      | 42    |
| Reviewer 5 | 6      | 6      | 6      | 6      | 6      | 6      | 36    |
| Reviewer 6 | 7      | 7      | 4      | 5      | 7      | 7      | 37    |
| Total      | 40     | 40     | 33     | 37     | 40     | 41     | 231   |

**Maximum possible score=7x6 items x 6 reviewers=252**

**Minimum possible score= 1x6 items x 6 reviewers=36**

The scaled domain percentage score will be:

$$\frac{\text{Obtained score} - \text{minimum possible score}}{\text{Maximum possible score} - \text{minimum possible score}} \times 100$$

$$\frac{231-36}{252-36} \times 100 = 90.2\%$$

## DOMAIN FOUR: CLARITY OF PRESENTATION

|            | ITEM 1 | ITEM 2 | TOTAL |
|------------|--------|--------|-------|
| Reviewer 1 | 6      | 6      | 12    |
| Reviewer 2 | 7      | 7      | 14    |
| Reviewer 3 | 6      | 7      | 13    |
| Reviewer 4 | 7      | 7      | 14    |
| Reviewer 5 | 6      | 6      | 12    |
| Reviewer 6 | 4      | 5      | 9     |
| Total      | 36     | 38     | 74    |

**Maximum possible score=7x2 items x 6 reviewers=84**

**Minimum possible score= 1x2 items x 6 reviewers=12**

The scaled domain percentage score will be:

$$\frac{\text{Obtained score} - \text{minimum possible score}}{\text{Maximum possible score} - \text{minimum possible score}} \times 100$$

$$\frac{74-12}{84-12} \times 100 = \frac{62}{72} \times 100 = 86.1\%$$

## DOMAIN FIVE: EDITORIAL INDEPENDENCE

|            | ITEM 1 | TOTAL |
|------------|--------|-------|
| Reviewer 1 | 7      | 7     |
| Reviewer 2 | 7      | 7     |
| Reviewer 3 | 7      | 7     |
| Reviewer 4 | 7      | 7     |
| Reviewer 5 | 6      | 6     |
| Reviewer 6 | 7      | 7     |
| Total      | 41     | 41    |

**Maximum possible score=7x1 items x 6 reviewers=42**

**Minimum possible score= 1x1 items x 6 reviewers=6**

The scaled domain percentage score will be:

$$\frac{\text{Obtained score} - \text{minimum possible score}}{\text{Maximum possible score} - \text{minimum possible score}} \times 100$$

$$\frac{41-6}{42-6} \times 100 = \frac{35}{36} \times 100 = 97.2\%$$