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DISCLOSURE AND QUALITY OF LIFE AMONG HIV PREGNANT WOMEN AND NURSING MOTHERS ACCESSING CARE AT 37 MILITARY HOSPITAL.

BY

NETTEY REGINA ODARKOR

(10807181)

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DECLARATION

I NETTEY REGINA ODARKOR, hereby declare that excluding precise references which have been duly acknowledged, this research protocol is my original work and that, to the best of my knowledge, it has not been presented for a degree in any other University. This research protocol was undertaken under the supervision of Dr. Frances Baaba da-Costa Vroom.

Signature:  …… Date:…29th October, 2020…….

Nettey Regina Odarkor

(Student)

Signature:…… Date:…29th October, 2020…….

Frances B. da-Costa Vroom, PhD

(Academic Supervisor)

DEDICATION

This work is dedicated to the Almighty God for His grace and mercies. I also dedicate this work to my family for their support and understanding throughout my program.

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ABSTRACT

Background: There is little research with regards to the psychological well-being and psychosocial impact of disclosure among women living with HIV. Quality of life has been an important factor to consider in the development of the medical outcome measures looking at the success rate of the current prophylactic and therapeutic strategies for PLHIV. Some key predictors that may be used as interventions in promoting QOL of women living with HIV include spiritual well-being, social support systems, physical indications, antiretroviral therapy, psychological well-being, coping strategies and psychiatric co-morbidities. Nevertheless, disclosure of HIV positive status is a major factor that needs to be addressed because it is only after disclosure that one is able to access the full support required to live positively with the infection. Quality of life of PLHIV may be affected both negatively and positively after disclosure and it is for this reason that this study was conducted to determine the factors that play a role in the disclosure of HIV status among pregnant women and mothers living with HIV and how it affects their quality of life.

Objective: To determine how disclosure affects the quality of life of pregnant women and nursing mothers living with HIV.

Methods: A facility based cross-sectional study of 110 pregnant women and mothers with live births who knew their status before giving birth within the period of 2015 to date and are currently actively receiving care and treatment at the 37 Military Hospital. This study was conducted using a mixed method approach. Quantitative and qualitative research methods were used to assess how disclosure affects quality of life of pregnant women and nursing mothers living with HIV. Two forms of data collection tools were used for the study. These were a structured interviewer administered tool designed by the investigator to gather information on the disclosure of status and other variables which were of importance to the

study and an adopted WHOQOL-HIV BREF tool which was used to measure the quality of life of the participant. There were in-depth interviews as well using an interview guide.

Result: Of the 110 women that were interviewed, 86.4% had disclosed their status to their sexual partners. Majority (65.3%) disclosed immediately after diagnosis to their sexual partners due to counsel from counselors at the ART clinic. Fears of being rejected, stigmatized and discriminated were the key drivers of non-disclosure of HIV positive status. However, 92.6 % of the women who disclosed their HIV positive status to sexual partners have received some form of support. Those who had disclosed their HIV positive status to their sexual partner had a lower quality of life compared to those who had not disclosed in the physical domain but this difference was not significant. However, those who had disclosed their status had a higher quality of life than those who had not disclosed their HIV positive status in the psychological, social relationships and environment domains.

Conclusion: The study showed that the general quality of life of participants was high. In general, status disclosure was not significantly related to QOL. However, participants who had disclosed their HIV positive status to their sexual partners had the added advantage of receiving support.

Key Words: HIV/AIDS, Quality of Life, Status Disclosure

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
FAHI	Functional Assessments of HIV Infection
GAC	Ghana Aids Commission
GAFACP	Ghana Armed Forces HIV/AIDS Control Program
HAART	Highly Active Anti-Retroviral Therapies
HADS	Malay Hospital Anxiety Depression Scale
HCF	Crescendos Foundation
HIV	Human Immunodeficiency Virus
IPV	Intimate Partner Violence
MTCT	Mother-To-Child Transmission
NACP	National Aids Control Program
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
QOL	Quality of Life
SEM	Structural Equation Modeling
USAID	United States Agency for International Development
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life

CHAPTER ONE

INTRODUCTION

1.1 Background

World Health Organisation (WHO) defines health as “A state of complete physical, mental, and social well-being not merely the absence of disease or infirmity" (“WHO, 2014). The WHO further explains that the capacity and outcome of health care does not only have to do with the changes of occurrence and gravity of diseases but also an evaluation of well-being which can be measured by the advancement in the quality of life associated to health care. Generally, the occurrence and gravity of diseases are under control as compared to the well-being and quality of life. Quality of Life (QOL) is “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO | WHOQOL, 2014). It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relations to salient features of their environment” (WHO | WHOQOL, 2014).

The above definitions of health and QOL means that one can be physically fit but emotionally, mentally or socially unwell thus making the person unhealthy which reduces the quality of life. Similarly, one can have chronic conditions such as hypertension, diabetes or Human Immunodeficiency Virus (HIV) with their medical condition being under control using appropriate medications and yet still be mentally unstable and thus will be considered unhealthy. HIV is known to be incurable; however, one can live with it positively for years with the right care and treatment. Although one can live with the virus positively, intense counselling and support needs to be given to a person living with HIV (PLHIV). Lack of

good counselling can affect the psychological and social state of a PLHIV therefore affecting their overall quality of life (Health Crescendos Foundation, 2018).

HIV is a blood borne virus transferred through sexual intercourse (approximately 80% mode of transmission), shared intravenous drug paraphernalia and mother-to-child transmission (MTCT), which can occur during pregnancy, childbirth and breastfeeding. HIV is caused by the retroviruses in the *Retrovidae* family. The HIV destroys and impairs the functions of the CD-4 cells of a person's immune system. The clinical manifestation of HIV is non-specific. Signs and symptoms are as a result of the presenting infection or illness (Bennett, 2019); ("WHO | HIV/AIDS," 2017).

In 2016, approximately 36.7 million people were living with HIV globally. Over 1.8 million people were newly infected and 1 million people died of HIV related causes. Sub-Saharan Africa accounted for 66% of the global burden of PLHIV. There is a global estimation of 1.8 million children under 15 years of age living with HIV with over 90% of this number living in Sub-Saharan Africa ("AIDSinfo | UNAIDS," 2016).

Ghana is not exempted from the current HIV epidemic. In 2014, the prevalence of the HIV infection in Ghana was 1.37% of the total population (Health Crescendos Foundation, 2018). However, there was an upward rise to 2.4% in 2016 which dropped gradually to 1.67% in 2017. It is expected to drop further to 1.51% in 2022 (Ghana Aids Commission National and Sub-National HIV and AIDS Estimates and Projections 2017 Report, 2017). In 2017, the prevalence at the regional level ranged from 0.6% in the Northern region to 3.2% in Greater Accra and Ashanti region (Ghana Armed Forces HIV/AIDS Control Program, 2019). There is insufficient data on the prevalence of pregnant women living with HIV in Ghana.

However, a research by GAC suggested that mother-to-child transmission accounted for 15% of people living with HIV in Ghana (Health Crescendos Foundation, 2018). It is stated in the summary of the 2016 HIV Sentinel Survey (HSS) report that national HIV prevalence amongst pregnant women attending antenatal clinic was 2.4% ("Ghana AIDS Commission," 2016). Free care and treatment is offered to all PLHIV. Interventions are being put in place with emphasis on scale-up and implementation of effective strategies to help reduce the risk of HIV in Ghana and the world as a whole. The aim of these interventions are to prevent new infections and improve the quality of life of infected persons (Eustace & Ilagan, 2010).

QOL has been an important factor to consider in the development of the medical outcome measures looking at the success rate of the current prophylactic and therapeutic strategies for PLHIV. Some key predictors that may be used as interventions in promoting QOL of women living with HIV include spiritual well-being, social support systems, physical indications, antiretroviral therapy, psychological well-being, coping strategies and psychiatric co-morbidities (Douaihy and Singh, 2001).

Disclosure of HIV status means informing someone that you are living with HIV. HIV disclosure adds to the improvement of the psychological and overall well-being of PLHIV (Collins & Miller, 1994). It also allows women living with HIV to go through childbirth interventions such as the prevention of mother-to-child transmission (PMTCT) which allows healthy reproductive options and results, as well as improved adherence to anti-retroviral therapy (ART) (Waddell & Messeri, 2006). Sharing your HIV status is a way of dealing with the fears and anxieties of living with HIV. However, it can be challenging when it comes to whom to tell and how to tell them (The Well Project, 2019). Disclosure of HIV status to sexual partners is a significant part of HIV counseling and testing when it comes to HIV

prevention procedures. There are benefits of disclosure that affect PLHIV and the general public as a whole. These benefits include less anxiety and increased social and emotional support especially for women living with HIV (Seid, Wasie, & Admassu, 2012). Despite the benefits, there are disadvantages such as loss of key necessities with which women place much importance to; such as their employment, housing, health insurance, friends, or custody of children, anger, yelling, rejection, physical violence, loss of economic support, blame, abandonment, physical and emotional abuse, fear of stigma and discrimination and disruption of family relationships which affect the quality of life of PLHIV (Seid et al., 2012). Pregnant women living with HIV are significant in public and social health because they pose a threat to both heterosexual and vertical HIV transmission (Kisakye, Akena, & Kaye, 2010).

1.2 Problem statement

There is little research with regards to the psychological well-being and psychosocial impact of disclosure among women living with HIV. Quality of life is depreciated by HIV infection despite the increased survival rate due to the progress of highly active anti-retroviral therapies (HAART) (Drummond et al., 2010). As survival with HIV advances, PLHIV are often identified with other co-morbidities which affect quality of life negatively (Drummond et al., 2010). To improve their quality of life and that of their babies, pregnant women and mothers with live birth(s) living with HIV are referred for psychological care. Psychological care targets stigma, low self-esteem and HIV-knowledge (Kotzé, Visser, Makin, Sikkema, & Forsyth, 2013).

According to GAC, status disclosure is a challenge for PLHIV and this limits the care and treatment they can receive ("Ghana AIDS Commission," 2012). Non-disclosure of HIV status is common among infected pregnant women (Jasseron et al., 2013). It is associated

with non-optimal PMTCT, which is the late initiation of antiretroviral therapy, detectable viral load at delivery and lack of neonatal prophylaxis. Non-disclosure is mostly influenced by vulnerability and or stigma (Jasseron et al., 2013). Stigma shown to PLHIV is a major factor that can be attributed to the fact that people usually associate HIV with character flaws and immoral acts such as infidelity and un-prescribed injection drug use. This double stigma can result in denial. Non-disclosure of HIV stat us to partners due to denial leads to the increase of HIV prevalence (Hasanah, Zaliha, & Mahiran, 2011). This is because PLHIV maintain the standards of marriage and reproduction in heterosexual sexual relationships (Hasanah, Zaliha, & Mahiran, 2011). Disclosure on the other hand serves as a means to contact and treat potentially positive partners. The quality of life of potentially positive partners is well-maintained because they start treatment if needed and this prevents AIDS which leads to premature death. Disclosure serves as a preventive measure and it is encouraged by organizations in their procedures for HIV testing and counseling (Seid et al., 2012). However, the expectant mother, if found HIV positive needs to be comfortable enough to disclose to her partner. Quality of life of PLHIV may be affected both negatively and positively after disclosure and it is for this reason that this study is being conducted to determine the factors that play a role in the disclosure of HIV status among pregnant women and mothers living with HIV and how it affects their quality of life.

1.3 Justification of the study

Quality of life is currently a key subject in all parts of the world. Although there are a number of studies on both disclosure and quality of life among PLHIV, there is a dearth of evidence on the subject in Ghana. This study aims to gather evidence that can be used by stakeholders and policy makers in the development of HIV/AIDS interventions to improve the quality of life of PLHIV and reduce the spread of HIV from women to their partners and babies.

Evidence from such a study can also provide a guide on health promotion activities that can benefit and ensure total satisfaction for pre-natal and postnatal care among women living with HIV. It is hoped that evidence from this study will contribute positively to literature on HIV disclosure discourse.

1.4 Conceptual framework

The figure below is the conceptual framework on the proposed study to examine how disclosure of HIV status may influence the quality of life of pregnant women and mothers living with HIV. There are various factors such as stigma and discrimination that may influence the decision making of a person living with HIV to disclose their status, however, the main focus of this study is on socio support systems, physical indicators, psychological well-being and coping strategies; and socio demographic information which may or may not affect the quality of life of the PLHIV. As illustrated in figure 1, these predictors influence both quality of life and state of disclosure. This study will therefore prove how they influence quality of life and disclosure in pregnant women and mothers living with HIV. Disclosure of HIV status among pregnant women and mothers living with HIV will be influenced by socio-demographic factors such as age, parity, education, socio-economic status, ethnicity, marital status and employment. There is information suggesting that pregnant women and mothers living with HIV's decision to disclose their HIV status is dependent on key predictors or otherwise. It is important to note that although quality of life of pregnant women and mothers living with HIV can be positively affected when support is given after disclosure of status, disclosure of status can also affect the quality of life of pregnant women and mothers living with HIV negatively as a result of abandonment and depression. Therefore disclosure of HIV status can influence the quality of life of the pregnant women and mothers living with HIV either positively or negatively.

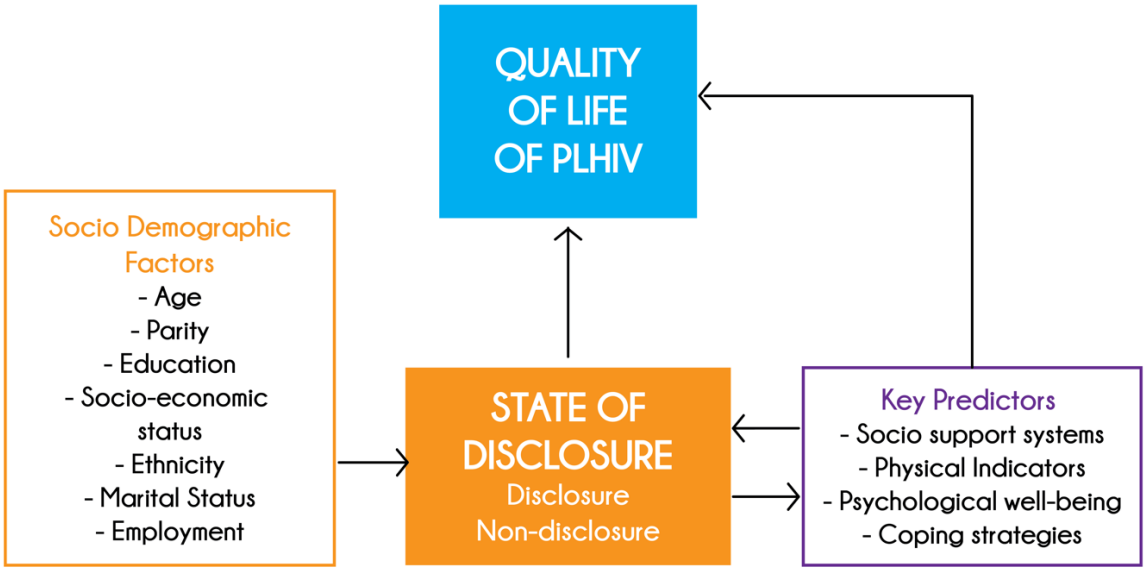

Figure 1: Conceptual framework on HIV disclosure and quality of life among PLHIV

1.5 Objectives

1.5.1 General Objective

The main objective of this study is to determine how disclosure affects the quality of life of pregnant women and mothers living with HIV.

1.5.2 Specific Objectives

Specifically, the study seeks:-

1. To determine the level of disclosure and its associated factors.
2. To assess the quality of life of pregnant women and nursing mothers living with HIV.
3. To determine the influence of disclosure on quality of life.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The literature review for this study focused on existing literature related to the factors that influenced the quality of life of PLHIV after disclosure of their HIV status. The following databases were used to search for literature: Jstor, Cochrane Medical Library, Liebert Online Inc, Sage Journals, Sage Research Methods Online, ScienceDirect, University of Chicago Journals, Medscape, Google Scholar, and the University of Ghana library. The key words used in the search engine included: “disclosure”, “quality of life”, “women and HIV”, “risk factors and impact of disclosure on pregnant women living with HIV”. Free words were added when specific information was needed. The titles and abstracts from the databases that seemed relevant to the search question were noted and analysed. The Population or Patients, Intervention, Comparison and Outcome (PICO) question method was used to formulate appropriate research questions.

2.2 Epidemiology of HIV

The Human Immunodeficiency Virus (HIV) is the main cause of Acquired Immune Deficiency Syndrome (AIDS). It was internationally known in 1981 for the first time and has since caused so many deaths in the world (Afful-Mensah, 2013).

According to Richard D Moore, there is a substantial change in the epidemiology of HIV. It all began in the 1980’s and it was common among men having sex with men (MSM). Today, HIV is common among all sexes, ages, races and income levels with numerous ways of transmission. It is necessary to know the variety of the epidemiology of HIV in order to know

the interventions needed to diagnose and treat this virus and possibly reduce the spread of the virus (Moore, 2011).

In a research article on Epidemiology on HIV by McCutchan (2006), HIV is one of the most common variables of the human pathogens. A good basis for diagnosis, treatment and prevention of this virus can be reached with a complete understanding of the HIV strains in the pandemic. HIV has about 800 genome sequences which include HIV-1 groups M, O, and N, and HIV-2. The HIV-1 M strains are responsible for most of the HIV infections globally. They have 743 sequences which symbolise 9 genetic subtypes, 16 circulating recombinant forms (CRF) and a selection of unique recombinant forms (URF). There are six (6) strains that are responsible for most HIV infections. These are: HIV-1 subtypes A, B, C, D, and two of the CRF, CRF01-AE and CRF02_AG. HIV-2 is mainly limited to West Africa (McCutchan, 2006).

HIV is a global challenge and it has infected over 70 million people in the past 30 years ("WHO | HIV/AIDS," 2017). Sub-Saharan Africa is the most affected region of HIV in the world with a 67% rate out of the total population. Its main mode of transmission is through heterosexual intercourse. Some other modes of transmission include men having sex with men (MSM), injection drug use and sex work. Despite the high rate of infection in Africa, infection rates are decreasing in some countries within the sub region while increasing in other areas such as eastern Europe and central Asia (Kilmarx, 2009). There was an estimation made by the Joint United Nations Programme on HIV/AIDS that 2.1 million new individuals worldwide were affected with HIV in 2015. About 1.9 million people out of the total population were adults aged 15 years and above with 47% of them being women. Among the 2.1 million new cases, 58% were adolescent girls and young women between the ages of 15 and 24 years. In 2016, over 1.8 million people were newly infected and 1 million people died

of HIV related causes ("AIDSinfo | UNAIDS," 2016; "WHO | HIV/AIDS," 2017). According to World Health Organisation, in 2016, about 36.7 million people were infected with HIV worldwide with majority being adults aged 15-49 years. The HIV and AIDS statistics show that 1.8 million out of the total population were children aged 15 years and below with a greater percentage of these children living in sub-Saharan Africa (WHO, 2016). The number of people infected with HIV in sub-Sahara Africa was 25.5 million people as compared to 4.2 million in Europe and America and 6.7 million in Asia in the same year (WHO, 2016). In 2017, the ten countries with the highest prevalence were Swaziland (27.2%), Lesotho (25%), Botswana (21.9%), South Africa (18.9%), Namibia (13.8%), Zimbabwe (13.5%), Zambia (12.4%), Mozambique (12.3%), Malawi (9.2%) and Uganda (6.5%) (World Bank, 2017). According to the UNAIDS factsheets for 2018, there is an estimated total number of 37,900,000 adults and children living with HIV with 36,200,000 being adults aged 15 and over, 18,800,000 being women aged 15 and over, 17,400,000 being men aged 15 and over and 1,700,000 being children aged 0 to 14 years. A total number of 1,700,000 adults and children living with HIV were newly infected ("AIDSinfo | UNAIDS," 2018).

The prevalence of HIV in the world is due to factors such as demographic factors, smoking, multiple sexual partners, alcohol use, late testing for HIV, infrequent use of condom, previous history of STI and lack of knowledge on HIV. It differs in every country and most of the cases recorded are from low income and middle-income countries (WHO, 2016). The prevalence rate for adults aged 15 to 49 living with HIV was 0.8 [0.6 – 0.9] in 2018. Women and men living with HIV aged 15 to 49 had a prevalence rate of 0.8 [0.7 – 1.0] and 0.7 [0.5 – 0.8] respectively while HIV prevalence among young women and men in 2018 were 0.4 [0.2 – 0.6] and 0.2 [0.1 – 0.3] respectively ("AIDSinfo | UNAIDS," 2018).

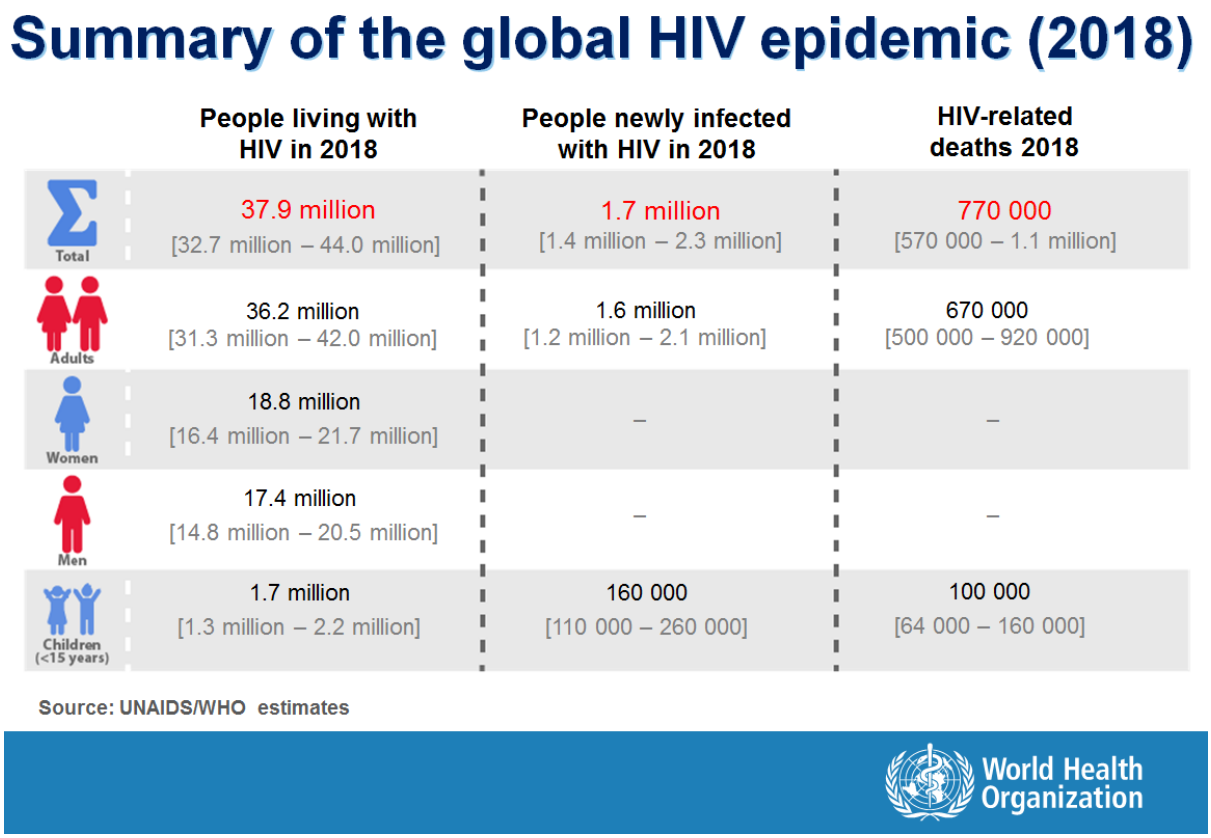

Figure 2: Summary of the global HIV epidemic in 2018 by WHO

Adapted from World Health Organization, 2018.

2.3 HIV in Ghana and Interventions for PLHIV in Ghana

The first HIV case to be known in Ghana was in March 1986. By the end of that year, a total number of 42 cases were officially reported. In Ghana, the most common ways of transmission is through heterosexual contact and mother-to-child transmission. One is said to be HIV positive only after he or she has been tested, however, one is suspected to have the virus when signs and symptoms such as persistent fever, persistent and chronic diarrhoea, significant weight loss, persistent cough, persistent skin infection, aggressive skin cancer, oral thrush, recurrent shingles and the enlargement of lymph glands are seen (Afful-Mensah, 2013).

According to an estimation made by the UNAIDS for the year 2018, Ghana has a total number of 330,000 adults and children living with HIV. There are 310,000 adults aged 15 and over living with HIV out of the total estimation with women and men being 200,000 and 100,000 respectively. Children aged 0 to 14 years living with HIV are 30,000. The newly infected both adults and children are 20,000 out of the total estimation with 11,000 being women aged 15 and over, 6,000 being men aged 15 and over and 3,300 being children aged 0 to 14. The prevalence rate for adults living with HIV aged 15 to 49 is 1.7 [1.4 – 2.0]. Women and men aged 15 to 49 have a prevalence rate of 2.3 [1.9 – 2.8] and 1.1 [0.8 – 1.3] respectively. Young women and young men have a prevalence rate of 1.0 [0.5 – 1.6] and 0.4 [0.2 – 0.5] respectively. The HIV incidence per 1000 population for all ages is 0.70 [0.53 – 0.91]. It is 1.10 [0.83 – 1.41] among adults aged 15 to 49. It is also estimated that about 14,000 adults and children have died due to AIDS. Ghana has 230,000 orphans due to AIDS aged 0 to 17. The epidemic transition metrics shows a -8 percent change in new HIV infections since 2010 ("Ghana | UNAIDS," 2018).

From the time when HIV was discovered in 1981, several antiretroviral medicines have been made to treat HIV. The first antiretroviral medicine to be made was in the year 1983. Antiretroviral medicines come in various classes and they fight against HIV in different ways with some being more effective at controlling the virus when combined. Currently, when one is tested and found HIV positive, there is a combination of at least three antiretroviral medicines put together as standard treatment. This method of treatment stops the virus from reproducing and can suppress HIV to undetectable levels in blood. The immune system of such a person can recover, overcome infections and prevent long-term effects such as AIDS ("HIV treatment | UNAIDS," 2020). About 190,000 (57%) out of the 330,000 people living with HIV in Ghana know their status with 113,171 (37%) on antiretroviral therapy (ART).

There are 34% [28 – 39] coverage of adults and children receiving ART. There are 30,410 adults and children who are newly initiating ART ("Ghana | UNAIDS," 2018).

There are so many interventions that have been put in place to help with the awareness, prevention and treatment of HIV worldwide by both local and international organizations such as World Health Organization (WHO), Planned Parenthood Association of Ghana (PPAG), Family Health International (FHI), United Nations Program on HIV/AIDS (UNAIDS), U.S. Agency for International Development (USAID), Health Crescendos Foundation (HCF) and many more. Although these interventions are effective, new infections among adults globally have not decreased sufficiently (UNAIDS," 2020).

An intervention that was implemented in the 2016 United Nations Political Declaration on Ending AIDS is the 90–90–90. The main aim of the 90–90–90 is to ensure that by the year 2020, 90% of people living with HIV know their HIV status, 90% of the people living with HIV that know their HIV-positive status are on treatment and 90% of people living with HIV on treatment have suppressed viral loads. Achieving this goal can lead to the end of the HIV/AIDS epidemic by 2030. UNAIDS works with civil society, government and private sector partners promote HIV prevention, testing, treatment and care services which lead to economic benefits in low- and middle-income countries ("HIV treatment | UNAIDS," 2020).

Another intervention is the combining of the TB treatment with HIV testing and treatment which was a plea made by Mandela at the Bangkok International AIDS Conference to strengthen the fight against tuberculosis in 2004. "TB is too often a death sentence for people with AIDS," Mandela said. This intervention can save up to about 500,000 HIV- positive Africans every year. It is also known to be a cost-effective way in increasing the survival rate

of PLHIV. In the year 2004, an estimation of 8 million out of 25 million Africans living with HIV also had the bacillus that causes TB. It is a part of the WHO policy to provide ARVs to HIV infected TB patients. As part of these interventions, to diagnose and treat TB, counseling and testing for HIV has been included in TB control programs. Screening for TB has also been included in HIV/AIDS programs (UNAIDS, 2004).

2.4 HIV Disclosure

HIV disclosure is informing another person(s) that you are HIV positive (Collins & Miller, 1994). It is a significant aspect of living with HIV which plays a role in HIV care and treatment. The decision to disclose one's status can be difficult because of stigma and issues about social support (WHO, 2011). Disclosure can be done by PLHIV himself or another person with or without the knowledge of the PLHIV. It can be between the PLHIV and a close relative like lover, partner, spouse, children, friends and other family, the PLHIV and an employer, employees or clients, the PLHIV and health service providers, the PLHIV and an institutional setting such as prisons and schools and the PLHIV and the general public via the media (Maclean et al., 2003). There isn't one way to tell someone about your status; you can do it in various ways. Likewise, there is no way to know the reaction of the person you choose to disclose to. Although not everyone needs to know your HIV-positive status, it is necessary to talk to someone about your status especially your current and past partners so that they get care and treatment if needed. Before you share your status, you need to ask yourself questions such as who do you want to disclose your status to, why do you want to disclose to that person and how both you and the person you are disclosing to will be affected. You can also take into consideration the environment in which disclosure will take place ("Disclosure and HIV | The Well Project," 2019).

There are different disclosure rates for different countries. In 2017, it was recorded that the disclosure rate for India and Nigeria were 14% and 13% respectively (Gyamfi, Okyere,

Enoch, & Appiah-Brempong, 2017). According to a study made on women practicing PMTCT in Abidjan by Brou et al., (2007), there was a high percentage of 96.7% of HIV-negative women who had disclosed their status to their partners while only 46.7% HIV-positive women had disclosed their status to their sexual partners (Brou et al., 2007). A research study by Lugalla, Yoder, Sigalla, & Madihi, (2012) stated that in Tanzania 55% of married men whether HIV positive or not disclosed their status to their wives while 34% of married women disclosed their status to their husbands. Generally, women are afraid to share their status as compared to men (Deribe, Woldemichael, Bernard, & Yakob, 2009; Lugalla et al., 2012).

Disclosure of HIV status brings about support from family and friends, risk reduction of HIV transmission to others, prevention of stress and depression and maximum care and treatment from health care providers. Despite these advantages, there are disadvantages such as stigma, discrimination, loss of friends and many more. It is therefore very important to consider whom you tell because the moment you disclose, it cannot be reversed.

2.5 Impact of Disclosure on PLHIV

Research shows that living with HIV without disclosure of HIV-positive status can be emotionally harmful as compared to the negative effects of disclosure. There is a sense of relief when women living with HIV talk to at least one person about it. Although there is a chance of not being accepted or supported by everyone you disclose to, there is a chance of receiving love and support from some of the people you tell. This makes disclosure stressful and complicated. Disclosure of one's status does not only have an effect on the PLHIV but also on the person being told. Everyone is different and people react differently to situations. While some may immediately embrace the news, others may need time to process what they

have been told due to fear which is caused by lack of education and they may need more information about your status and time to accept the situation. In certain cases, people who are told may need support ("Disclosure and HIV | The Well Project," 2019).

Disclosure of HIV status has negative impacts on the PLHIV such as discrimination, stigma, rejection, abandonment, divorce, violence and denied socio-economic support (Kadowa & Nuwaha, 2009; Lugalla et al., 2012; Wong et al., 2009).

In a qualitative research that was carried out by Cusick and Rhodes, (1999), it was thought that revealing one's HIV status had the potential to improve trust and invariably, society's acceptance. It was believed to also significantly reduce the incidence of transmission where at least one partner is HIV positive. Findings revealed that sexual safety was not necessarily directly proportional to disclosure (Rhodes & Cusick, 2000).

Stigma is a major disadvantage to disclosure. It has a major influence on the high rates of HIV/AIDS transmission in the world (Akpa, Adeolu-Olaiya, Olusegun-Odebiri, & Aganaba, 2011). It is known as the main fear of non-disclosure among PLHIV (Adedimeji, 2010). A study by Gaskins, (2006) shows that stigma is magnified in rural communities.

Discrimination of HIV-positive individuals in relation to the care provided due to non-disclosure of their status was a concern in a study by Skinner & Mfecane, (2004). The capacity to deal with discrimination was also a concern showed in a study by Goudge, Ngoma, Manderson, & Schneider, (2009) as it affects their decision to disclose. PLHIV refuse to disclose their HIV-positive status due to the fear of discrimination and this brings about the lack of support from family and friends (Skinner & Mfecane, 2004). In some countries, HIV is seen as a prostitute's disease and women living with HIV are seen as prostitutes. This discourages them from going to the hospital for medical care and treatment.

Studies show that pregnant women living with HIV in Thailand would rather abort the baby than to go for PMTCT (Türmen, 2003).

Simbayi et al, (2006) stated that due to bad remarks, PLHIV often hide their HIV-positive status to avoid blame, rejection and abuse after disclosure. Wong et al. (2009) also stated that PLHIV refuse to disclose their status because of the need of privacy, fear of losing a partner and fear of violence. Most pregnant women depend on their sexual partners for financial and social support and therefore refuse to disclose their status to them for fear that their sexual partners will stop supporting them (Visser, Neufeld, De Villiers, Makin, & Forsyth, 2008). Marais et al., (2019) found in their study that pregnancy comes with an increased potential for intimate partner violence (IPV), whereas being HIV positive all the more makes this group susceptible. IPV created some shame and stigma thus negatively affecting HIV care and HIV management conduct. The outcome brings to the fore the difficulties women face in disclosing both their positive status and violence meted out by their partners, receiving much needed assistance and participating in HIV and pregnancy related care (Marais et al., 2019). In sub-Saharan Africa, the rate of violence due to the disclosure of a person's HIV-positive status is high and this violence is mostly experienced by women in sero-discordant relationships (WHO, 2004).

According to a study by Kimberly et al., (1995) on disclosure, five (5) women were interviewed in a clinical setting within a period of 45 to 90 minutes each on their experiences on disclosure. Each woman experienced a unique outcome after disclosure, however there were some similarities in their way of disclosure. All 5 women had to adjust to the diagnosis. They told no one because they wanted to deal with it themselves. After they accepted the situation, they evaluated themselves to see if they were capable of disclosing to others. They

also took into consideration who needed to be told and who did not need to be told and assessed the situations that might disallow disclosure. These women tried to predict the reactions of those they wanted to disclose to. They finally decided to disclose due to support and obligation (Kimberly et al., 1995).

A study by Kgwete, (2008), Pam was an HIV-positive woman who did not accept her status after she was tested. She was in denial although she had an unhealthy sexual behaviour. She refused to disclose her status to her friends even after she accepted her status because of the fear of losing those around her. However, she disclosed to her mother who was very supportive. She gathered courage after six years to share her status with others. Some were supportive and others reminded her of the life she used to live years ago, saying that HIV-positive was the result of that behavior. She admitted that although she was well physically, she was emotionally unwell but what kept her going were the projects she took part in the community. Pam got pregnant with a man who already knew her status and he was supportive although she was afraid and emotionally devastated. She had supportive healthcare workers. Unfortunately, the support from the baby's father stopped after childbirth (Kgwete, 2008).

2.6 Quality of Life

World Health Organization defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". QOL can be affected by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment ("WHO | WHOQOL," 2014.). Although many researchers have studied quality of life among PLHIV with several tools, WHO have created quality of life instruments (WHOQOL) which are used globally. These instruments

include WHOQOL-100 and WHOQOL-BREF, WHOQOL-HIV and WHOQOL HIV BREF, WHOQOL-OLD and WHOQOL-SRPB. The assessment of a person makes his or her perceptions known with the help of these instruments which help to make targets, opportunities and concerns (Canavarro, Pereira, Simões, & Pintassilgo, 2011; Mweemba, Zeller, Ludwick, Gosnell, & Michelo, 2011; Saddki et al., 2009; Zimpel & Fleck, 2007). The WHOQOL instruments were created to understand how individuals with different backgrounds interact with each other. The WHOQOL-100 was created in 15 different centres worldwide. There was strict testing done to ensure that the instrument was effective and valid in each of the 15 centres. The WHOQOL-BREF is an abridged version of the WHOQOL-100 with 26 elements using information gathered during the trial stages of the WHOQOL-100. Although the WHOQOL instruments can be used in specific locations, results gathered can be linked to various backgrounds ("WHO | WHOQOL," 2014). The WHOQOL HIV BREF has 31 questions selected out of the WHOQOL-HIV which is used to measure the QOL of PLHIV.

The WHOQOL BREF and the WHOQOL HIV BREF have both been used to measure the QOL among PLHIV. It was discovered that PLHIV in Bangladesh had low quality of life in all areas after their quality of life was measured using the WHOQOL HIV BREF instrument (Imam, Karim, Ferdous, & Akhter, 2011). Also, a study by Fosu, (2016) showed that PLHIV who were receiving antiretroviral therapy at the New Juabeng Hospital had a low quality of life in all areas using the WHOQOL HIV BREF. An evaluation made using the WHOQOL HIV BREF on the quality of life of PLHIV in Zhejiang, China showed that the scores in the areas of social relation and environmental could be strengthened using social relation and environmental interventions (Liping, Peng, Haijiang, Lahong, & Fan, 2015).

2.7 Relationship between Disclosure and QOL

Disclosure of HIV-positive status is one of the initial processes one has to go through for HIV treatment and care. This helps in the risk reduction of transferring the virus to others ("Global Health Care: Issues and Policies - Google Books," 2016). However, disclosure and non-disclosure give double results. PLHIV who disclose their HIV-positive status get better outcomes as compared to those who not disclose. They are given social support which gives them access to resources and helps to improve their health (Stutterheim et al., 2011). Social support given to PLHIV affects their quality of life positively as a whole (Waddell & Messeri, 2006; Charkhian et al., 2014).

A study by Hasanah et al., (2011) stated that people who acquire HIV by means of heterosexual sex have a very low social well-being while those who got infected through drug injection did not have a loss in their QOL. Surprisingly, the study shows that psychological and social well-being are affected greatly by non-disclosure and suggested that PLHIV needed to get better psycho-education and psychological interventions. This clearly confirms the fact that HIV disclosure affects the QOL of PLHIV.

A study conducted by Fuster-Ruizdeapodaca, Molero, Holgado, & Mayordomo, (2014) on stigma and quality of life of PLHIV shows that stigma is a common result of disclosure of HIV status. The study showed that stigma has a negative effect on the QOL of a PLHIV but this occurs in various ways. Enacted stigma has a negative influence on quality of life and there is no way the PLHIV could be protected from its negative influence. Certain aspects of group identification have however managed to totally mediate the adverse effects of internalized stigma using in-group effect. Not only did group identification fail to protect HIV infected persons from stigmatization but may potentially be lethal in the case of

internalized stigma. It therefore implies that severely affected groups tend to harbor negative opinions of them which will more likely worsen over time, bolstering the need for new strategies to improve the lives of persons living with HIV.

2.8 Conclusion

In conclusion, status disclosure may have both positive and negative effects on the quality of life of PLHIV based on their socio-cultural and economic interactions, marital status and availability of institutional interventions. Therefore the decision to disclose or not to disclose by a PLHIV depends on their appraisal of the risk for support. To improve on the quality of life in PLHIV, attention needs to be given to the gap in knowledge about disclosure and quality of life and the role of the persons.

CHAPTER THREE

METHODS

3.1 Study design

The study design was a mixed method cross-sectional study which made use of quantitative and qualitative data. Data triangulation informed the use of the two data types to undertake the current study (Saunders, 2011). The use of qualitative data in this study was used to support the findings from the quantitative data (Yin, 2003).

3.2 Study area

The study was conducted at the Public Health unit of 37 Military Hospital. The hospital was originally called the No. 37 General Hospital. 37 Military Hospital is a specialist hospital located in Accra, on the main road between Kotoka International Airport and central Accra. It is currently the largest hospital in the Republic of Ghana after the Korle-Bu Teaching Hospital. The hospital has 17 departments and wards with a total bed capacity of about 400 beds.

The Public health department is responsible for managing PLHIV. The prevention of PMTCT program has spearheaded free services for prevention of HIV transmission for women attending the antenatal and postnatal clinics. It conducts health education, pre-test and post-test counseling, HIV testing using rapid methods, administration of antiretroviral therapy and community sensitization on HIV strategies.

3.3 Study population

The study population comprised of pregnant Ghanaian women and mothers with live births who knew their HIV positive status before giving birth.

3.4 Inclusion and exclusion criteria

Inclusion criteria by the study included pregnant women and mothers with live birth(s) who were eighteen (18) years and above, have been diagnosed HIV positive and were receiving care and support at the 37 Military Hospital. They could readily give their consent to contribute in the study. However, PLHIV who were critically ill were not involved in the study.

3.5 Study variables

The dependent variable for this study was "quality of life" among pregnant women and mothers with live births living with HIV. This variable was adapted and created from the WHOQOL HIV BREF tool. The tool was divided into four (4) main areas which include physical domain, psychological domain, social relationship domain and environment domain with two (2) other parts that focused on the overall QOL and general health. In relation to this study, the dependent variable (quality of life) was a continuous variable which was measured on a Likert scale that was transformed to a score of 0 - 100 with 0 being the lowest score and 100 being the highest.

The independent variable was "disclosure". Variables which were linked to socio-demographic features included age, marital status, year of diagnosis, education, employment status and pregnancy status.

Age in the study was measured as completed age in years. It was an open ended question which was later coded to 20 – 24, 25 – 29, 30 – 34, 35 – 39 and 40 and above.

Marital status of the study participants was a nominal variable that was grouped as single, married, co-habiting and divorced.

Year of diagnosis was an opened ended question which was later coded to 2001 – 2005, 2006 – 2010, 2011 – 2015, and 2016 – 2020.

Level of education was an ordinal variable which was treated as a categorical variable (no formal education, primary level, middle/JSS/JHS, SSS/SHS/Tech/Vocational and Tertiary). Employment status was treated as a categorical variable which was either employed or unemployed.

Pregnancy status was a nominal variable which was categorized into (yes and no).

Number of children was an opened ended question which was treated as a continuous variable was later coded to 0, 1, 2, 3 and 4 or more.

Disclosure status of the HIV positive participants was a nominal variable which was treated as a categorical variable (yes and no).

3.6 Sampling

3.6.1 Sample Size

The current study sampled from the study population, pregnant HIV positive Ghanaian women within the period of 2015 to date and are currently actively receiving care and treatment at the 37 Military Hospital. The quantitative phase of the study was set out to use a census of all one hundred and eight (108) expectant mothers with live births, however, during the period of gathering of data, a total of one hundred and ten (110) women were actively receiving care and treatment. A total of nine (9) women were interviewed using the in-depth interview. Data saturation was expected to be reached by 10 interviews; however, one interview could not be used after transcription. They consisted of women living with HIV between the ages of 23 years old and 36 years old. Majority (6) of these women were pregnant during the interview. Few (3) gave birth within the past year. Participants were volunteers and were informed about the objective of the study. An informed consent form was signed and secured by each participant before the recording of data. Each participant was given information on the benefit of the study and the option to participate voluntarily or

redraw at any time. Questions for the in depth interviews were developed from the research literature and were reviewed by the interviewer and her supervisor.

Table 1: In-depth interview participants

The table below shows each participant that took part in the in-depth interview

Interviewee	Age (years)	Ethnicity	Pregnancy status	Disclosure status
1	23	Akan	Yes	Yes
2	31	Ewe	Yes	Yes
3	33	Ga	Yes	Yes
4	26	Akan	Yes	Yes
5	21	Akan	No	Yes
6	28	Dagati	Yes	Yes
7	26	Akan	No	Yes
8	28	Akan	Yes	Yes
9	36	Akan	No	Yes

3.6.2 Sampling procedure

The study adopted the use of a purposive sampling technique in order to draw the sample. All expectant HIV positive women and mothers with live births at the 37 Military Hospital were used for the quantitative phase of the study. There were thirty four (34) expectant mothers and seventy seven (77) mothers with live births since 2015 who were actively receiving treatment from the 37 Military Hospital. Participants who were willing to provide in-depth information about their current status on their state of disclosure and quality of life were interviewed.

3.7 Data collection procedures

3.7.1 Instruments for data collection

Two forms of data collection tools were used for the study. These were a structured interviewer administered tool designed by the investigator to gather information on the disclosure of status and other variables which were of importance to the study and an adopted WHOQOL-HIV BREF tool which was used to measure the quality of life of the participant. The tool was used to observe the participant's general thoughts of quality of life as well as the participant's general thoughts of health. The WHOQOL-HIV BREF instrument with four domains and 29 facets that was adopted was used to measure the quality of life of the participants. A Likert scale was used to score these facets from a range of 1 to 5 with 1 being very poor and 5 being very good. The overall perception of quality of life and general health was also measured.

There were in-depth interviews as well using an interview guide.

3.7.2 Data collection method

Participants who had clinical appointments during the period set for the interviews were approached and face to face interviews were conducted. Participants who did not have clinical appointments during the period set for interviews were called and a date was set for them to report to the clinic to be interviewed. The interviews were conducted by the principal investigator.

In depth interviews were conducted with women living with HIV between the ages of 21 and 36 years old who were either pregnant or nursing mothers. Most (70%) participants were in their twenties. Firstly, participants were asked about their general knowledge and understanding of HIV disclosure which included their opinion on what disclosure is and how they would describe their experiences on stigma and negative reaction and the contributing factors (drivers) to why PLHIV do not disclose their status. Secondly, participants were asked

about why they would keep their HIV positive status a secret and their experiences in disclosing their HIV positive status to the sexual partners. Thirdly, participants were asked about their quality of life which included how accepted they felt by their sexual partners after disclosing their HIV positive status, how satisfied they were with their ability to perform their daily living activities, how satisfied they were with the support they get from their sexual partners after disclosing your status, how satisfied they were with their access to health services and a description of any negative feelings such as despair, anxiety, depression they had experienced due to their HIV-positive status.

3.8 Data processing and analysis

Data gathered from participants was coded and entered manually into Stata. Frequencies and proportions were descriptively analyzed using means with standard deviations and medians with interquartile range. Differences in the QOL scores were analyzed using Wilcoxon Rank Sum due to skewness in the data. Quantile regression was also used to investigate differences in QOL scores across disclosure, controlling for age, marital status, education, employment status, pregnancy status and number of children.

The WHOQOL-HIV BREF instrument was coded into four main domains; physical, psychological, social relationships and environment. The questions in the WHOQOL-HIV BREF were verified for completion. All questions that had inverted answer scales were reversed. All results for each domain scores were then transformed to a scale of 0 to 100 by transforming each raw scale score using the method below:

Transformed scale = [(Actual score – lowest possible raw score)/Possible raw score range] x 100

Actual raw score = Value achieved through summation

Lowest possible score = Lowest possible value that could occur through summation

Possible raw score range = Difference between maximum possible raw score and minimum possible raw score.

This transformation changes the lowest possible score to 0 and the highest possible score to 100. The scores signify the percentage of the total possible score attained. Internal consistency and reliability were measured in all domains of the WHOQOL – HIV BREF instrument using the Cronbach's alpha.

Interviews were evaluated using the Thematic Analysis framework by Braun & Clarke (2006). In order to gain better understanding and awareness, the interview transcripts were read and re-read. Transcripts were coded and themes were generated based on the codes and the data located under them.

3.9 Ethical considerations

Ethical clearance was granted by the 37 Military Hospital Ethical Review Board (37MH-IRB IPN/MP/384/2020). Before the collection of data, a formal letter with the research proposal was sent to the administrators of the hospital.

The objective of the study was introduced and informed consent was secured from all participants before the data was gathered. There were no risks or discomfort to the participants. Each participant who took part in the study was given information on the benefits of the study and the option to participate voluntarily or withdraw at any time without any effect on services provided. Counseling was arranged with the counseling unit of the 37 Military Hospital for participants with problems. There were no direct or immediate benefits, however, responses would be helpful in policy planning and formulation of recommendations

in the development of HIV/AIDS interventions to improve the quality of life of PLHIV and reduce the spread of HIV from women to their partners and babies.

All participants who were invited to the hospital to be interviewed were given an amount of 20ghc and snacks. Participants who were coming to the hospital for review that were interviewed were given snacks but no transportation.

There was strict confidentiality.

3.10 Informed consent documents

The interviewer explained the study to the participants and allowed the participants to ask questions before the recording of the main interview started. A short introduction was given before the recording of the main interview started. After permission was granted by the participant and recording started, another introduction was given by the interviewee. All interviews took place from the 4th of June to the 10th of July. It took at most 20 minutes to get all answers during the in-depth interviews. All transcriptions were done by the interviewee traditionally. No software was used.

The consent document will be provided in the appendix.

CHAPTER 4

ANALYSIS AND RESULTS

4.1 Introduction

This chapter presents described and complete information on the findings of the study based on both questionnaires and in-depth interviews.

The findings from the questionnaires present demographic characteristics of the participants, their state of disclosure and their quality of life. The findings from the in-depth interviews cover participants' perception and experiences of disclosure.

4.2 Demographic characteristics of participants

Table 2 describes the characteristics of the participants. A total of 110 women living with HIV responded to the questionnaire for this study. The majority (33.6 %) of these women were between the ages of 35 and 39 years old. The majority (62.7 %) was married and a few (3.6%) were divorced. Most (56.4%) were diagnosed HIV positive between the years 2016 and 2020. According to table 1, the number of women who are diagnosed HIV positive increases each year. Most (91.7 %) women had some kind of formal education while few (8.2%) had no formal education. The majority (77.3 %) were employed while a minority (22.7 %) was unemployed. Among those who were unemployed, few (28%) were unemployed due to their HIV status and the majority (72%) were unemployed due to several reasons including nursing babies, other health issues, pregnancy, education, and lack of funds to continue with business. Also, majority (69.1 %) of the respondents were not pregnant. However, all participants who were not pregnant were nursing mothers. Majority (79.1 %) of women had one, two or three children. All (12.7 %) women who did not have children were pregnant.

Table 2: Socio-demographic characteristics of participants

	Frequency	Percentage (%)
Age (years)		
20 – 24	9	8.2
25 - 29	20	18.2
30 - 34	29	26.4
35 – 39	37	33.6
40+	15	13.6
Marital Status		
Single	20	18.2
Married	69	62.7
Co-Habiting	17	15.5
Divorced	4	3.6
Date of Diagnosis (Year)		
2001 - 2005	3	2.7
2006 - 2010	8	7.3
2011 - 2015	37	33.6
2016 - 2020	62	56.4
Level of Education		
No formal education	9	8.2
Primary level	9	8.2
Middle/JSS/JHS	27	24.5
SSS/SHS/Tech/Vocational	31	28.1
Tertiary	34	30.9
Employment Status		
Employed	85	77.3
Unemployed	25	22.7
If Unemployed		
Unable to work due to HIV positive status	7	28
Other	18	72
Other for Unemployed		
Pregnant	4	3.6
Nursing mothers	6	5.5
Cervical cerclage	1	0.9
I am a house wife	1	0.9
Student	4	3.6
Inadequate funds	1	0.9
Stopped working to take care of mother	1	0.9
Pregnant		
Yes	34	31.8
No	76	69.1
No. of Children		
0	14	12.7
1	33	30
2	30	27.3
3	24	21.8
4 or more	9	8.2
Total	**110**	**100**

4.3 State of disclosure of participants

Table 3 describes the status of HIV disclosure to sexual partners and the support received by the respondents from their sexual partners. Majority of the respondents, (86.4%), have disclosed their status to their sexual partners. The results showed that the majority (65.3%) disclosed immediately after diagnosis to their sexual partners. The emotion exhibited the most by partners after disclosure was sadness (35.8%). The majority (92.6%) of the respondents have received some form of support from their partners after disclosure while about 7.3% have not received any kind of support. Among the 110 participants interviewed, half (50%) had fears that their husbands would withdraw from them while the remaining half did not. Minority (24.3%) had fears that their husbands would get angry while majority did not. A few (2.7%) had fears that their partners would commit suicide compared to 97.3% who did not have such fears. Also, 10% feared that other people would find out about their HIV status while the remaining 90% did not. Few (7.3%) had fears of being maltreated by their partners compared to the majority who did not express such fears. Also, 0.9% received no or inadequate counseling with respect to HIV status disclosure. About 37.3% of participants had other reasons. The majority (30.9%) of the respondents in this category had no fears while the minority (0.9%) did not receive adequate counseling with respect to HIV status disclosure.

Table 3: Participants' disclosure

	Frequency	Percentage (%)
Disclosed status to sexual partner(s)	95	86.4
Time to disclosure to sexual partner(s)		
Immediately	62	65.3
Less than a year	23	24.2
1 year or more	4	4.2
Other	6	6.3
Reasons for time lapse before disclosure		
Advised by health facility	15	15.8
Fear and anxiety	22	23.2
Partner had travelled	4	4.2
Partner knew HIV status first	6	6.3
Separated before HIV test was done	1	1.1
Tested together	17	17.9
To keep both PLHIV and partners informed	15	15.8
Trust and avoid issues	7	6.4
No reason	8	8.4
Sexual partner's reaction to disclosure* **		
Sadness	34	35.8
Anger	12	12.6
Denial	17	17.9
Frustration	12	12.6
Depression	13	13.7
Relaxed/Normal/Indifferent	12	10.9
Supportive and caring	15	13.6
Surprised	7	6.4
Received support from partner(s) since HIV status disclosure	88	92.6
Reasons for non-disclosure* **		
Fear that my husband will redraw (divorce/separate) from me	55	50
Fear that my husband will get angry	27	24.6
Fear that my partner will commit suicide	3	2.7
Worry about other people finding out about my HIV status	11	10
Fear of family maltreatment	8	7.3
Fear of partner physical violence	7	6.4
Fear of accusation/condemnation by partner of infidelity	16	14.5
Fear of withdrawal or loss of financial support from sexual partner	5	4.6
	7	6.3
May get ridiculed by others	1	0.9
I received no or inadequate counseling with respect to HIV status disclosure	5	4.6
Anger	34	30.9
No fears	1	0.9
Sadness	1	0.9
Denial		

***: Multiple answers allowed

4.4 Availability of treatment monitor

In Table 4, among the 110 participants, 96.4% have a treatment monitor. The majority (60.4%) used their partners as their treatment monitor and 31.1% used other family member. Most (62.3%) chose these treatment monitors because they are trustworthy.

Table 4: Participants' treatment monitors

	Frequency	Percentage (%)
Treatment monitor	106	96.4
Participants' treatment monitor		
My partner	64	60.4
My pastor/Church member	1	0.9
Friend	8	7.6
Family member	33	31.1
Reasons for designated treatment monitor		
Treatment monitor is HIV positive	15	14.2
Treatment monitor is trustworthy	66	62.3
Treatment monitor provides or offers care & support	21	19.2
Treatment monitor is a social relation/relative	4	3.8
Total	**106**	**100**

4.5 Perception about disclosure

Table 5 describes the perception of participants on HIV disclosure. Results on the knowledge of participants' partners HIV status showed that about 71.8% knew their partner's status while the remaining 28.2% did not know their partner's status. Out of those who knew, majority (46.4 %) knew their partners were HIV negative. On disclosing their status to partners, the majority (85.5 %) reported that it is important to disclose their HIV status to sexual partners. Majority (67.3 %) of the respondents believed it was important to inform sexual partners about their HIV positive status because it makes them aware of their status and prevents AIDS and death. Again, most (94.6 %) of the participants were informed about the importance of disclosing their HIV positive status to their sexual partner(s) through counseling at the ART clinic. Also, most (94.5 %) participants did not see the need to inform

others who are not their partners about their HIV positive status. Further, majority (83.6%) were not part of any support group. Most (48%) of these respondents were not aware or informed about any support groups and some (34.6%) were not interested.

Table 5: Participants' perception about HIV disclosure

	Frequency	Percentage (%)
Partner's HIV status		
Positive	28	25.5
Negative	51	46.4
Don't know	31	28.2
Important to tell sexual partner about status	94	85.5
Reasons for telling sexual partner about HIV positive status		
Based on counseling	2	1.8
For support	9	8.2
He is your partner/husband	10	9.1
He will leave you or maltreat you	13	11.8
To avoid AIDS and death	74	67.3
Informed about importance of HIV positive status disclosure		
ART Clinic	104	94.6
I feel that is the right thing to do	1	0.9
Self-informed	5	4.5
Important to tell others about your status	6	5.5
Member of a PLHIV group	18	16.4
Reasons for not being a part of a PLHIV group		
Fear/Lack of trust	6	5.5
Not informed	48	43.6
Not interested	38	34.6
Total		

4.6 Quality of life of participants

Table 6 displays the summary statistics for Quality of Life for the different domains from the WHOQOL-HIV BREF tool. From the findings, the lowest score obtained by a participant using the transformed scores for quality of life was 0. This score was obtained in the psychological domain and overall. The maximum score obtained in all domains and overall QOL and general health was 100. Findings show that the mean score which rates the average quality of life of participants within a given domain had the highest mean score of 83.2 which was within the social relationships domain. The lowest mean which shows the lowest quality

of life was 53.1 from the psychological domain. The wide differences between the means and medians however is an indication of the quality of life scores being skewed making the medians more reliable.

Table 6: Summary of the scores on quality of life domains

QOL domain	Min	Max	Mean	SD	Median	IQR
Overall QOL and general health	0	100	77.7	18.7	70.0	20.0
Physical	25	100	70.1	16.8	50.0	37.5
Psychological	0	100	53.1	23.4	87.5	25.0
Social relationships	25	100	83.2	18.0	68.8	18.8
Environment	25	100	66.9	15.2	75.0	12.5

QOL: quality of life. SD: standard deviation. p50: Median.

The overall quality of life and general health median obtained by participants was 70.0. The physical domain had a median quality of life score of 50.0, social relationships had a median score of 68.8, psychological had a median score of 87.5 and environment had a mean score of 75.0.

Figure 3 shows the distributions of the quality of life scores.

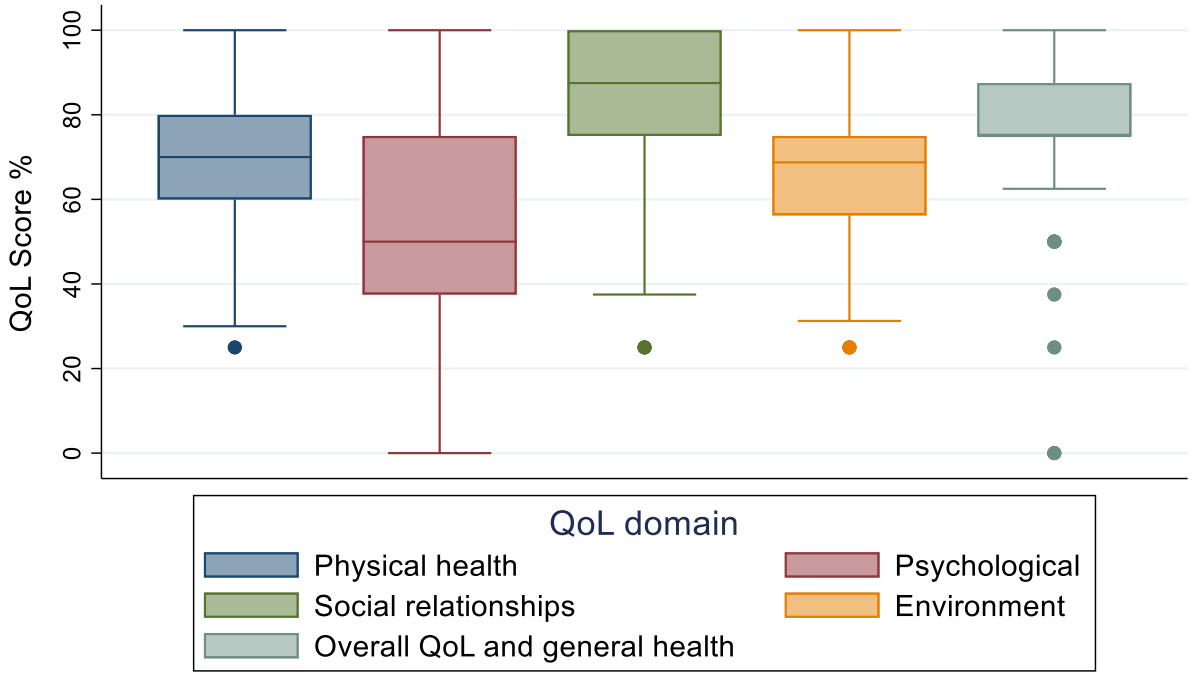

Figure 3: Quality of life scores

4.7 Quality of life and HIV disclosure

Table 7 displays the median quality of life scores for those who have disclosed their HIV positive status and those who have not disclosed their HIV positive status. According to data gathered from participants, there are no significant differences in the distribution of quality of life scores between those who have disclosed and those who have not disclosed in all domains except the social relationships domain (p = 0.032) where the median QOL score for those who disclosed was 87.5 and that for those who did not disclose was 75.0. Also, there was no significant difference between those who have disclosed and those who have not disclosed in the overall quality of life and general health facet (p = 0.146) where the median for both those who have disclosed and those who have not disclosed was 75.0.

Table 7: Median QOL scores for those who disclosed compared to those who did not disclose

	Did not disclose		Disclose		
QOL domain	**Median**	**IQR**	**Median**	**IQR**	**P value**
Physical	70.0	30.0	70.0	20.0	0.957
Psychological	37.5	37.5	50.0	37.5	0.061
Social relationships	75.0	37.5	87.5	25.5	0.032
Environment	75.0	31.3	68.8	18.8	0.540
Overall QOL and general health	75.0	25	75.0	12.5	0.146

Table 8 shows the median differences in quality of life from quantile regression, for those who have disclosed and those who have not disclosed controlling for age, marital status, education, employment status, pregnancy status and number of children. Those who have disclosed their HIV positive status to their sexual partner have a lower quality of life compared to those who have not disclosed in the physical domain but this difference is not significant as seen in table 7. However, those who have disclosed their status have a higher quality of life than those who have not disclosed their HIV positive status in the psychological, social relationships and environment domains. Also, with a median difference of 4.93, the overall quality of life and general health of participants who have disclosed was higher than participants who had not disclosed their HIV positive status.

Table 8: Median differences in QOL for those who disclosed compared to those who did not disclose controlling for background characteristics

	Median difference	95% CI Lower	Upper	P-value
Physical health	-5.00	-20.98	10.98	0.536
Psychological	16.25	-0.06	32.56	0.051
Social relationships	14.58	0.02	29.14	0.050
Environment	0.00	-12.98	12.98	1.000
Overall QOL and general health	4.93	-5.09	14.96	0.331

Controlling for age, marital status, education, employment status, pregnancy status and number of children.

4.8 Qualitative Overview (In depth interviews)

The main objective of this section was to determine how disclosure affects the quality of life of participants. The responses of the participants add more meaning to the quantitative findings. The main themes that were derived from the data included experiences of negative feelings, satisfaction with access to health services, satisfaction with support from partners, satisfaction with ability to perform daily activities, physical and emotional support from partners, reasons for disclosure of HIV status, reasons for keeping HIV status a secret, reasons for failure to disclose HIV status, experiences of Stigma and Discrimination, importance and consequences of disclosure and participant's understanding of disclosure. These are discussed below.

4.9 Participant's understanding of disclosure

According to the participants, the main characteristics that define disclosure are to inform someone about their HIV positive status, and to explain their situation to somebody. Table 1 provides excerpts of the participants' responses that support these findings. One participant stated that

"HIV disclosure is you telling someone else about your status."

Another participant also stated that disclosure means taking partners to the hospital for counselors to inform them about the HIV status. It was stated that:

"It means bring your partner to the hospital so that they explain the situation to him."

4.10 Importance and consequences of disclosure

Regarding the importance of disclosure, majority (66.7%) of participants agreed that disclosure was necessary. A participant's stated that:

"Disclosure is very necessary."

However, respondents indicated that disclosure has to be done to either sexual partners or trusted persons only. One reason given was that sexual partners needed to know their HIV status and take the necessary treatment if they are also positive. A participant stated that:

"Informing my husband about my condition was the best thing to do because if I keep it to myself and take the medication alone, it is not good. I am the only one taking medication hence if I am not cautious, he will contract this."

Respondents also believe disclosure is important to prevent reinfection. A respondent stated that

"…if you disclose it to whoever you are close with, it helps you in a manner that you will not be re infected again."

Further, respondents also mentioned the possible consequences of disclosing to people who are not trusted including entrenching judgmental attitude of people towards PLHIV, shunning or avoiding of PLHIV, maltreatment of PLHIV. The following quotes explain further:

"…when you take your medication you would look okay or normal but when you don't and you start looking really sick people will begin to judge you",

"…it is necessary but (with emphasis) you will tell the person and the person will not come near you again"

"…it is unnecessary sometimes because maybe when you tell someone else, how the person is going to treat you. Maybe the person will not want to be your friend or come close to you."

Some participants did not perceive disclosure as important. One participant said:

"I don't think it's important because I don't want people to know. I don't trust people to keep it a secret. I am afraid that anyone will know. Yes I have a partner but I prefer sharing my status with someone who also has HIV."

Other participants believe disclosure is only important when it is done to health care workers because it informs the quality of care given. One person mentioned that :

"It is important to tell the doctors who will take care of you so that they can give you the best treatment."

4.11 Experiences of Stigma and Discrimination

Most (77.8%) participants had not experienced stigma or any negative reaction in the past year because of the HIV positive status. Most of them believe they had not experienced stigma because no one knows about their status except their sexual partners. One participant said:

"Because I didn't tell friends, I didn't go through the stigma. It's only one or two people that I told; my mom and my partner. So I didn't go through any stigma at all."

A second participant said:

"I haven't experienced stigma in anyway before."

A third participant said;

"No, I don't have any experiences. But that is because I haven't told anyone my status. The only people who know my status are my husband and the health workers."

A fourth participant mentioned that:

"Well for me apart from my husband no one knows my status. But I have seen situations where people run from PLHIV and be pointing fingers at them. Some people even refuse to sell to HIV positive persons."

Few (22.2%) participants had personal experiences of stigma and discrimination to share however, only one participant had experienced stigma within the past year. She mentioned that

"Stigmatization is bad because getting HIV is mostly through blood means so having a normal relationship with someone with HIV is okay. I used to sell food at a school and we were asked to do general test for selling at the school and a friend of mine had heard of this and told people not to buy my food because I was positive. I have stopped selling the food because of this. I was scared if people got to know about this the news would spread so I stopped selling. That was the only job I was doing and now I'm jobless."

4.12 Reasons for failure to disclose HIV status

In response to the contributory factors (drivers) for failure of PLHIV to disclose their status, the participants stated fear of stigma and discrimination, insufficient information, lack of trust and tarnishing the image of PLHIV. They however believe all these result from the lack of information. One participant said:

"...People do not really know much about HIV so they discriminate. Other also just want to take advantage of the situation to tarnish your image. Also, they will disclose your status to others and people will eventually draw away from you."

Another participant said:

"...At first, people did not have the right understanding about HIV/AIDS. So they thought that if you are HIV positive and they come near you, they will also get some."

A participant was concerned about the possible effect of disclosure on her mother's health. She stated that:

"...someone like my mother, if I tell her, she will think too much about my condition and it may affect her health. Other people will also spread the news to others. So I don't want my mother or my friends to know that I have HIV."

Table 9: Participants' Responses to Awareness/Perception/Knowledge of HIV disclosure

Main Theme (and definition)	Example of data located under each code
Understanding of disclosure	"…letting your partner or whoever you are close with be aware." "…bring your partner to the hospital so that they explain the situation to him." "…telling someone else about your status." "…telling someone you know that you have acquired HIV."
Importance and consequences of disclosure	"…it helps you in a manner that you will not be re infected again." "…to be able to protect him or her from being infected as well." "…to tell the doctors who will take care of you so that they can give you the best treatment." "…you will tell the person and the person will not come near you again." "…I thought maybe he might leave because he will know my HIV status that I am HIV positive." "…the person will not want to be your friend or come close to you." "…out of respect or out of love you have for your partner." "…I don't want people to know. I don't trust people to keep it a secret. I am afraid that anyone will know." "…when you don't take your medication and you start looking really sick people will begin to judge you."
Experiences of Stigma and Discrimination	"Because I didn't tell friends, I didn't go through the stigma." "Because I didn't tell friends, I didn't go through the stigma." "…a friend of mine had heard of this and told people not to buy my food because I was positive. I have stopped selling the food because of this. I was scared if people got to know about this the news would spread so I stopped selling." "…When we go for waiting honour, the way they treat me. In my previous office, before I moved from there, it wasn't easy. I went through a lot of pain." "So I find it difficult to mingle with people so I always redraw myself."
Lack of knowledge and education	"…they are afraid that they will lose their friendships." "People do not really know much about HIV so they discriminate." "…if you are HIV positive and they come near you, they will also get

some."
"…take advantage of the situation to tarnish your image."
"…the person will not love you but rather move away from you. The person will not even eat with you."
"…they will disclose your status to others and people will eventually draw away from you."
"…people will also spread the news to others."
"…they will tell other people and those people will gossip about you or pull away from you."
"…fear of being rejected."

4.13 Reasons for keeping HIV status a secret

Participants would want to keep their HIV positive status a secret due to lack of trust, destructive and negative feedback and fear of rejection. A participant mentioned disclosure would depend on trustworthiness of her partner. She said:

" After monitoring my partner and I realised that he is that type that if you tell him a secret he cannot keep it to himself, then there is no need. I will not tell him. I would rather prefer to keep it as a secret than telling him."

Another participant said:

"I feel embarrassed that I will tell others about it. People are also very disruptive with the way they spread information and may cause others to stay away from you completely."

A participant who initially had fears that her husband would divorce her had this to say:

"I was thinking that if I told him, he would divorce me. But after the counsellors helped me to tell him and he was supportive, the fears went away. At a point I wanted to tell my mother but I changed my mind because my husband and I sat down to talk about it and we decided not to tell anyone. I also fear when I tell them, they will not be supportive but rather tell others about it. So what matters is that my sexual partner who is my husband knows and we can both do what we need to do to stay healthy."

4.14 Reasons for disclosure of HIV status to partner

Based on the responses, participants would disclose their HIV positive status to their partners because they are partners, for support, for protected sex and peace. One participant said: *"...it's for my own good and for him too."*

Another participant said:

"I am with him and so he needs to know everything happening with me. Then we can come to the doctors for counselling."

A third participant said:

"As we all know, there is only one truth. If you tell him and he accepts it, fine. If you tell him and he doesn't accept you too, it is also fine. It is God that watches everything. So if you do not speak the truth and he hears it from someone else, that one will also worry him. If you are not careful, the marriage you have entered will be destroyed. Because I don't want such a situation or for people to have something to talk about me, I went forward and I told him the truth that this is the situation and when I went for counselling they said I am HIV positive and they counselled me. So every year, he comes to test to know his status. My husband is currently HIV negative. Please I have four children. If I count this in addition, I have four children. They are all negative."

A fourth participant said:

"It is important for the partners to know because you might get the support you need from him. Because he might be the only one who will support you."

Few (33.3%) would disclose their status to their partners to prevent transmission if they are HIV negative. A participant mentioned that:

"it's just about protecting him or her or for me.. yeah, it's about him being protected. I don't want him to be infected. So I prefer to let him know than to hide it from him."

Table 10: Participants' responses to disclosure

Main Theme (and definition)	Example of data located under each code
Peace of mind	"…I realised that he is that type that if you tell him a secret he cannot keep it to himself…" "…I feel embarrassed that I will tell others about it." "People are also very disruptive with the way they spread information and may cause other to stay away from you completely." "…he would divorce me."
To encourage living positively with the virus	"…it's for my own good and for him too." "We are in this together." "…he needs to know everything happening with me." "I needed to tell him because he is my support in everything." "…you might get the support you need from him." "I thought about my well-being." "…by telling him I would be protecting him from getting infected." "Even though I am pregnant, I still have sexual intercourse with my husband." "He can also make it an issue that why didn't I tell him…"

4.15 Physical and Emotional support from partners

The data shows that all participants have received substantial care or support both emotionally and physically from their partners after disclosing their HIV positive status to them. One participant stated explicitly that:

"Oh he was grateful and he accepted me very well after telling him and if I could remember he said it's now that he knows the reason that if he wants to do this I say hai and if he wants to do that I say hai. And I told him that I was trying to protect you and then later tell you so when I told him, he was very happy and from that day till date we are still together and we even have a child through that."

Another participant also stated that:

"Oh he accepted it very well. He doesn't use it against me. He doesn't think I cheated and that is how I got it."

She went ahead to say that:

"...he's negative but he is okay with me being positive and he gives me the support I need."

Another participant said:

"In our situation, he came to do the test first and was tested HIV positive and so he asked me to also come and do the test."

A participant said:

"He accepted me wholeheartedly and he still does. He is the one who even encourages me. He helped me actually. He helped me to forget about my status. He helped me so much. He would just talk me through, encourage me that it is not the end of life.. you know.. yeah. He's been there."

4.16 Satisfaction with ability to perform daily activities

According to the participants, the main characteristics that explain satisfaction of the participants with their ability to perform their daily living activities are "satisfied and medication". Majority (88.9%) were very satisfied and okay.

A participant said:

"Very satisfied. My status hasn't hindered me from doing anything. I am still strong, I can still do what I could do before I became HIV positive."

Another participant said:

"I am very satisfied. I can perform my daily activities very well ...I still perform the same way. I am not affected physically."

Also, a participant said:

"I will say things are still the same like when I was negative. I only get weak sometimes because of the pregnancy. I do everything on my own."

Few (33.3%) were satisfied because of the medication. One participant said:

"Oh, because I'm on the medication living is just fine. When I didn't know about my status it was very difficult because I was constantly ill."

Another participant said:

"I can see that the medication they gave to us is very helpful. The medication needs to be taken well. When you come for counselling, the counsellors encourage you to eat well and take the medication."

4.17 Satisfaction with support from partners

In response to satisfaction with support from partners of respondents after disclosing their HIV positive status, the codes satisfied, supportive, feeling and no stigma was developed. A participant stated that

"...I am very satisfied because sometimes when it's time to even take the medication and I forgot he will call me "babe, have you taken your medication? It's time oh." If it's 8'oclock, he will say "it's 8 o'clock oh, go ahead and take your medication. So he has been very supportive."

Another participant stated that:

"He has been so supportive. I am very happy with it. I was given drugs and told I will deliver soon. My husband has agreed to come to the hospital for my medication without me even asking so I am very grateful to him."

Some of the support participants receive came in the form of financial support. A participant mentioned that:

"My husband has been very supportive for example even today when I was coming to the hospital there was only 15ghc at home because his car is spoilt. He is a driver. When I was supposed to set off he told me there is no money but it's only 15ghc that is available and that I should take 12ghc for my transport in and out. He kept the remaining 3ghc to use in case of anything."

4.18 Satisfaction with access to health services

Most (88.9%) participants are satisfied and have no challenges with access to health services. One participant said:

"Oh as for the health service, I am very satisfied. The doctors and the nurses are very good to all of us. I will say yeah, they are very good."

Another participant said:

"I am very happy with the services because the healthcare workers are very patient and when you ask questions they take their time to explain things to you."

A participant explained that:

"They take very good care of me. I do my labs and show it to them and the drugs that I take… right now let's say the first one that I was taking and I came they said right now there is none and there is a new one in the system so they are changed it for me. Right now, after doing my lab and showing them the results, they said my viral load is low so I can go ahead and continue with the medication."

Few (22.2%) participants have financial difficulty. One participant said:

"Well, coming to the hospital is difficult for me because of finances. I am currently not working so my husband is the only support so it's difficult for us."

Another participant said:

"Transportation is a problem for me and when I come for the services at the hospital, I'm taken care of very well."

4.19 Experiences of negative feelings

According to the participants, the main characteristics that describe any negative feelings such as despair, anxiety, depression that the participants have experienced due to their HIV positive status are depression and confusion, financial difficulty, optimistic and fear. One participant explained that:

"I do feel sad because I do not know what people will say if they get to hear that I am HIV positive. They may say that I am a bad person or a prostitute. My concern is more about what people would say and not necessarily my health."

Some participants had fears initially but they no longer have such fears. A participant explained that:

"You know it normally happens especially when you are new. For the first day that they will break the news to you and tell you that so so person you are positive, you will be asking so many questions. You will be depressed and you will be confused. You will be thinking and going through so many things but as time goes on, you meet a counsellor who knows his or her job and he or she counsel you very well. As time goes on, you will begin to feel very okay with the situation and accept it that it has happened and there is a medicine that if you take your medicine very well you will not go through any sicknesses or whatever. You will get your life back and you can manage it."

One participant said:

"Oh in the beginning I was very scared but after I came to see the counsellors and they spoke to me everything became fine. I did not feel any negative thoughts or feeling."

Another participant said:

"Right now, I don't have any issues oh. I am very very okay. I see it as I have any sickness like malaria or BP and it is being treated."

A participant with financial difficulty said:

"The negative feelings I have about my status is that I feel I do not have to work and financially it has become difficult for me and my family."

A participant worries that the virus will kill her based on what she has heard. She stated that:

"Yes, I sometimes become scared because I feel I may die from this disease because people talk about how you can die from HIV."

Table 11: Responses to quality of life

Main Theme (and definition)	Example of data located under each code
Provision of care and comfort	"Oh he was grateful and he accepted me very well." "I am okay. Like, he doesn't worry me about it." "Sometimes, we argue but he never uses my medical state against me." "Oh he accepted it very well. He doesn't use it against me." "…he gives me the support I need." "Things haven't changed between us." "…treating me with more love and care."
Satisfying	"My status hasn't hindered me from doing anything. I am still strong, I can still do what I could do before I became HIV positive." "Oh yes, I still perform the same way. I am not affected physically." "I'm on the medication living is just fine." "I can see that the medication they gave to us is very helpful."
Important attachments	"I am very satisfied because sometimes when it's time to even take the medication and I forgot he will call me "babe, have you taken your medication? It's time oh."" "He supports me a lot. He doesn't stigmatize me in anyway." "He is very supportive and shows a lot of love." "He has been so supportive. I am very happy with it. I was given drugs and told I will deliver soon. My husband has agreed to come to the hospital for my medication without me even asking so I am very grateful to him."
Satisfying	"oh as for the health service, I am very satisfied. The doctors and the nurses are very good to all of us." "Transportation is a problem for me and when I come for the services at the hospital, I'm taken care of very well." "Well, coming to the hospital is difficult for me because of finances. I am currently not working so my husband is the only support so it's difficult for

	us." "…the healthcare workers are very patient and when you ask questions they take their time to explain things to you." "I am very satisfied. I haven't been stigmatized by any health care worker. They give me the right treatment." "…mostly ask about my wellbeing and how I am doing and make sure I am living positively with the virus."
Emotional Stance	"You will be depressed and you will be confused. You will be thinking and going through so many things…" "The negative feelings I have about my status is that I feel I do not have to work and financially it has become difficult for me and my family." "Oh in the beginning I was very scared but after I came to see the counselors and they spoke to me everything became fine. I do not feel any negative thoughts or feeling." "Right now, I don't have any issues oh." "I do feel sad… they may say that I am a bad person or a prostitute." "I get scared and worried sometimes but I forget about it and accept my status." "I don't feel sad thinking my end has come because COVID-19 is even more deadly than my sickness so I don't think that way." "…sometimes when I think a lot and lose weight people ask if I am sick... sometimes I think will I die and leave my kids because I don't have a father or mother to even take care of them if I die." "…sometimes become scared because I feel I may die from this disease because people talk about how you can die from HIV." "At the beginning, yes. I was very depressed. I didn't know how to handle it… my husband was there, yes. And then knowing that he supported me helped me to… how do I say it?... to overcome the depression and all that, yeah."

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This chapter discusses the results of the study as compared to past literature which includes key findings, justification of findings and their implications.

5.2 Summary of Findings

5.2.1 Disclosure

Maclean et al. described that disclosure is between the PLHIV and a close relative, the PLHIV and an employer, employees or clients, the PLHIV and health service providers, the PLHIV and an institutional setting and the PLHIV and the general public via the media. Participants in this study had similar definition that disclosure is telling someone about your HIV status. The Wellness Project explained that it is important to disclose HIV positive status to sexual partners, however, one needs to ask him or herself certain questions before choosing who to disclose to. Participants in this study had similar responses that it was necessary to disclose HIV positive status only to sexual partners and trusted people. This could be as a result of support and care received from sexual partners after disclosure which increases their bond. Women in this study were however not afraid to disclose their status to their sexual partners and this was contrary to studies by Deribe et al. and Lugalla et al... Findings also showed that it was not necessary to disclose HIV positive status to other people especially if there is no trust and this was in agreement with studies which stated that there is a chance of not being accepted or supported by everyone you disclose to although non-disclosure can be emotionally harmful; disclosure of HIV status leads to discrimination, stigma, rejection, abandonment, divorce, violence and denied socio-economic support (The Wellness Project, 2019; Kadowa & Nuwaha, 2009; Lugalla et al., 2012; Wong et al., 2009;

Akpa et al., 2011). Cusick and Rhodes however disagreed, stating that revealing one's disclosure had the potential to improve trust and society's acceptance. Although, most participants who had not disclosed their HIV positive status was due to fear of their partners withdrawing from them, participants who did not disclose their HIV positive status immediately to their sexual partners but took time due to fear received some form of support from their sexual partners. Most of the women interviewed had not experienced any form of stigma and discrimination due to the fact that they had not disclosed to anyone besides their sexual partners. The participants who had experiences to share on stigma and discrimination were hearsay; only one participant had a personal experience to share. Also, few participants who were unable to disclose their HIV positive status to their sexual partners were because their sexual partners abandoned them and their unborn child before they tested. This suggests that the actions of their partners were not due to their HIV positive status.

Most respondents were informed about the importance of telling their sexual partners their HIV positive status through the ART clinic. As part of the pre-natal process at 37 Military Hospital, all pregnant women are tested for HIV. Counseling is given before and after HIV testing. Counselors encourage pregnant women who test HIV positive to disclose their HIV positive status to all sexual partners. Findings showed that most of the pregnant women who test HIV positive disclose their status immediately to their sexual partners. This is because counselors encourage early disclosure of HIV positive status to sexual partners in order to make sexual partners aware of their status and start treatment if needed or stay HIV negative. This explained the high percentage of participants who had disclosed their HIV positive status to their sexual partners. Findings therefore suggest that counseling plays a key role in HIV disclosure.

World Health Organization and The Well Project state that disclosure plays a role in HIV care and treatment and this can be seen in this study as well where disclosing your HIV positive status to your sexual partner(s) avoids reinfection or initiation of treatment if sexual partner(s) are HIV positive as well.

5.2.2 Quality of life

According to the study, most participants had a relatively high quality of life in all domains whether they had disclosed their HIV positive status or not. This was not in agreement with past studies which stated that PLHIV who disclose their HIV-positive status get better outcomes as compared to those who did not disclose; social support given to PLHIV affects their quality of life positively as a whole (Stutterheim et al., 2011, Waddell & Messeri, 2006; Charkhian et al., 2014). The few respondents rated their quality of life as poor due to financial issues and not their HIV positive status. Fuster-Ruizdeapodac et al. stated that stigma is a common result of disclosure of HIV status which has a negative effect on quality of life and there is no way PLHIV can be protected from its negative influence. This ia contrary to this study's findings were some participants who had fears when they were diagnosed HIV positive, no longer had such fears after disclosing to their sexual partners because of support received. However, these participants also stated that they did not disclose to others besides their partners due to fear of being stigmatized.

Findings showed that taking of ART drugs played a key role in the health of pregnant women and mothers living with HIV which helped to maintain and or improve their quality of life. They began to deteriorate when they stopped taking their drugs. Participants went ahead to state that they were not adversely affected physically by their HIV positive status because they took medication well and looked better than before.

Although findings proved participants can live positively with the virus, it also proved that all participants had negative feelings such as despair, anxiety and depression even if it was once in a while or very often. Health care workers played a key role in helping pregnant women and mothers living with HIV live positively with the virus. How they are treated during clinical consultations affects their quality of life.

5.2.3 Disclosure affecting Quality of life

Findings from study show that there were significant differences in the distribution of quality of life scores between those who had disclosed their status and those who had not disclosed their status in the psychological and social relationship domains. This signifies that participants who had disclosed their status had a higher quality of life than those who had not disclosed. Hasanah et al. had similar study which showed that psychological and social relationships are affected greatly by non-disclosure and suggested that PLHIV needed to get better psycho-education and psychological interventions.

There was no significant difference between those who disclosed and those who had not disclosed their status in the physical and environment domains. Also, there was no significant difference in the overall quality of life and general health facet.

Findings from the in-depth interviews showed that disclosure of HIV positive status is related to the quality of life of women and mothers living with HIV. Most respondents who had disclosed their status were satisfied with their quality of life and health. However, most of them disclosed to their sexual partners only. This therefore seems to suggest that receiving any form of support from sexual partners improves the quality of life of pregnant women and mothers living with HIV. Most respondents who disclosed to others besides their sexual

partners were stigmatized or discriminated. Health workers, however, were very supportive and caring according to findings. This suggests that it is not necessary to disclose your HIV status to others besides health workers or sexual partners. Despite the suggestion noted above, there were few participants who used people other than their sexual partners as their treatment monitor and stated that they were satisfied with their quality of life and health. This means that they told others besides their sexual partners about their HIV positive status. This suggests that whoever you disclose your HIV positive status to needs to be a trusted person. By this means, the person gives you the needed support to aid you in living positively with the virus.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Conclusion

The study showed that a high percentage (86.4%) of participants had disclosed their HIV positive status to their sexual partners due to good counseling given to them at the ART clinic. The main driver of non-disclosure of HIV status was the fear of being stigmatized and discriminated. The study also showed that the general quality of life of participants were high. In general, status disclosure was not significantly related to QOL. However, participants who had disclosed their HIV positive status to their sexual partners had the added advantage of receiving support.

6.2 Recommendations

Based on the findings, the following recommendations are being made:

- The provision of HIV care and services by the health workers at ART clinics need to be strengthened.
- The quality of life of PLHIV should be assessed as part of HIV service provision at health facilities.
- There should be education and sensitization by stake holders to the public to help reduce HIV related stigma and discrimination. This will enable PLHIV live positively without fear.
- The Psychosocial Support and Counseling portion of the Community Home Base Care (CHBC) policy by Ghana AIDS Commission should be enforced to enhance the quality of life of PLHIV.

6.3 Study limitations

The study was transverse and hence, causation cannot be established from statistical extrapolations. The study was conducted in a facility and does not represent the general Ghanaian HIV/AIDS population.

The WHOQOL HIV BREF instrument used in this study has not been hitherto validated in this population and probably resulted in the lower internal consistency of some domains of QOL assessed. However, the WHOQOL HIV BREF is recommended as the most suitable tool for assessing QOL among PLHIV. Therefore, the conclusions based on the findings of this study are still valid.

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APPENDICES

APPENDIX 1: PARTICIPANTS INFORMED CONSENT

Title: HIV STATUS AND QUALITY OF LIFE AMONG PREGNANT WOMEN AND WOMEN WITH LIFE BIRTHS LIVING WITH HIV ACCESSING CARE AT THE 37 MILITARY HOSPITAL.

Principal Investigator: REGINA ODARKOR NETTEY

Address: School Of Public Health, P. O. Box LG 25, Legon, Accra.

General Information about Research
I am a post-graduate student from the school of Public Health, University of Ghana and I am carrying out a study in this department to determine the factors that play a role in the disclosure of HIV status among pregnant women and mothers living with HIV and how it affects their quality of life in this hospital and I would be glad if you would participate in it. Your participation would involve either a 30-minute interview where you will fill a questionnaire or a 20-minute in-depth interview. Both questionnaire and in-depth interviews have questions about yourself and how this relates to you.

Possible Risks and Discomforts
The only inconvenience, if any that you would face by accepting to take part in this study perhaps is your time.

Possible Benefits
You may not have any immediate or direct benefits from my interview but your responses would be helpful in policy planning and formulation of recommendations in the development of HIV/AIDS interventions to improve the quality of life of PLHIV and reduce the spread of HIV from women to their partners and babies**.**

Confidentiality
The information you would provide is going to be treated with strict confidentiality. Apart from my research team and members of the Ethics Committee of this hospital, no body shall have access to the information since it shall be under lock and key. We also assure you that your name shall not appear or be mentioned in any report that will come out from this study.

Compensation
An amount of 20ghc for transportation and snacks will be given to participants who will be invited to the hospital to be interviewed. Participants who are coming to the hospital for review that will be interviewed will be given snacks but no transportation.

Voluntary Participation and Right to Leave the Research
If you indeed decide to take part, you are allowed to withdraw whenever you wish to, and are also allowed to skip answering any of the questions that you are not very comfortable with.

Contacts for Additional Information
Regina Odarkor Nettey
0249571470
netteyregina@gmail.com

Your rights as a Participant
This research has been reviewed and approved by the 37 Military Hospital Institutional Review (37MH-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 7:30am-3:00pm through the landline 0302 769667 or IRB Administrator (Prince Yaw Ashitey – 024 300 4247) or email addresses: irbmilhosp@gmail.com

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title "Hiv Status And Quality Of Life Among Pregnant Women And Women With Life Births Living With Hiv Accessing Care At The 37 Military Hospital" has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

_____ _____

Date Name and signature or mark of volunteer

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

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

_____ _____

Date Name and signature of witness

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

_____ _____

Date Name Signature of Person Who Obtained Consent

APPENDIX 2: QUESTIONNAIRE

HIV STATUS DISCLOSURE AND QUALITY OF LIFE AMONG PREGNANT WOMEN AND WOMEN WITH LIFE BIRTHS LIVING WITH HIV ACCESSING CARE AT THE 37 MILITARY HOSPITAL.

Dear Respondent,

This is a research being carried out on *Disclosure and Quality of life among pregnant women and women with life births living with HIV in Ghana: A cross- sectional study at 37 Military Hospital*. I will, therefore, like to take some minutes of your precious time to answer these questions. You are assured that the answers you give will be strictly confidential and your name will not be mentioned in our research reports. Thank you.

Unique ID for Respondent ……

Date of interview ……

SECTION A. BACKGROUND INFORMATION OF PLHIV

Instructions

We would like to ask you to answer a few general questions about yourself by circling the correct answer or filling in the space provided.

How old are you? ……..... years

What is your marital status? 1. Single 2. Married 3. Co-habiting 4. Divorced

When were you diagnosed HIV positive? ……..…….

What is your highest level of education completed?

1. No formal education
2. Primary level
3. Middle / JSS / JHS
4. SSS / SHS / Tech / Vocational

5. Tertiary

What is your employment status?

1. Employed
2. Unemployed

If unemployed, why are you not working now?

1. Unable to work due to HIV positive status
2. Other (please specify) ……..…….

Are you currently pregnant?

1. Yes
2. No

How many children do you have? ……..…….

SECTION B. STATE OF DISCLOSURE

No.	**Question**	**Respond**
1.	Have you disclosed your HIV status to your partner(s)?	1. Yes 2. No
2.	How long did it take to disclose your status to your partner(s)?	
3.	Give reasons for response	
4.	What was your partner's reaction? **(Please you may tick more than 1**	1. Sadness 2. Anger

	option)	3. Denial 4. Frustration 5. Depression 6. Other (please specify)……
5.	Have you received any support from your partner(s) since you disclosed your HIV status?	1. Yes 2. No
6.	Which of these reasons prevents you from disclosing your status to your sexual partner? **(Please you may tick more than 1 option)**	1. Fear that my partner will withdraw (divorce/separate) from me 2. Fear that my partner will get angry 3. Fear that my partner will commit suicide 4. Worry about other people finding out about my HIV status 5. Fear of family maltreatment 6. Fear of partner physical violence 7. Fear of accusation/condemnation by partner of infidelity 8. Fear of withdrawal or loss of financial support from sexual partner 9. May get ridiculed by others 10. I received no or inadequate counselling with respect to HIV status disclosure 11. Other (please specify) ..... ……
7.	Do you have a treatment monitor?	1. Yes 2. No
8.	If Yes, who is your treatment monitor?	1. My partner 2. My pastor/Church member 3. Friend 4. Family member

		5. Other (please specify) .....
9.	Why did you choose him/her as your treatment monitor?	1. Treatment monitor is HIV positive 2. Treatment monitor is trustworthy 3. Treatment monitor provides or offers care & support 4. Treatment monitor is a social relation/relative 5. Treatment monitor is a pastor/counsellor 6. Other (please specify) .....
10.	What is your partner's HIV status?	1. Positive 2. Negative 3. Don't Know
11.	Is it important to tell your sexual partner about your HIV positive status?	1. Yes 2. No
12.	Why is it important to tell your sexual partner that you are HIV positive?	
13.	How did you get informed that it is important to tell your sexual partner?	1. ART Clinic 2. Church 3. Internet 4. Media 5. Family 6. Friends 7. Other (please specify) .....
14.	Is it important to tell others about your status?	1. Yes 2. No

15. Are you part of any PLHIV support group?
    1. Yes
    2. No

16. If No to Q15, why not?

SECTION C. QUALITY OF LIFE

Instructions

This assessment asks how you feel about your quality of life, health or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

No.	Question	Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks

No.	Question	Not at all	A little	A moderate amount	Very much	An extreme amount
3.	How much are you bothered by any physical problems related	1	2	3	4	5

	to your HIV infections?					
4.	To what extent are you bothered by people blaming you for your HIV status?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks

No.	**Question**	**Not at all**	**A little**	**Moderately**	**Mostly**	**Completely**
5.	Are you able to accept your bodily appearance?	1	2	3	4	5
6.	Have you enough money to meet your needs?	1	2	3	4	5
7.	To what extent do you feel accepted by the people you know?	1	2	3	4	5
8.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
9.	To what extend do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks

No.	**Question**	**Very dissatisfied**	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
10.	How satisfied are you with your sleep?	1	2	3	4	5
11.	How satisfied are you with	1	2	3	4	5

	your ability to perform your daily living activities?					
12.	How satisfied are you with your capacity for work?	1	2	3	4	5
13.	How satisfied are you with yourself?	1	2	3	4	5
14.	How satisfied are you with your personal relationships?	1	2	3	4	5
15.	How satisfied are you with your sex life?	1	2	3	4	5
16.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
17.	How satisfied are you with the conditions of your living place?					
18.	How satisfied are you with your access to health services?					
19.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks

No.	**Question**	**Never**	**Seldom**	**Quite often**	**Very often**	**Always**
20.	How often do you have negative feelings such as despair, anxiety, depression?	1	2	3	4	5

Thank you very much for your time.

APPENDIX 3: IN DEPTH QUESTIONS

HIV STATUS DISCLOSURE AND QUALITY OF LIFE AMONG PREGNANT WOMEN AND WOMEN WITH LIFE BIRTHS LIVING WITH HIV ACCESSING CARE AT THE 37 MILITARY HOSPITAL.

Dear Respondent,

This is a research being carried out on *Disclosure and Quality of life among pregnant women and women with life births living with HIV in Ghana: A cross- sectional study at 37 Military Hospital*. I will, therefore, like to take some minutes of your precious time to answer these questions. You are assured that the answers you give will be strictly confidential and your name will not be mentioned in our research reports. Thank you.

Introduction

Thank you very much for agreeing to participate in this in depth interview today. My name is Regina Odarkor Nettey. I am currently undergoing a study for educative purposes. I am collecting information on HIV disclosure among pregnant women and how it affects them to guide future interventions. The information you give me will be kept confidential and you will NOT be identified by name in relation to contributions you make.

Awareness/Perception /Knowledge of HIV disclosure

1. Tell us about what you understand by HIV disclosure?
2. Based on what we now know as disclosure, tell us why disclosure is necessary or not.
3. If any, describe your experiences on stigma or any negative reaction in the past year because you made your HIV status known.
4. What do you think are the contributing factors (drivers) to why PLHIV do not disclose their status? Probe thoroughly?

Disclosure

5. Based on your current situation, give reasons why you would want to keep your HIV positive status a secret?
6. Give reasons why you would want to disclose your HIV positive status to spouse/ partner?

Quality of Life

7. How accepted do you feel by your partner after disclosing your status? Explain

8. How satisfied are you with your ability to perform your daily living activities? Explain
9. How satisfied are you with the support you get from your partner after disclosing your status? Explain
10. How satisfied are you with your access to health services? Explain
11. Describe any negative feelings such as despair, anxiety, depression you experience due to your HIV-positive status. Probe thoroughly?

APPENDIX 4: ETHICAL CLEARANCE

Institutional Review Board
37 Military Hospital
Neghelli Barracks
ACCRA .

Tel: 0302 769667
Email:irbmilhosp@gmail.com

16 April 2020

ETHICAL CLEARANCE

37MH-IRB IPN/MP/ 384/2020

On I6 April 2020, the 37 Military Hospital (37MH) Institutional Review Board (IRB) at a Board Meeting reviewed and approved your protocol.

TITLE OF PROTOCOL: HIV status Disclosure and Quality of Life among Pregnant Women and Women with Life Births Living with HIVaccessing Care at 37 Military Hospital

INVESTIGATOR: Regina Odarkor Nettey

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 until 15 April 2021.

Edward

DR EDWARD ASUMANU
(37MH-IRB, Vice Chairman)

37 MILITARY HOSPITAL
INSTITUTIONAL REVIEW BOARD
DATE 16-04-20

Cc: Brig Gen (Dr) NA Obodai
Commander, 37 Military Hospital