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TO DISCLOSE OR NOT TO DISCLOSE THE HIV/AIDS STATUS OF CHILDREN: HEALTH-RELATED OUTCOMES AND EXPERIENCES OF CAREGIVERS.

THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF MPHIL IN CLINICAL PSYCHOLOGY.

JULY, 2019

DECLARATION

I, **Delight Abla Klutsey**, hereby declare that except for the references made to other studies which have been duly acknowledged, this thesis titled "***To Disclose Or Not To Disclose The HIV/AIDS Status Of Children: Health-Related Outcomes And Experiences Of Caregivers***" is a true reflection and product of my own research which was undertaken with the supervision of two faculty members of the Department of Psychology by names Dr. Margaret Amankwah-Poku and Dr. Kwaku Oppong Asante in pursuant of an MPhil Degree in Clinical Psychology. I also declare that this thesis has neither in part nor in whole been presented for another degree anywhere.

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DR. KWAKU OPPONG ASANTE DATE

DEDICATION

This work is first and foremost dedicated to my loving parents Mr. Cornelius Atsu Kwaku Klutsey and Mad. Emelia Ami Akorttia for their belief in me and support in sponsoring my education up to this level. This thesis is a product of the sacrifices you have made for me to get here. My dream came true because of your love, care, and support.

It is also dedicated to my siblings Desire Mawutor Klutsey and Ellen Eyi Klutsey for their immense contribution and support which has made the work seen the light of day.

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"*To God be the glory, great things He has done*" (MHB 313)

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ABSTRACT

It has been shown that disclosure of status to children living with HIV has a beneficial effect on health outcomes in children living with HIV. In most sub-Saharan African nations, however, the prevalence of disclosure remains low, leading to poor compliance or adherence and adverse psychological results in these children. This study explored the disclosure experiences among caregivers of children living with HIV and the influence of disclosure on health outcomes in both children and their caregivers. Using an exploratory sequential mixed method design, 15 caregivers between the ages of 27 and 55 years comprising 4 males and 11 females with a mean age of 41 years (SD= 6.23) were interviewed in the qualitative stage, while 155 HIV-positive children between 6 – 15 years of age with a mean age of 9.55 years (SD=2.72) and their caregivers with mean age of 41.60 years (SD= 10.38) were administered standardized questionnaires measuring adherence to medication, children's psychological well-being, caregiver burden, and caregivers' psychological health. Results indicated that age/maturity, stigma, and fear of child telling others about the diagnosis were the main reasons for non-disclosure whereas non-adherence, curiosity, and transition to high or boarding school were some of the factors that prompted disclosure. Disclosure of HIV status led to improved adherence and psychological wellbeing in children living with HIV. However, disclosure did not affect health outcomes in caregivers. Age was an important predictor of disclosure, and duration of disclosure mediated the relationship between disclosure and psychological wellbeing. Inadequate finances, anxieties about lifelong medication for children and high levels of psychological distress and burden were the challenges reported by caregivers. These findings emphasize the need for disclosure of status among children living with HIV using an interdisciplinary approach.

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CHAPTER ONE

INTRODUCTION

1.1 Overview

The abbreviations HIV and AIDS represent, respectively, human immunodeficiency virus and acquired immune deficiency syndrome. The disease is a chronic one and a world health challenge (Fajardo-Ortiz et al., 2017) because like many other chronic conditions, HIV/AIDS has no cure and people diagnosed with the disease have to manage it with drugs throughout their lifespan (Deeks, Lewin, & Havlir, 2013; Siegel & Lekas, 2002). The condition is also a world health challenge because it has claimed millions of lives worldwide since it was discovered over three decades ago. Living with HIV has implications on individuals, families, societies and nations at large (Fajardo-Ortiz et al., 2017).

The HIV virus is part of a class of viruses called retroviruses which fight and destroy the cells of the immune system, in particular the T lymphocyte cells (CD4 cells), suppressing its ability to fight diseases and infections thereby causing a gradual deterioration of immune function (Duggal, Chugh, & Duggal, 2012; Klimas, Koneru, & Fletcher, 2008). In healthy individuals, CD4 cell count ranges from 800 to 1200 for every cubic millimeter of blood, however, once the HIV virus enters the T lymphocyte cells, it begins to destroy them leading to a decrease in number (Williams et al., 2006). The HIV virus progresses to AIDS in a few years, usually between 6-10 years if it remains untreated in an individual (Bagby et al., 2015; Langford, Ananworanich, & Cooper, 2007).

It has been almost three decades and a half since the HIV/AIDS epidemic started, but the disease continues to be a major public health issue in sub-Saharan Africa because most of the problems related to disease prevention and management are more common in the sub-region

(Kharsany & Karim, 2016; Kimanga et al., 2014). Although sub-Saharan Africa has merely 12% of the worldwide prevalence, it has been shown to bear an overwhelming 71% of the global illness burden (Kharsany & Karim, 2016; Short & Goldberg, 2015). The most prominent of this global burden is that relating to pediatric HIV (Ubesie, 2012) which is the infection of HIV in neonates, children, and adolescents (Burchett & Pizzo, 2007).

Statistics indicate that an estimated 1.8 million children and adolescents below 15 years of age live worldwide with the disease, 91% of whom reside in sub-Saharan Africa (UNAIDS, 2018; UNICEF, 2018). Also, approximately 66% of the new infections that occurred globally in both children and adults in 2017 were in sub-Saharan Africa (UNAIDS, 2018).This implies that the sub-region is home to almost 2 million children with HIV, mostly infected during pregnancy or through breastfeeding by their mothers (Kassa, 2018; Wudineh & Damtew, 2016). The statistics again show that an estimated 12.2 million children and adolescents under the age of 18 years have lost either one or both of their parents to HIV in 2017(UNICEF, 2018). In Ghana, as of 2017, a total of 313,063 individuals were living with HIV and AIDS (Ghana AIDS Commission, 2017). Of this figure, 33,000 were children (Ghana AIDS Commission, 2017) most of whom are infected by mother-to-child transmission (Dako-Gyeke et al., 2016). Children living with HIV face many medical and psychosocial problems that greatly contribute to the worldwide burden of HIV. Among the many problems faced by children living with HIV, poor access to antiretroviral therapy due to poverty, stigma and low levels of HIV disclosure have been highlighted as main psychosocial issues in sub-Saharan Africa related to pediatric HIV (Hope & Fraderick, 2015; Ubesie, 2012; Vranda & Mothi, 2013).

A diagnosis of HIV/AIDS some few decades ago meant death was near and inevitable because it had no cure and there were no efficient vaccines to combat it. Although a cure for the disease has still not been found, significant strides have been made over the years in developing vaccines to treat and manage the condition (Kharsany & Karim, 2016; Nachega, Uthman, Mills, & Quinn, 2012; Palmisano & Vella, 2011). The advent of antiretroviral therapy (ART) however, has shifted the HIV epidemic from a lethal or fatal disease to a long-term or chronic disease that can be managed, resulting in a substantial reduction in HIV-related fatalities, a decrease in mother transmission to children and new infections (Kharsany & Karim, 2016; Nachega et al., 2012; Palmisano & Vella, 2011). However, in mitigating the destructive impacts of the HIV virus, the efficacy of antiretroviral therapy depends mainly on the capacity or ability of patients to adhere strictly to prescribed regimens or dozes (Iacob, Iacob, & Jugulete, 2017; Letta, Demissie, Oljira, & Dessie, 2015; Silva, Dourado, Brito, & Silva, 2015; Wasti, Simkhada, Randall, Freeman, & van Teijlingen, 2012).

Antiretroviral treatment regimen adherence increases the amount of CD4 cells in the bloodstream (as indexed by CD4 count test) which are destroyed by the HIV virus. It also decreases the quantity of the HIV virus in the bloodstream or what is termed as “viral load” and slows disease progression (Erb, Battegay, Zimmerli, Rickenbach, & Egger, 2000). However, adherence to ART regimens has generally been unsatisfactory. In some studies, it has been shown that, across different populations, adherence ranges between 27% to 80% instead of the required 95% (Iacob et al., 2017; Nsheha, Dow, Kapanda, Hamel, & Msuya, 2014; Simoni et al., 2007; Vreeman, Wiehe, Pearce, & Nyandiko, 2008; Wadunde et al., 2018). Adherence in children and adolescents living with HIV is also reported to be suboptimal owing to the fact that only a minute fraction of these children are genuinely aware of their status (Ammon, Mason, & Corkery, 2018; Mehta, Ekstrand, Heylen, Sanjeeva, & Shet, 2016). Though studies on antiretroviral therapy coverage and adherence are limited, it has been found that barely a small proportion of children with HIV obtain optimum adherence and that adherence in adults is better compared to children (Ammon et al., 2018; Nsheha et al., 2014). For instance, Ammon et al. (2018) in a systematic review reports 20.7 % adherence rate across sub-Saharan Africa and Nsheha et al. (2014) reported a 24.6% adherence rate in Tanzania. Also, the fact that adherence in children and adolescents with HIV depends mostly on their parents or caregivers makes optimum adherence more challenging (Akahara, Nwolisa, Odinaka, & Okolo, 2017; Endalamaw, Tezera, Eshetie, Ambachew, & Habtewold, 2018). There are several determinants of poor adherence in children with HIV. Key among these are caregiver forgetfulness and illness, poor socioeconomic status, side effects of antiretroviral drugs and non-disclosure of HIV status (Nyogea et al., 2015; Ugwu & Eneh, 2013; Wadunde et al., 2018).

Disclosure of status is one of the pertinent issues in the management of the HIV epidemic. It has also been found to be a major psychosocial challenge encountered by individuals living with HIV/AIDS (Li, De Wit, Qiao, & Sherr, 2015; Madi et al., 2015; Vaz et al., 2011). This is due to the fact that disclosure can have both good and bad outcomes or consequences. Pediatric disclosure refers to a child or an adolescent’s awareness of his/her HIV status or diagnosis. It could also mean a child having awareness about the HIV status of his/her parent or caregiver, or a child informing others willingly about her or his diagnosis (Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013). In this thesis, disclosure will refer to a child’s knowledge or awareness of his or her HIV status or diagnosis. This form of disclosure has been found to be essential in the management of HIV in the long term and movement into adolescence and adulthood care (Vreeman et al., 2013, 2014) and it is considered a significant precondition for improving health outcomes in children living with HIV (Gyamfi, Okyere, Enoch, & Appiah-Brempong, 2017; Hayfron-Benjamin, Obiri-yeboah, Ayisi-addo, Siakwa, & Mupepi, 2018; Wiener, Mellins, Marhefka, & Battles, 2007).

Any change in the health of an individual, a group of people or population, which is wholly or partially attributable to an intervention or series of interventions is defined as a health outcome (Sansoni, 2016). This change in individuals can be measured using varying methods including clinical indicators, patient-reported outcome indices, health performance indicators and standardized clinical evaluations (Sansoni, 2016). Examples of health outcomes may include reduced mortality or morbidity, controlled blood pressure, optimum medication adherence, reduced viral load, quality of life, psychological wellbeing and psychological health, etc. Disclosure of status has been reported to be related to the following health outcomes in HIV-positive children: increased adherence to antiretroviral treatment (Kidia et al., 2014; Odiachi, 2017), improved accessibility to support services, open discussions within the family setting (Hayfron-Benjamin et al., 2018; Vaz et al., 2011; Wiener et al., 2007) and improved psychological wellbeing (Gyamfi, Okyere, Appiah-Brempong, Adjei, & Mensah, 2015; Nichols, Steinmetz, & Paintsil, 2017).

Burns (2016) explains psychological well-being as the inter- and intra-individual levels of beneficial functioning that may include a relationship with others and self-referential or reflexive attitudes that comprise a feeling of mastery and personal development. This implies that psychological well-being is attained if one is able to function positively by having a good relationship with others and attaining happiness within which translates to personal growth, mastery, and development. In the study of psychological well-being, there are two wide approaches, namely the hedonic and eudaimonic approaches (Kahneman, Diener, & Schwarz, 1999; Ryan & Deci, 2001; Ryff, 1989, 2013; Ryff & Keyes, 1995). The hedonic view or approach regards psychological well-being as the quest for a happy existence or happiness whereas the eudaimonic view believes in the realization of one's potential and living a meaningful life (Chen, Jing, Hayes, & Lee, 2013; McMahan & Estes, 2011; Vázquez, Hervás, Rahona, & Gómez, 2009).

Thus, psychological wellbeing encompasses both the ability to experience positive affects or emotions and ability to flourish in the face of life's difficulties, achieving significant goals, growing and evolving as an individual, and building quality connections with others. There are many models of psychological wellbeing but one of the most cited is by Ryff (1989). According to Ryff (1989), there are six primary aspects of well-being: independence, personal growth, beneficial interactions, mastery of the environment, the purpose of life and self-acceptance. An individual is therefore said to have optimum wellbeing when he or she is able to strike a balance between these different dimensions. Disclosure, therefore, aids children to achieve optimal psychological wellbeing as they are able to gain mastery and a sense of purpose with particular reference to their health while striving for personal growth and development in other facsets of their lives.

Disclosure also has an association with certain outcomes in caregivers such as the burden of care and psychological health (Asadullah, Kamath, Pattanshetty, Andrews, & Nair, 2017; Bachanas et al., 2001). In Ghana, poor health outcomes have been reported for both HIV positive children and their caregivers. (e.g. Doku, 2016; Doku & Minnis, 2016; Nichols et al., 2019). High rates of antiretroviral non-adherence, as well as symptoms of depression and other psychiatric disorders, have been reported in children living with HIV in Ghana (Doku & Minnis, 2016; Nichols et al., 2019). Similarly, peer problems and delinquency have also been reported in children affected by HIV (Doku, 2016). Caregivers of children living with HIV have also been reported to have varying degrees of psychological distress and burden (Gyamfi et al., 2017).

The World Health Organization (WHO) acknowledges and recognizes the significance of disclosure and states that non-disclosure of HIV status to children living with the disease affects their wellbeing as well as access and adherence to antiretroviral treatment and other health-related outcomes (WHO, 2011). The WHO, therefore, recommends that all children with HIV who are of school-going age should begin the process of being informed of their status (WHO, 2011). However, HIV status disclosure to children affected with the disease continues to be a challenge in many countries with low and middle income especially those in sub-Saharan Africa including Ghana (Madi et al., 2015; Vreeman et al., 2013). Studies that assessed the disclosure prevalence rates among caregivers in Ghana found that disclosure rates are as low as 21% (Kallem, Renner, Ghebremichael, & Paintsil, 2011) and 33.3 % (Gyamfi et al., 2017) respectively. Several reasons account for these low prevalence rates of disclosure. In studies that have examined the reasons or barriers to disclosure, it has been found that, the reasons most mentioned or referenced for not disclosing children's HIV status include: fear of disclosure affecting the child's psychological well-being, fear that the child might not keep the diagnosis confidential, fear of being blamed for infecting the child, stigma, and the assertion that the child is not old enough to understand the meaning of the disease (Gyamfi et al., 2017; Vreeman et al., 2014). Caregivers are therefore faced with the dilemma of whether ‘to disclose or not to disclose’ the status of their children to them.

The welfare of children living with HIV depends greatly on their primary caregivers or parents who aid in providing most health needs including ensuring adherence to drugs, etc. Children with HIV need support from their primary caregivers for social and emotional development (Pacheco, Nobre, Gomes, Xavier, & Aquino, 2016). A primary caregiver is “a person who provides ongoing practical assistance with activities of daily living to a friend, partner, or family member” (Lua & Mustapha, 2012 p. 197). Providing all these needs for a child with HIV can be draining, burdensome and exhausting for the caregiver. It suggests that caregivers of children with HIV are likely to face several burdens in attending to the health needs of these children. Caregiver burden according to George and Gwyther (1986) can be defined as “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired relatives” (p. 253). Studies have revealed that caregivers report varying degrees of psychological distress and burden (Asadullah et al., 2017; Bachanas et al., 2001; Osafo, Knizek, Mugisha, & Kinyanda, 2017). Some of the common distress reported by caregivers include stress, anxiety, and depression owing to the many psychosocial problems they face while caring for such children including poverty, the dilemma of disclosure, stigma, etc. (Asadullah et al., 2017; Osafo et al., 2017). One reason that contributes to this distress in caregivers is the lack of disclosure. This is because non-disclosure creates anxieties and tension within the family setting as there are no open discussions within the family about the child's condition (Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013; Negese et al., 2012; Wiener et al., 2007). Therefore, when disclosure is made, these distress, burden, and tensions are likely to be eased hence there are open communications about the child's conssdition.

To summarize, status disclosure to children living with HIV is a pertinent issue faced by caregivers. Disclosure has been reported to be related to adherence and psychological wellbeing in children with HIV. It is similarly related to burden and psychological health in caregivers. A majority of caregivers find disclosure a challenge. Given that poor health outcomes have been reported in both children with HIV and their caregivers, it is crucial to understand how disclosure of status to children with HIV influences adherence and wellbeing in these children. It is also key to understand the experiences of these caregivers and how disclosure affects their psychological health and burden because the roles of caregivers are very vital in the care of these children and cannot be underestimated. However, this has not been thoroughly investigated because studies on disclosure have mainly focused on the post-disclosure experiences and health of children with HIV to the neglect of caregivers (Baker et al., 2018; Beck-Sagué et al., 2015; DeSilva et al., 2018; Lorenz et al., 2016). Hence this study will focus on health outcomes in both children and their caregivers.

1.2 Problem Statement

HIV status disclosure to children has several benefits namely: improved adherence to antiretroviral therapy, improved psychological health and wellbeing, enhanced access to support services and open family discussions or communications (Gyamfi et al., 2015; Kidia et al., 2014; Wiener et al., 2007). However, disclosure of status to children infected with HIV continues to be a huge problem in most sub-Saharan African countries including Ghana (Gyamfi et al., 2017). While disclosure is encouraged and recommended for children of school-going age by professionals and health institutions such as the World Health Organization, a large proportion of caregivers shy away from it for different reasons, some of which include, stigma, fear of disclosure causing psychological harm to the child and fear of blame from the child (Vreeman et al., 2013).

The problem of non-disclosure of status has resulted in unsatisfactory health-related outcomes in children living with HIV (Ammon et al., 2018; Doku & Minnis, 2016; Doku, 2016; Nichols et al., 2019). In relation to antiretroviral adherence in Sub Saharan Africa, it has been shown that children with HIV are able to achieve only 20.7% adherence as compared with the required 95% for optimal physical health (Ammon et al., 2018). In Ghana, a high prevalence of antiretroviral non-adherence and poor psychological health outcomes has been reported in children with HIV (Nichols et al., 2019). For instance, research has indicated that children with HIV or affected by HIV have a higher prevalence of developing psychological or psychiatric disorders (Doku & Minnis, 2016; Vranda & Mothi, 2013). Common among the psychological disorders in children with HIV include depression and other mood disorders, conduct disorders, oppositional defiant problems, anxiety disorders, and attention deficit hyperactive disorder (ADHD) (Bizimana et al., 2014; Vranda & Mothi, 2013). Non-disclosure, therefore, can have a detrimental effect that can greatly affect the health of infected children. It is, therefore, necessary to investigate the reasons for non-disclosure among affected families in order to understand and help improve the rate of disclosure for better health outcomes amongst these children.

Also, the problem of non-disclosure significantly contributes to psychological distress and burden in caregivers (Asadullah et al., 2017; Gyamfi et al., 2017; Osafo et al., 2017) yet post-disclosure quality of life studies and experiences have focused mainly on children and not their caregivers. These problems, therefore, warrant the need for a study that explores the viewpoints and experiences of caregivers on status disclosure to children with HIV/AIDS. There is the need to also examine the impact of disclosure on health outcomes (antiretroviral adherence and psychological wellbeing) in both children who know their HIV status and those who do not know their status and on caregiver burden and psychological health in caregivers. This will help to identify the burdens of caregivers and how they can be supported to care for their affected children. Also, caregivers will understand the importance of status disclosure and make informed decisions for the physical and psychological benefits of their children.

1.3 Aims of the Study

This study primarily aimed at exploring the experiences of caregivers with issues relating to the disclosure of status to children living with HIV/AIDS and to examine how disclosure influences health outcomes in caregivers and children living with HIV/AIDS.

1.4 Specific Objectives

The following were the specific objectives of the study:

i. To explore the views and experiences of caregivers on HIV status disclosure to children living with HIV/AIDS.

ii. To explore and understand the views of caregivers on the impact of HIV status disclosure on health-related outcomes (particularly on adherence and psychological health) of children living with HIV/AIDS.

iii. To examine the differences between caregivers who have disclosed and those who have not disclosed, on caregiver burden and psychological health.

iv. To examine the differences between disclosed children and non-disclosed children living with HIV on psychological wellbeing and antiretroviral adherence.

1.5 Relevance of the Study

This study is of great significance in terms of literature and practice. In practice, results from this study will aid health professionals and other stakeholders to, first of all, understand the experiences of caregivers in relation to status disclosure to children living with HIV. It will throw more light on the barriers or obstacles to status disclosure, factors that promote disclosure among caregivers as well as how caregivers go about the disclosure process. Understanding these experiences will also aid healthcare providers to understand the problems that caregivers face in relation to HIV status disclosure so as to provide the needed collaboration and assistance that caregivers may need during the disclosure process. Also, findings will help in understanding the context-specific challenges of caregivers on status disclosure to children living with HIV.

Again, findings will aid policymakers to develop culturally appropriate and specific disclosure guidelines that will guide and encourage disclosure of status among caregivers of children living with HIV as recommended by the WHO, since Ghana is yet to have a disclosure framework. This will ensure that children with HIV take more responsibility for their health for better psychological and adherence outcomes and ultimately, for optimum health and management of the HIV epidemic. Caregivers of children living with HIV will also be educated on the positive impacts of disclosure on health outcomes in children with HIV which will go a long way in eradicating the fears that caregivers have towards disclosure.

Furthermore, findings from this study will contribute greatly to the literature available on the treatment outcomes, health and psychological benefits that both children living with HIV/AIDS and their caregivers derive as a result of HIV status disclosure, given the fact that it is an emerging psychosocial issue and there paucity of data and research on the subject (Nichols et al., 2017; Odiachi, 2017). Finally, findings from the study will throw more light on some of the challenges children living with HIV face with regards to medication adherence and psychological wellbeing so that caregivers can be given the necessary support to help address such challenges.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter synthesizes the literature relevant to the topic under investigation. It begins with a review of the theories that are relevant to the subject under study. The chapter also presents a review of related studies which puts together other studies that have examined the variables under investigation. These include experiences of disclosure in caregivers, disclosure and antiretroviral adherence, disclosure and psychological health in children living with HIV, disclosure and caregiver burden and disclosure and psychological health of caregiver of children with HIV.

2.2 Theoretical Frameworks

Two main theories underpinned this study, namely: the Consequences Theory of HIV/AIDS Status Disclosure (Serovich, 2001) and the Social Influence Theory of HIV Disclosure (Zea, Reisen, Poppen, Bianchi, & Echeverry, 2007).

2.2.1 Consequences Theory of HIV/AIDS Status Disclosure

This Consequences Theory of HIV/AIDS status disclosure was built on an earlier theory of disclosure known as the Disease Progression Theory developed by Kalichman (1995). The disease progression theory states that an individual’s intention to disclose their HIV status is basically as a result of the progression of the disease (Kalichman, 1995). Before the introduction and widespread coverage of highly active antiretroviral therapy to people infected and living with HIV, being diagnosed with HIV/AIDS meant death was imminent because the disease progressed faster. As a result, Kalichman postulated that, as HIV progresses steadily to AIDS, it may lead to physical weakness and deterioration and may also require hospitalization. Hence, the individual in a bid to seek assistance and resources to manage the disease would have to explain their illness leading to disclosure (Kalichman, 1995). With the success of antiretroviral therapy however, it has become evident that there are more angles to HIV status disclosure than just disease progression, because people living with HIV who are receiving treatment and are on antiretroviral therapy, and achieve optimum adherence are able to live normal healthy lives and function well in work and other settings.

Building on the Disease Progression Theory, Serovich (2001) theorized that the relationship between HIV status disclosure and disease progression is determined by a third variable: that is, the consequences that the individual believes will result from disclosure. That is, the disclosure of a person’s HIV status to others is not only a factor of how fast the disease progresses but on the consequences that the individual perceives will result from the disclosure. These perceived consequences can either be positive (rewards) or negative (costs). Some of the costs of the disclosure include anger, rejection, isolation, and stigma while rewards include the access to social support, as well as emotional and physical support and the provision of medical information (Serovich, Lim, & Mason, 2008). If the perceived rewards of status disclosure are greater than the cost, then the individual is able to disclose their HIV status and vice versa.

According to Serovich (2001), the core assumption of the social exchange theory by Hare, Thibaut, and Kelley (1960) lies at the center of consequence theory of HIV/AIDS status disclosure. The social exchange theory posits that people prohibit relationships and associations that are costly but seek rewarding ones where rewards are high and the cost are low (Hare et al., 1960). As such, when individuals are faced with a variety of choices, they select the ones with the most benefits/rewards and least costs. Therefore when people with HIV perceive that the costs of the disclosure are more than the rewards, they are unlikely to disclose, however, if the perceived rewards are greater than the costs, then disclosure can take place. Applying this to children living with HIV, caregivers can either choose to disclose the HIV status of their children to them or otherwise based on the consequences that the caregivers perceive will result from the disclosure process. If the caregivers are convinced that disclosure will lead to more positive outcomes for the children, they are likely to disclose. However, if more negative outcomes are perceived for the children, then disclosure may be unlikely.

2.2.2 Social Influence Theory of HIV Disclosure

Zea et al. (2007) are of the view that psychological explanations of behaviour should not only include individual psychological factors but also larger social factors or variables such as societal norms and culture as well as individual or subjective factors (such as consequences). They believed that these social influences play a powerful role in explaining behaviours particularly for people who are from highly relational cultures such as Africa (Zea et al., 2007). They postulated three main social influences that affect disclosure namely: norms, culture, and experiences of discrimination.

Norms are basically patterns of behaviour or patterns of group attitude that have a significant impact or social influence on behaviour. The norm regarding disclosure of one’s HIV status varies across different settings particularly with reference to the target of the disclosure. In western countries, the norm has been that people living with HIV disclose their status most of the time to their partners and close friends than family members (Zea et al., 2007). Another social factor that affects disclosure according to Zea et al., (2007) is the individual's cultural values and beliefs. It has been mostly reported that cultural values such as protecting one’s family from embarrassment and protecting the family’s peace and harmony are one of the main reasons for non-disclosure. In children living with HIV, these cultural norms may prevent parents or caregivers from disclosing their wards HIV status because of the fear that both the parent and child will be stigmatized or that the child might blame their parents for the infection.

Experiences of discrimination is also a social influence which affects disclosure of a person's HIV status to others. According to the proponents of the social influence theory, a person's prior experience of discrimination due to disclosure could cause feelings of powerlessness in the individual leading to fewer communications about his or her diagnosis. Disclosure of a person's HIV status to others or a child's HIV status to him or her, therefore, involves an interplay of these three social influences as well as other individual factors such as perceived costs and benefits of disclosure to determine whether or not disclosure will be made or not.

2.3 Review of Related Studies

2.3.1 Experiences of HIV/AIDS status disclosure by caregivers

Caregivers across the globe have had varied experiences in relation to the disclosure of status to children living with HIV. Beck-Sagué et al. (2015) found that different reasons prompted caregivers to either disclose or not to disclose the HIV status of their children to them. They conducted a mixed-method study that aimed to find out the percentage of children living with HIV who knew their HIV status and also describe the experiences of caregivers and adolescents on disclosure in the Dominican Republic. Anonymized data were obtained from hospital records of a sample of 327 children with HIV aged 6–18years who were attending pediatric HIV clinics in Santo Domingo, and Clinica de Familia La Romana as part of the quantitative study. A total of 41 caregivers and 36 adolescents also took part in focus group discussions as part of the qualitative study.

Results indicated that only 74 out the 327 children knew about their HIV status which represents 22.6%. Caregivers who had disclosed reported that lack of medication adherence and constant questioning and inquisitiveness on the part of these children prompted them to disclose whereas those who did not disclose gave reasons such as the age of the child. They were of the view that disclosure should be made at an older age, preferably between 10 to 16 years in order to help these children understand and cope with the condition. Other reasons for non-disclosure on the part of caregivers include the concern for the emotional wellbeing of these children as most caregivers feared that disclosure might lead to feelings of sadness and low self-esteem (Beck-Sagué et al., 2015). Also, caregivers had fears that children might tell others if they know about their diagnosis and this can lead to stigmatization, discrimination, and rejection which the child may not be old enough to deal with (Beck-Sagué et al., 2015). These societal factors of discrimination and rejection are costs or negative consequences that caregivers perceive their children may not be able to cope with, hence reiterating the social influence of discrimination on disclosure.

In rural Uganda, Lorenz et al. (2016) explored the attitudes of caregivers towards HIV testing and disclosure of status to at-risk children. They sought to find out the age of disclosure, the disclosure process, and challenges faced during disclosure. Twenty-eight (28) primary caregivers of children with HIV who were on antiretrovirals and whose status had been disclosed to them were interviewed. It was found that most caregivers initiated the disclosure process at the age of 7 years. Before that, caregivers admitted to giving partial disclosure; that is telling their children initially that they have other medical conditions such as malaria and anemia. The reason for this partial disclosure was because caregivers feared the children's reactions to the knowledge of their diagnosis and whether they would understand what the condition is. In most cases, caregivers felt it was their duty to disclose the HIV status of their children to them. Some caregivers sought advice from health professionals and HIV counselors before they disclosed to the children. Reasons that prompted disclosure were children's curiosity about why they were taking medications continually, poor adherence and refusal to attend regular clinic appointments. In the process of disclosure, caregivers also disclosed their own HIV status or that of the child's biological parents. Caregivers doubted whether the children understood the information being disclosed at the time however, a majority of them were sure it will lead to positive outcomes such as increased adherence and health (Lorenz et al., 2016). This shows that caregivers' beliefs that disclosure will have positive outcomes or rewards for the children lead to disclosure hence reinforcing the consequences theory of disclosure.

Baker et al. (2018) found in Peru that caregivers and health care providers' frustration about non-adherence to medication on the part of children who did not know their status, as well as, curiosity on the part of others were some of the factors that prompted disclosure. Some caregivers and health care providers also became fed up with consistently lying to these children and eventually had to disclose. In addition, unintentional discoveries by children such as seeing medication labels, learning through television, internet, brochures and overhearing HIV discussions at the clinic prompted parents to open up about their HIV status. Health care providers prepared caregivers for the disclosure process by engaging in discussions about how and when disclosure should take place. Most caregivers reported using child-friendly analogies during disclosure for the children to understand. For instance, some caregivers told their children they were born with bugs in their body and to prevent this bug from growing, the children needed to consistently take their medication. After HIV status disclosure, most caregivers reported that children initially experience emotional distress and depression but with time, they were able to overcome such depression with the needed support from family and friends. Caregivers also reported worse adherence immediately after disclosure but admit that this improved after time. Children with HIV, caregivers and health care professionals all had varied opinions as to what age disclosure should happen. Children suggested between the ages of 6 and 7 years, health care professionals suggested from 8 years while caregivers preferred adolescence, (12 to 14 years). Since caregivers are the ones who mostly disclose to children, this can perhaps explain why older adolescents are more often than not disclosed to than younger children.

In China, DeSilva et al. (2018) explored issues relating to the disclosure of HIV status to older children and adolescents living with HIV. They interviewed clinicians, caregivers, and adolescents themselves using one-on-one interviews and focus group discussions. In all, forty (40) interviews were conducted with twenty adolescents/caregiver dyads as well as four focus group discussions. Findings show that some adolescents actually knew their status without it being disclosed to them by their caregivers. Only 6 caregivers reported disclosing to their children but interviews with the adolescents showed that 9 actually knew their status. This confirms the problem of unintentional discoveries by adolescents living with HIV leading to accidental disclosures as reported by Baker et al. (2018). Adolescents who knew their status were 13 years and above. Caregivers reported that they had earlier disclosed a less stigmatized condition like respiratory conditions to the adolescents as reported by Lorenz et al. (2016). They also reported using analogies such as the children having bugs in their tummies. Caregivers’ reasons or barriers to disclosure included stigma, anxiety about children’s reaction, and lack of preparedness for disclosure.

In Ghana, research has shown similar trends in relation to HIV status disclosure to infected children. Gyamfi et al. (2017) in a study to find the prevalence of disclosure to HIV infected children and to assess the problems that caregivers face during disclosure found that, disclosure happens mostly between the ages of 6 to 19 years with the mean age for disclosure being 15 years. Some of the reasons cited for this late disclosure include the age of the child (too young to understand the diagnosis), possible aftermath of disclosure (that the child will be psychologically harmed or devastated), stigmatization of HIV (isolation and rejection because of the diagnosis) and the child not being discrete about his/her diagnosis. Although in a previous study caregivers were aware and perceived disclosure as having positive outcomes such as responsible adolescent sexual behavior, increased adherence to medications and empowerment of children to take responsibility for their own health, most of them preferred to wait until teenage years before they disclose (Gyamfi et al., 2015). Others also postponed disclosure until they were either alerted by the health care worker or until the child became reluctant in taking medications on the grounds that they were not ill anymore before disclosure was made (Gyamfi et al., 2017).

In summary, it can be noted that the experiences of disclosure are quite similar as seen in the studies reviewed above. However, most of these qualitative studies reviewed above focused mainly on the reasons for disclosure and non-disclosure (Baker et al., 2018; Beck-Sagué et al., 2015; DeSilva et al., 2018; Lorenz et al., 2016). The studies did not explore the impact and aftermath of disclosure on medication adherence among the children qualitatively. Also, these studies reviewed above have not also explored the impact of disclosure on caregivers as well.

2.3.2 Disclosure and Health Outcomes in Children

2.3.2.1 Disclosure and Antiretroviral Therapy Adherence

Although disclosure of status to children living with HIV is believed to positively impact health outcomes in children such as improved adherence, research on the association between disclosure of status to children living with HIV and medication adherence have reported mixed findings.

In an unmatched case-control study by Bulali, Kibusi, and Mpondo (2018) in Tanzania, HIV status disclosure was found to be positively associated with ART adherence. The study aimed to find out the factors that prompt HIV status disclosure and its consequence on medication adherence and quality of life among children aged 6 to 17 years living with HIV/AIDS. A total of

309 children were randomly sampled from Southern Highlands Zone and administered questionnaires. HIV status disclosure was measured by asking the parents/ guardians if their child knew their HIV status followed by verification from healthcare providers. Adherence was measured by using WHO adherence manual. Results showed that only 33% (102 of 309) of the participants knew their status. Age of the child, the educational level of the child and the educational level of the parent/guardian were factors that were significantly associated with the disclosure of HIV status. Disclosure was more prevalent among older adolescents between 10 and 17years than younger children. Also, children in high school or secondary had more odds of disclosure than those in primary school. Disclosure was positively and significantly associated with ART therapy adherence. Age of the child and relationship with the caregiver also indicated marginal significant relationships with disclosure (Bulali et al., 2018).

Also in Tanzania, Ramos et al. (2018) assessed the association between disclosure and stigma, mental health and adherence, and explored the psychosocial context among youth living with HIV in mixed-method approach. In the quantitative study, a total of 280 participants were conveniently sampled and administered questionnaires. The questionnaire asked if children knew their HIV status and how they found out. Self-reported adherence was measured with two questions developed by researchers. Results showed that 223 (80%) out of the 280 participants had found out their diagnosis on their own before they were eventually told. Also, thirty-two percent (32%) of the total 248 youth who were on antiretroviral therapy had poor adherence. Researchers concluded that although disclosure results in some improved adherence, however, the manner in which the children found out about their HIV status significantly affected adherence levels. Youth who had figured out their diagnosis on their own had poorer or incomplete adherence as compared to those who were purposefully told. This means that disclosure in itself is important and how this disclosure is done determines whether or not adherence will improve (Ramos et al., 2018).

Nichols et al. (2017) conducted a review to help understand the effect disclosure has on HIV-infected children in resource-limited countries. A systematic search of electronic medical databases was conducted. Studies were qualified for selection if they used a quantitative design to find the association between HIV status disclosure and adherence to antiretroviral therapy in pediatric patients and if they were conducted in a resource-limited setting. In all, a total of 14 studies met these criteria were included in the review.

Results indicated that the relationship between disclosure and antiretroviral adherence varied across studies. Five out the fourteen studies included in the review showed that there was no statistically significant association between disclosure and adherence while five other studies reported a positive association. Two studies, on the other hand, found that disclosure was related to non-adherence and the remaining two found that non-disclosure to be associated with adherence (Nichols et al., 2017). Seven studies examined the bivariate relationship between the two factors (disclosure and adherence) aside from other demographic factors that were found to have an effect on adherence. Of this, one found no association, three indicated a negative association while three also showed a significant positive association between disclosure and adherence (Nichols et al., 2017). Possible explanations for the positive associations were that disclosure empowers the children to work together with health care providers and their caregivers in maintaining adherence. It also allowed the children to willingly take medications knowing why they have to be taken. Again, disclosure created the atmosphere for more open communication about the condition between the caregivers, the healthcare providers, and the children (Nichols et al., 2017). For those studies that reported a negative association between disclosure and adherence, fear of social stigma and denial of status, leading to a decreased desire to take medications were cited as reasons. Others were that disclosure leads to depressive symptoms in children with HIV hence decreasing strong adherence habits (Nichols et al., 2017).

These results show mixed findings with no clear pattern. The authors cited different reasons for these inconclusive findings. The first is that there were varied methods of determining adherence in the studies reviewed. Some used the pill count method, while others used self-reported adherence or caregiver reported adherence. Also, sample sizes were not large enough hence sub-analyses were not conducted, thereby restricting the generalizations that can be made from the data (Nichols et al., 2017).

In another systematic review, Odiachi (2017) also explored the relationship between pediatric disclosure and health outcomes (adherence to antiretroviral therapy, psychosocial outcomes, and sexual and reproductive health) among children living with HIV. A multi-stage procedure was used to search for and extract data. A total of fifteen studies met the inclusion criteria and were used in the final review. Results showed that of all the studies that met the criteria for the review, only three focused on the effect of status disclosure on antiretroviral adherence. Of these three, two studies from Puerto Rico and South Africa found a positive association between disclosure and adherence while a study in Kenya showed that disclosure was not in any way associated with adherence as reported in their clinical data form or by caregivers (Odiachi, 2017).

A limitation of this review is the small sample sizes used the studies included the review. The Puerto Rican and South African studies, for instance, had sample sizes as small as 40 and 25. This did not allow for more rigorous analysis to be done and this limits any conclusions that can be drawn from such data on the impact of disclosure on treatment adherence. The authors, therefore, recommended more studies on the importance of disclosure on adherence to HIV treatment for children living with HIV (Odiachi, 2017).

2.3.2.2 Disclosure and Mental/Psychological Health

One of the commonly cited reasons for not disclosing among caregivers is the fact that disclosure will lead to psychological harm and emotional trauma to the children involved (Baker et al., 2018; Beck-Sagué et al., 2015; Gyamfi et al., 2017; Vreeman et al., 2014). However, studies that have investigated the relationship between disclosure and health outcomes have been inconclusive. While some studies report negative psychological outcomes in these children as a result of the disclosure, others reported positive mental health after disclosure.

For instance, in a study in Nigeria, Adefalu, Florence, Ayinmode, and Issa (2017) found that disclosure did not have any association with psychiatric morbidity or psychological health and wellbeing. This study was conducted among a sample of 196 children with HIV and their caregivers who were attending the HIV clinic at UITH Kwara State, Nigeria. Results indicated that only 18.4% of the children and adolescents sampled knew their HIV/AIDS status. Also, 19.4% of the children had mental health problems, the majority of whom did not know their HIV status. However, the children's knowledge about their HIV status was not significantly related with mental health problems hence the conclusion that disclosure of status to children does not lead to psychological problems in these children (Adefalu et al., 2017).

Pinzón-iregui, Beck-sagué and Malow (2013) conducted a systematic review to evaluate the global literature on disclosure of HIV status to infected children. Thirty-one (31) articles that were published from January 1996 to September 2011 were identified and included in the review. Results indicated that only three of the studies specifically investigated the relationship between disclosure and mental health. All three studies found no evidence that supported the assertion that a child's knowledge of his or her HIV status had a negative impact on mental health. A study in the review that assessed an intervention found that, at 6 months post-disclosure, over 70% of the children reported normalcy, and only one out of 40 participants still reported feelings of depression and would have preferred not to be told about the diagnosis. The other children, however, stated that they were happy to have found out about their status. Seven studies also examined how children, caregivers, and their families experienced disclosure. Six of these reported disclosure as a positive event. However, one study which assessed the quality of life found no difference in the quality of life indicators in the children before and after disclosure (Pinzón-iregui et al., 2013).

Although these studies above found no negative relationship between disclosure and mental health issues in children living with HIV, another review by Odiachi, (2017) indicated otherwise. This review reported that some studies found negative mental health issues in children whose status has been disclosed. Eleven out of the fifteen studies included in the review examined the effect of disclosure on mental and psychological outcomes of children with HIV (Odiachi, 2017). Five (5) of these eleven (11) studies showed an adverse impact of disclosure on some domains of mental health, two found that disclosure had a good impact on mental health while the rest either showed no effect at all, little or short-term negative impact. These five studies that indicated negative mental health outcomes stated that disclosure leads to increased risk of psychiatric hospitalization and poorer quality of life (Odiachi, 2017).

It is obvious from the studies reviewed above that there is inconsistency in the literature. However, a review by Vreeman et al. (2013) throws more light on the association between disclosure and mental or psychological outcomes in children living with HIV. The aim of this review was to ascertain the prevalence of HIV disclosure among children with HIV and to identify factors that influence pediatric disclosure and the effect of disclosure on the physical and emotional health of the children (Vreeman et al., 2013). A total of thirty-two articles were included in the review. It was found that quantitative studies mostly reported negative outcomes. However, qualitative studies have shown that although children experienced psychological and emotional difficulties after disclosure, these were mitigated over time as the children showed no signs of psychological difficulties (Vreeman et al., 2013). For instance, of the studies reviewed, a qualitative study in the Democratic Republic of Congo and Brazil found that children reported feelings of great sorrow, pain, and anxiety after learning about their HIV diagnosis, but these were followed by some feelings of comfort and relief after some period of time. This means that the duration of disclosure was a mediating factor in the association between disclosure and mental or psychological health outcomes in children with HIV. Hence, there is a need to consider the duration of disclosure as a factor when examining the relationship between disclosure and psychological health of children living with HIV.

2.3.3 Disclosure and Health Outcomes in Caregivers

While many studies have examined and explored the effect of disclosure on health outcomes in children living with HIV, few have actually examined its effect on the health and wellbeing of caregivers. Of these few, the focus has generally been on the psychological impact of caring for children living with HIV. For instance, a study conducted in rural China by Lv et al. (2010) investigated depressive symptoms in 160 caregivers of children in families affected with HIV and found that more than 50% of caregivers reported very high levels of depression. The participants were administered the Centre for Epidemiological Studies Depression Scale (CES-D) and over 50% of these caregivers had scores greater than 16 indicating the presence of depression. Variables that were significant predictors of depression in these caregivers included lower educational level and poor socio-economic status of caregivers (Lv et al., 2010). Researchers recommended that psychological interventions and social support be given to HIV-affected families particularly caregivers from lower socio-economic backgrounds.

Similarly, a study by Asadullah et al. (2017) on the psychological effect on caregivers of children with HIV in India found high levels of caregiver burden and psychological distress among caregivers. In this study, a total of 171 caregivers were conveniently sampled and were administered questionnaires. Results indicated that 84% of caregivers reported moderate to very severe caregiver burden and 49.7% of caregivers reported little to severe psychological distress (Asadullah et al., 2017). The caregiver's relationship with the child was a major predictor of caregiver burden whereas alcohol use and schooling of children was a predictor of psychological distress. Caregivers who were the biological parents of children with HIV experienced more caregiver burden than caregivers who were not the biological parents of the children. Also, caregivers who use alcohol and those whose children were not in school experienced more psychological distress.

Also, Gyamfi et al. (2015) explored the perceptions of caregivers on the benefits of disclosure of HIV status to infected children, adolescents, and caregivers in the Eastern Region of Ghana. Using the mixed methods design, a total of 118 caregivers took part in the quantitative phase and 10 took part in the in-depth interviews respectively. Results indicated that disclosure did not only improve the health of caregivers but also improved and increased adherence to medications, ensured that the children put up healthy and responsible sexual behavior and were responsive to health needs. A limitation of this study is that the questionnaires used were unstructured and unstandardized and this flaws the study because the measures did not show sound psychometric properties such as reliability and validity.

Ofori-Atta et al. (2019) found in a recent study in Ghana that there was a high prevalence of depression among caregivers of children living with HIV particularly those who have not disclosed the status of their children. Prevalence of depression among these caregivers was estimated at 28% meaning that this percentage of caregivers met the clinical criteria for the diagnosis of depression. They also found that HIV-positive caregiver status, low income, lower social support, lower HIV knowledge, HIV illness perception, and greater perceived HIV stigma were some of the factors significantly associated with depression among caregivers of children living with HIV. The study aimed to estimate the prevalence of depression in non-disclosed caregivers and also identify some risk and protective factors for depression among a sample of 446 caregivers of children living with HIV in Kumasi and Accra. A limitation of this study is that it only focused caregivers who have not disclosed to their children and not on caregivers who have disclosed. Thus, there was no comparison between caregivers of children who do not know their diagnosis and caregivers of children who know their diagnosis on depression.

2.4 Rationale

Although a number of studies have been done in the sub-region on pediatric disclosure, few studies have focused on the impact of status disclosure on health-related outcomes in both children living with HIV and their caregivers. A majority of the studies that have been done on post-disclosure quality of life and experiences were conducted in children living with HIV and not their caregivers (Adefalu et al., 2017; Bulali et al., 2018; Pinzón-iregui et al., 2013; Ramos et al., 2018). Also, studies that assessed the influence of disclosure of status on health outcomes in children with HIV have also reported mixed findings (Nichols et al., 2017; Odiachi, 2017). In Ghana, the focus of most disclosure studies have been on the patterns of disclosure (Kallem et al., 2011) as well as the barriers to HIV status disclosure in children (Gyamfi et al., 2015) and not necessarily the impact of disclosure. In some of the studies reviewed above, researchers acknowledged the paucity of data on the subject of pediatric disclosure and indicated the need for more research in the field (Nichols et al., 2017; Odiachi, 2017; Ofori-Atta et al., 2019).

Secondly, studies that have been conducted on the subject of pediatric disclosure, particularly those reviewed above have some methodological flaws and limitations. For instance, some of the quantitative studies reviewed above had sample sizes as small as 25 and 40 (Nichols et al., 2017; Odiachi, 2017). In addition, few studies used standardized measures to test for the variables under study. For instance, antiretroviral adherence was determined using methods such as pill count and child report (Nichols et al., 2017) whereas the perceived benefits of disclosure such as psychological health were measured using open-ended questions instead of structured questionnaires with good psychometric properties (Gyamfi et al., 2015).

Similarly, most of the qualitative studies have focused generally on the experiences of caregivers of children living with HIV/AIDS and have not explored in particular the experiences of disclosure and its impact of the health of caregivers who play an important role in the wellbeing of children with HIV (Asadullah et al., 2017; Osafo et al., 2017). In the context of these gaps in the literature, the present study was therefore conducted to explore the experiences of caregivers on HIV status disclosure to children and to further examine the influence of disclosure on the health outcomes of both children with HIV and their caregivers using an exploratory sequential mixed method.

2. 5 Research Questions

The following research questions were formulated and explored in the qualitative study

1. What factors promote disclosure and non-disclosure in caregivers of children living with HIV?
2. How do caregivers go about children’s HIV status disclosure?
3. What changes does HIV status disclosure bring in children living with HIV?
4. How does HIV status disclosure affect caregivers health and their caregiving experiences?

2.6 Hypotheses

Based on the literature reviewed above, the following hypotheses were tested for the quantitative study:

1. Children whose HIV status have been disclosed will report better antiretroviral adherence than those children whose HIV status have not been disclosed.

2. Children whose HIV status have been disclosed will report better psychological wellbeing outcomes than those children whose HIV status have not been disclosed.
3. Caregivers who have disclosed the HIV status of their children will have better psychological health than caregivers who have not disclosed.
4. Caregivers who have disclosed the HIV status of their children will have lesser caregiver burden than caregivers who have not disclosed.
5. The duration of disclosure will mediate the relationship between disclosure and antiretroviral adherence of children living with HIV.
6. The duration of disclosure will mediate the relationship between disclosure and psychological health of children living with HIV.
7. Age will predict disclosure of status in children living with HIV.

2.7 Hypothesized Conceptual Model

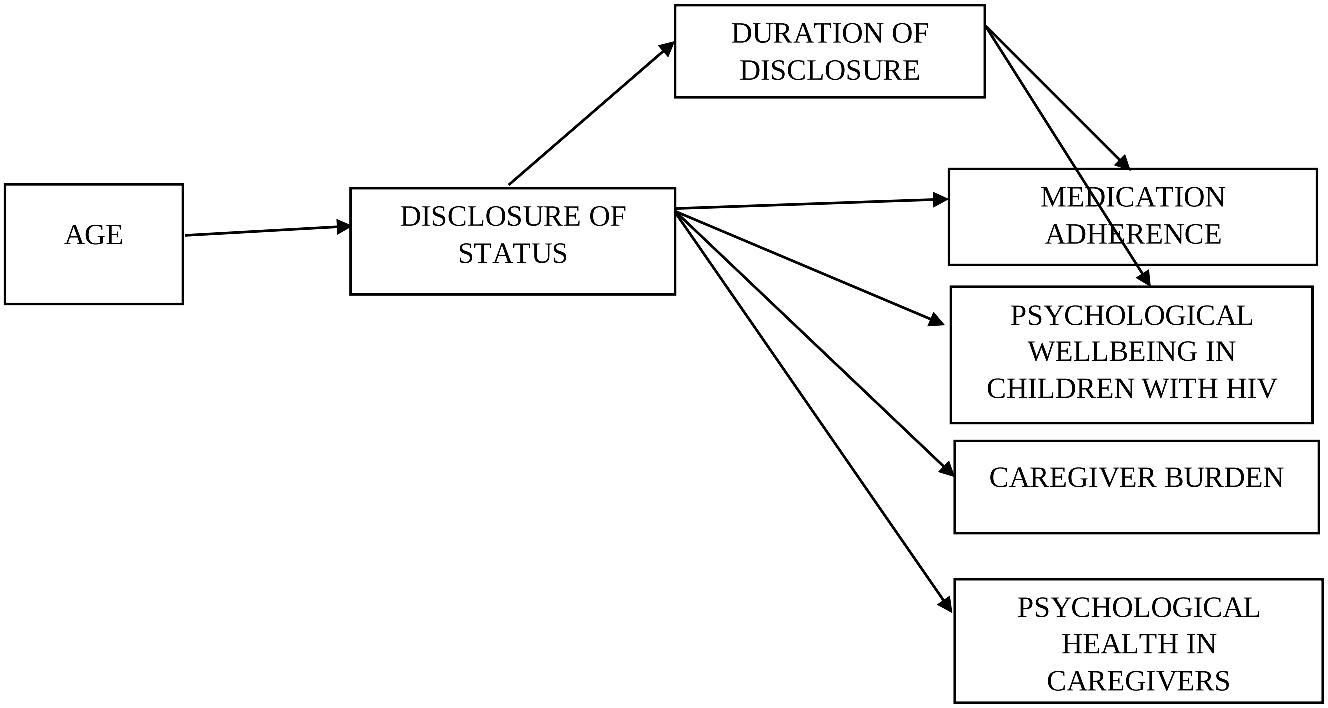

Figure 1. Diagram showing the hypothesized relationships between the variables under study.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter describes the methods used in gathering data, including the research design and setting, population and sample determination, sampling techniques, inclusion and exclusion criteria, ethical considerations, instruments or measures, the procedure for gathering the research data and methods of data analysis.

3.2 Research design

The research design used in this study was a mixed-method design where both qualitative and quantitative data were collected. Specifically, an exploratory sequential mixed method was used to achieve the objectives of this study. In this type of mixed-method design, the qualitative data is collected first and analyzed followed by quantitative data. According to Creswell (2014), the intent or purpose of using this mixed-method design is for the quantitative data to build on the results of the qualitative data. The justification for using this method is that this field of inquiry is relatively new, unexplored in Ghana and very few studies have been conducted in this area (Gyamfi et al., 2015, 2017; Ofori-Atta et al., 2019). As such, there is the need to first explore qualitatively the views and experiences of caregivers on disclosure of status which would then inform the quantitative phase of the study in addition to findings from existing literature. According to Andrew and Halcomb (2009), the quantitative component of an exploratory sequential mixed method is not only informed by the findings of the qualitative but also from preexisting literature. It therefore allows to a large extent, not only the inclusion of previous literature but also the active participation of population under study in refining study instruments or measures and hence increasing the ecological validity of these instruments or measures.

3.3 Research Setting

This study was set in the Greater Accra Region of Ghana, specifically in four main hospitals namely; the Greater Accra Regional Hospital (Ridge), the Princess Marie Louise Children's Hospital (PML), Tema General Hospital and the Korle Bu Teaching Hospital. The Greater Accra Region was selected as the setting for the study because it is the most urbanized, cosmopolitan and densely populated region in Ghana with dwellers and settlers from all the other regions of Ghana and beyond. The region has a total land area of 3,245 square kilometers with a population of 4,010,054 representing 16.3% of the total Ghanaian population (Ghana Statistical Service, 2010). Although it is one of the smallest out of the 16 administrative regions of Ghana and in terms of land area, it has 16 districts comprising two (2) metropolitan assemblies, nine (9) municipal assemblies, and five (5) district assemblies respectively (Local Government Service, 2015). The region is also home to over 80 government health facilities that provide health care services to the inhabitants of the region in addition to other privately owned facilities (Ghana Hospitals, 2012).

The Greater Accra Regional Hospital formerly called Ridge Regional Hospital is located at North Ridge in the Osu-Klottey Sub-Metro of the Accra Metropolis in the Greater Accra Region. As the regional hospital, its catchment area is the whole of the Greater Accra Region. With its recent redevelopment and transformation into an ultra-modern 620-bed capacity hospital, the hospital provides services including Outpatient Services, Accident & Emergency Services, Surgery and Endoscopy Services, Burns and Reconstructive Services, Mental Health Services, Clinical Psychology Services, and Child Health Services among others. The Child Health department provides health care services to children below the age of 18 including children with HIV who have special clinic days.

The Princess Marie Louise Children's Hospital is located within the Ashiedu Keteke sub-metro of the Accra Metropolis in the Greater Accra Region. It is the first-ever children's hospital in Ghana and was established to meet the needs of maternal and child health care delivery. The facility which has been in existence for over 90 years attends to children from ages 1day to 18yrs old. It provides medical care, child health services and nutrition services to these children as well as family planning services for mothers. The hospital also provides specialized medical care for children living with HIV as well as their caregivers and have special clinic days for them.

The Korle Bu Teaching Hospital (KBTH) is located within the Accra Metropolis. It is the largest referral unit in the Accra Metropolis. Specifically, the study was conducted at the Child Health Department of the Korle Bu Teaching Hospital. The Child Health Department is a tertiary referral center for children under 13 years with both medical and surgical problems. It has over 36, 000 outpatient attendance per year and it provides specialist care for referred medical and surgical cases and runs special clinics including Neurodevelopmental Clinic, Asthma Clinic, Diabetes & Endocrine Clinic, Cardiac Clinic and HIV Clinic for both children and adults, Sickle Cell Clinic, and Neonatal follow up clinic.

The Tema General Hospital is the largest government health facility within the industrial hub of the country, the Tema Metropolis. The hospital runs 24-hour general and specialist healthcare services including Outpatient Services, Accidents, Emergency and Surgery Services, Dental services, Pediatric or Child Health Services as well as Special Clinics for ENT and children and adults living with HIV.

3.4 Population, Sample and Sample Determination

The target population for the study was children living with HIV between the ages of 6 to 15 years who are receiving antiretroviral treatment at any of the health facilities described above and their caregivers. This population was selected because first of all, the facilities are located in the two cosmopolitan districts in the region, that is, the Accra and Tema metropolis. Hence participants recruited from these facilities reflected the diverse cultural, social and educational backgrounds across the region. Secondly, other studies have focused mainly on older children and adolescents between the ages of 15 and 19 (Nichols et al., 2017). The Ghana AIDS Commission reported that as of 2017, an estimated total of 28, 203 children below the age of 15 years were living with HIV/AIDS in Ghana with 6,626 of these children residing in the Greater Accra Region (Ghana AIDS Commission, 2017). Nonetheless, this population is hard to reach because of the stigma attached to the condition and so they could only be accessed through the hospitals where they attend special antiretroviral clinics.

A total of fifteen (15) caregivers were purposively sampled from three of the hospitals described above and engaged in a one on one in-depth interview on their views and opinions about the disclosure of status to children living with HIV. Eight (8) were recruited from the Princess Marie Louise Children's Hospital (PML), three (3) from Ridge Hospital and four (4) from the Tema General Hospital. According to Guest, Bunce, and Johnson (2006), a minimum of 12 in-depth interviews and above are enough to reach saturation and generate codes and themes in a qualitative study. The age of the caregivers interviewed ranged from 27 to 55 years [*Mean (SD)]*= [41years (6.23)] and the ages of the caregivers' children ranged from 6 to 15 years [*Mean (SD)]* = [10.2 years (2.88)]. Eleven (11) of the caregivers were females (73.33%). Table 3.1 below gives a summary of the participants interviewed.

Table 3.1 Demographic Characteristics of Participants Interviewed

Participants	Age	Sex	Age of Child	Residence	Occupation	Religion
P1	47	F	10	Korle- Bu	Trader	Christian
P2	34	F	6	Ashaiman	Sales Coordinator	Christian
P3	27	F	6	Newtown	Trader	Islam
P4	38	F	10	Sukura	None	Islam
P5	40	F	10	Mataheko	Food Vendor	Christian
P6	40	M	6	Ablekuma	Engineer	Christian
P7	41	F	7	Awoshie	Trader	Christian
P8	38	F	11	Ablekuma	Trader	Christian
P9	39	F	10	Nima	None	Islam
P10	46	F	11	Kanda	Trader	Christian
P11	42	F	12	Kasoa	Cleaner	Christian
P12	55	M	15	Taifa	Teacher	Christian
P13	45	M	14	Mamprobi	Mason	Christian
P14	42	F	12	Sakumono	Trader	Christian
P15	41	M	13	Odorkor	Electrician	Christian

For the quantitative study, one hundred and fifty-five (155) children living with HIV/AIDS between the ages of 6 to 15 years and their caregivers were purposively sampled from the hospitals described above. They were administered caregiver-child dyads that measured disclosure, psychological health, and caregiver burden in the caregivers and psychological wellbeing and medication adherence in the children respectively.

The sample size was determined using the G*Power sample size calculation software version 3.1.9.4. (Faul, Erdfelder, Lang, & Buchner, 2007). To ascertain the required sample size for this study, an a priori power analysis computation was performed using an alpha of 0.05 an acceptable power of .95, and a medium effect size of 0.15 as suggested by Cohen (1988;1992).

Other input parameters used in the calculation included the number of groups, number of response or dependent variables and number of predictors. In this study, there was one predictor variable (disclosure), two groups (children who have been told their HIV status and those who have not been told) and four dependent variables (adherence, psychological wellbeing, caregiver burden, and psychological health). The outcome analysis estimated that a required total of 129 participants were adequate to accept the alternative hypotheses and reject the null hypotheses. One hundred and fifty-five (155) children living with HIV aged between 6 and 15 years and their caregivers were eventually included as the final sample for the quantitative study.

3.5 Inclusion Criteria

Participants who met the following inclusion criteria were recruited in the study:

i. A child living with HIV/AIDS between the ages of 6 and 15years
ii. A caregiver of a child between ages 6 and 15 years
iii. The child attends HIV clinic at either the Korle Bu Teaching Hospital, Ridge Hospital, Tema General Hospital or the Princess Marie Louise Children's Hospital.
iv. The child has been enrolled on antiretroviral therapy for at least six months.

3.6 Sampling Technique

Participants of the study, that is, children living with HIV and their caregivers were sampled using the purposive and convenient sampling techniques, which are types of non-probability sampling. In purposive sampling, there is a thoughtful and intentional choice of a participant because of the characteristics the participant holds (Etikan, 2016). The researcher selects the study area to be investigated and embarks to discover individuals who can and are eager to give the needed information by virtue of their experience and knowledge about the topic under study (Palinkas et al., 2016). This technique was chosen because only caregivers of children living with HIV and the children themselves were proficient enough and well informed about the issues that the research sought to address. Sampling was also convenient in nature because only participants who were easily accessible and available at the special HIV clinics at the time of the data collection, and who expressed their willingness to participate were included in the study.

3.7 Materials

3.7.1 Interview Guide

A semi-structured interview guide comprising open-ended question was used to explore the experiences of caregivers of children living with HIV/AIDS on disclosure of status. It comprised two sections; a demographic section which obtained the demographic information of caregivers and their children and the interview guide section (see Appendix F). There were seven questions on the interview guide with each question having at least three probe questions. The interview questions focused on whether or not caregivers had disclosed the status of their children to them, how this had affected the children's health and medication adherence, reasons for non-disclosure and disclosure, and the problems or challenges caregivers encounter taking care of these children.

3.7.2 Measures

Demographic Questionnaire

A demographic questionnaire was developed and included in the instruments or measures for the data collection. The questionnaire aimed at obtaining relevant demographic information from both caregivers and children living with HIV/AIDS such as their age, gender/sex, level of education, caregiver's relationship with the child, disclosure of status and how long disclosure has been made (See Appendix E).

AMPATH Disclosure Questionnaire

Disclosure of HIV status in children was measured using the USAID-Academic Model Providing Access to Healthcare (AMPATH) disclosure questionnaire (Vreeman et al., 2014). This questionnaire assesses disclosure of HIV status in caregivers of children living with HIV/AIDS as well as to measure antiretroviral adherence, stigma, and depression experienced by children. The questionnaire consists of 15 items to which caregivers are to respond "Yes" or "No". The first four items which measure disclosure of HIV status in caregivers of children living with HIV was adopted for this study. Full disclosure is said to have been made if the caregivers responded "Yes" to all four items. Non-disclosure is said to have occurred if caregivers respond "No" to any of the four items (See Appendix E).

Medication Adherence Rating Scale (MARS)

This scale was developed by Thompson, Kulkarni, and Sergejew (2000) as a measure of medication adherence among schizophrenia patients. It is a ten (10) item questionnaire that assesses three different aspects or dimensions of adherence namely medication adherence behavior (items 1-4), attitude toward taking medication (items 5-8) and negative side effects and attitudes to psychotropic medication (9-10). Each item has a response option of "Yes" scored as "0" and "No" scored as "1". Items 7 and 8 are reverse scored, meaning a "Yes" response is scored (1) and "No" is scored (0) (See Appendix E). Total item score ranges from 0-10 with a higher score indicating better adherence and lower scores indicating poor adherence. An initial Cronbach alpha of .75 has been reported (Thompson et al., 2000) and a recent alpha of .77 (Owie, Olotu, & James, 2018). The questionnaire has been used to assess medication adherence in other chronic conditions including asthma (Nagakumar et al., 2014). In this study, the scale yielded a Cronbach alpha of .69. Although this is less than the acceptable value of .70, it is common for scales with fewer items (usually 10 items or less) to yield Cronbach alphas less than .70 (Pallant, 2016) in which case it is appropriate to check the mean inter item correlations of the items.

Stirling Children's Well-being Scale

This scale assesses or measures emotional and psychological wellbeing in children of 6 to 15 years (Liddle & Carter, 2015). Developed by the Stirling Council Educational Psychology Service (UK), the scale was put together in the quest to have an all-inclusive and positively worded measure of emotional and psychological well-being in children rather than that which focused on mental illnesses. It is a 15 item scale on a 5 point Likert scale ranging from 1 (Never) to 5 (All of the time) (See Appendix E). The questionnaire has two subscales namely "positive emotional state" and "positive outlook" all comprising 6 items each, and 3 social desirability indicator items which are not included in computing the total scores. In this study, the total scale score was used instead of the subscale scores. Scores for each of 12 items were summed to arrive at a total score ranging from 12 to 60 with higher scores indicating higher psychological wellbeing in children. The scale has an initial Cronbach alpha of .85 (Liddle & Carter, 2015) and has recently been adapted in Bangladesh with a Cronbach alpha of .75 (Haque & Imran, 2016). The scale yielded a Cronbach alpha of .86 in the current study.

Zarit Burden Interview

This questionnaire was used to measure self-reported caregiver burden among caregivers of children living with HIV. It assessed the stresses experienced by caregivers of children living with HIV and the impact of the children's ill health on their lives. It was developed by Zarit, Reever, and Bach-Peterson (1980) and comprises 22 items to which caregivers responded to on a 5 point Likert scale ranging from 0 (Never) to 4 (Nearly Always) (See Appendix E). The questionnaire is scored by summing up the responses of the individual items. Total scores range from 0 to 88 with higher scores indicating greater caregiver distress or burden. It has good internal consistency reliability indexed by an alpha of .92 (Hébert, Bravo, & Préville, 2000). In this study, the reliability of the Zarit Burden Interview was .81.

General Health Questionnaire- 28 (GHQ-28)

Caregivers' psychological health was measured using the General Health Questionnaire-28 (Goldberg & Hillier, 1979). It is a screening tool that measures emotional distress and psychological problems in individuals in medical settings or detects those likely to be at risk of developing psychological disorders. The questionnaire has four subscales which measure somatic symptoms (items 1 to 7), anxiety and insomnia (items 8 to14), social dysfunction (items 15 to 21) and severe depression (items 21 to 28) (See Appendix E). Each item is scored on a 4 point Likert scale from 0 (Not at all) to 3 (Much more than usual) with total scores ranging from 0 to 84. A total score of 24 is a threshold for the presence of psychological distress. The scale has reliability as indexed by a Cronbach alpha of .95 (Sterling, 2011) and .83 in the present study. The psychometric properties of the measures used in this study are presented in Table 1 below.

Table 3.2 Summary of Descriptive Statistics, Normality and Cronbach Alpha of the Various Measures (N=155)

	N	Min	Max	M	SD	A	Skewness	Kurtosis
Disclosure of Child's HIV Status	155	1	2	1.66	.474	N/A	-.70	-1.53
MARS	155	2	10	5.75	1.906	.69	.42	-.43
SCWBS	154	23	53	37.14	7.095	.85	.54	-.60
ZBI	143	8	71	32.82	12.119	.83	.48	.03
GHQ	147	6	73	23.15	10.534	.84	1.19	2.78

α = Cronbach alpha; MARS = Medication Adherence Rating Scale; SCWB =Stirling Child Wellbeing Scale; ZBI = Zarit Burden Interview, GHQ= General Health Questionnaire.

3.8 Pilot Testing

According to In (2017), a pilot study is an important and first step in an entire research process. It is usually a smaller-sized study which assists the researcher in testing adequacy of research instruments or tools assessing the viability of the main study and allows for the planning and modification of the main study among others (Van Teijlingen, Rennie, Hundley, & Graham, 2001). Before collecting the qualitative data, three pilot interviews were conducted to ascertain the effectiveness of the interview questions in capturing the relevant information or data for the study. Given the difficulties encountered by the researcher in explaining some aspects of the interview questions during the pilot interviews, a translator was engaged to translate the interview guide into Twi which is widely spoken across the region to allow participants understand the questions being asked and respond appropriately.

The measures used in the quantitative data collection were also pilot tested to check how reliable and comprehensible they were. A total of 35 caregivers of children with HIV and their children were purposively sampled from three of the research settings (PML Hospital, Ridge Hospital, and Tema General Hospital) for the pilot study. The outcome of the pilot study analysis indicated that participants understood the items on the questionnaire. Overall, the research instrument captured the relevant information related to medication adherence and psychological wellbeing in children living with HIV as well as caregiver burden and psychological health in caregivers of children living with HIV. Notwithstanding the small sample size for the pilot study, the findings suggested that the measures tested would be reliable in a larger sample.

Of the 35 caregiver-child dyads administered, approximately 91% of the caregivers were females, while 63% of the children were males. All questionnaires used in the pilot study demonstrated acceptable Cronbach alphas of .70 and above in exception of the Medication Adherence Rating Scale. The Stirling Child Wellbeing Scale had an alpha of .91, Zarit Burden

Interview had .79, General Health Questionnaire, .79, and the Medication Adherence Rating Scale, .50. Although medication adherence had an alpha of less the acceptable.70, Cronbach alphas can vary depending on the sample size (Pallant, 2016). Usually smaller sample sizes yield Cronbach alphas less than .70 and hence the questionnaire was still used in the main study given that sample size would be larger.

Based on these findings, the following modifications and decisions were made: It was decided that the caregiver-child dyads be administered to the participant by the researcher especially those who could not read and understand the English Language. This was due to the fact that most of the participants had a low educational background. About 60% of the participants included in the pilot study had either no or just primary education. Majority of participants indicated they would be able to understand and express themselves in the Akan language than the English language. Hence, the questionnaire items were translated into Akan after the pilot study and this afforded the participants to better understand and respond appropriately on the scale items in the main study.

3. 9 Procedure for Data Collection

Ethics approval was received from the Institutional Review Board of the College of Humanities, the University of Ghana through the Department of Psychology (ECH:008/18-19). Approval was also received from the Greater Accra Regional Directorate of Ghana Health Services (GHS/GARHD/007/19) to allow data to be collected in their facilities. Further ethical clearance was received from the Korle Bu Teaching Hospital’s Scientific and Technical Committee (KBTH/MD/G3/19) as well as their Institutional Review Board.

The research settings were visited a couple of times by the researcher to familiarize with the setting and staff of the facilities and also to ascertain how a typical clinic day looks like before data collection began. Caregivers attending antiretroviral clinics with their children in each of the hospitals were approached and the purpose, benefits and potential risks of the study were explained to them. Confidentiality, anonymity, and freedom to voluntarily withdraw were assured participants (American Psychological Association, 2010). Those who willingly agreed and had duly signed the consent forms were allowed to take part in the research. The interviews were then conducted and were audiotaped or recorded with the permission of the participant. The interviews took place at the counseling units of each of the hospitals and were either conducted in English or in Twi based on the participant's preference. The interview sessions spanned between 25 to 30 minutes using the interview guide. Each participant was given a transport reimbursement of GH¢20. 00 after the interview session. The qualitative data collection took place between 15th March and 31st March 2019.

The quantitative data collection begun after the qualitative results were transcribed and analyzed. Each of the hospitals described above was visited weekly on their specified clinic days from April to May 2019. All relevant information about the study was explained to the participants. After participants had signed the consent forms, items on the questionnaires were read out and response options given for participants to respond appropriately as the majority of the caregivers could not speak, read and understand English. A translated Akan version of the research questionnaire was therefore administered to them through the help of a trained research assistant. Those who were fluent and could read and write and were given the questionnaires to complete themselves. It took 15 to 20 minutes to complete each questionnaire. Caregivers did not receive any compensation for completing the questionnaires, however, each child was given tokens of pens, pencils, and erasers.

3.10 Ethical Considerations

The study received ethical approval from three institutions: The Ethics Committee for the Humanities, University of Ghana, Greater Accra Regional Directorate of Ghana Health Services and the Korle Bu Teaching Hospital Institutional Review Board. The aims, benefits and other relevant information about the study were explained to prospective participants and only those who were willing and consented were allowed to take part in the research. Permission was sought to audio record interview sessions. It was made known to all who consented to take part in the study that all information gathered would be used solely for the purpose of this research. Participants were assured of confidentiality and anonymity of all information given. They were also made aware of the voluntary nature of the study and the freedom to withdraw from the study at any time. By signing the consent forms, caregivers gave consent for themselves and their children to take part in the study. The children were below the age of 18 years and could not legally or ethically consent to take part in the study, hence the need for parental consent in compliance with the APA code of ethics in research (American Psychological Association, 2010).

3. 11 Data Analysis

3.11.1 Thematic Analysis

Thematic content analysis was used to analyze the qualitative data (Braun & Clarke, 2013, 2006; Maguire & Delahunt, 2017). According to Braun amd Clarke (2006), there are six (6) basic steps in doing thematic analysis. This includes; familiarizing yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. To help the researcher familiarize with the data, the transcript was read and re-read several times to allow her to be conversant with the entire data. Coding was then done which involved organizing the data into meaningful small chunks with labels. Themes were then searched for by looking for patterns in the codes generated that were significant or interesting to the researcher. The themes were then modified, reviewed, and defined, after which the final report was produced.

Trustworthiness of Data

Connelly (2016) explains a study's trustworthiness as the level of trust in the information, analysis, and techniques used in a qualitative study. According to Shenton (2004), there are four main ways of ensuring trustworthiness in qualitative studies. These include credibility, transferability, dependability, and confirmability.

Credibility relates to the confidence in the study's veracity. It responds to the issue of whether or not the study measures what is actually intended (Conelly, 2016; Shenton, 2004). Iterative questioning was used to ensure credibility by probe questions which ensured that data collected was comprehensive. Also, peer and academic review of the results made it possible to challenge certain assumptions that helped shape and redefine the results. Transferability, on the other hand, relates to the extent to which a study's results can be applied to other circumstances (Conelly, 2016; Shenton, 2004). To guarantee this, the context, place, and individuals researched were comprehensively described. Also, a thorough description of the method of collection and the duration of the data collection was given to allow the results to be understood in the context of the participants, organizations and geographical area where it was carried out.

Confirmability refers to how objective a study's findings are, while dependability relates to comparable outcomes if the study is repeated (Conelly,2016; Shenton, 2004). Detailed notes of all activities, decisions, and analyses during the research process were kept to ensure that the findings of this study reflect participants' experiences and opinions rather than researcher biases.

3.11.2 Quantitative Analysis

Quantitative data was coded and entered into the Statistical Package for the Social Sciences (IBM SPSS) version 23 for further analysis. The data was first cleaned of duplicates and errors by running frequency and descriptive statistics for each item on the questionnaire. This was to ensure that all entries were within the range of possible scores on an item (Pallant, 2016). Errors detected in the coding and entering of data were then cross-checked from the respective questionnaires and corrected. Items that needed to be reverse scored were then recoded. Descriptive statistics or analysis were then run for the data to describe the characteristics of participants before further analysis was carried out.

Preliminary Analysis

Preliminary analyses started with an examination for missing values in the data set. Using Little's MCAR test in SPSS, the result was not significant (p = .10). According to Tabachnick and Fidell (2013), a non-significant MCAR test shows that the likelihood that the pattern of missing diverges from randomness is greater than .05, hence it can be assumed that data were missing completely at random. As such, the missing data did not create any serious risk for further analysis. The "exclude cases pairwise" option was therefore used to tackle missing data (Pallant, 2016).

An important assumption underlying most parametric tests and multivariate analysis (in this case, MANOVA and Regression) is the assumption of multivariate normality which states that each variable and all linear combinations of the variables are normally distributed. Two measures of normality namely Skewness and Kurtosis were computed for each of the variables in the data set. All variables were within the range of -2 and +2 for skewness and -7 and +7 for kurtosis, indicating that scores on the variables were normally distributed (Byrne, 2013; Hair, Black, & Babin, 2010). Also, the reliabilities of the scales used were tested using Cronbach's reliability analysis.

According to Pallant (2016), a scale is considered reliable if its reliability coefficient is above .70. As shown in Table 3.2 above, all the Cronbach's alpha values were above .70 except the medication adherence questionnaire (α= .69) which was very close to the acceptable value.

Hypothesis Testing

Hypotheses one and two were tested simultaneously using multivariate analysis of variance (MANOVA). It was done in a bid to avoid using multiple independent sample t-tests and hence reducing the risk of an inflated type 1 error as suggested by Pallant (2016). Hypothesis three and four were also tested using multivariate analysis of variance. Hypotheses five and six were tested using the PROCESS macro version 3.3 created by Hayes (2012). PROCESS is a computational tool designed to simply examine moderation, mediation, and conditional process modeling. It is an easily downloadable file that can be installed in SPSS and SAS. In accordance with Hayes (2009) recommendation, bootstrapping was set at 5,000 bootstrap samples and confidence interval at 95% to ensure a more valid and robust testing procedure for mediating effects in the present study. All assumptions such as linearity, normality, multicollinearity, and singularity were checked prior to conducting the analysis and none were significantly violated. Hypothesis seven (7) was tested using hierarchical linear regression. The results of the study are presented in the next chapter.

CHAPTER FOUR

RESULTS

4.1 Introduction

This study was conducted in two phases; the qualitative study was the first phase and the second was the quantitative study. This chapter presents the findings or results from both the qualitative and quantitative studies. The analyses of the qualitative are presented first followed by that of the quantitative study. The qualitative results are discussed in themes and sub-themes followed the quantitative results which state whether each of the hypotheses stated was supported or not with detailed presentations of tables and their interpretations.

4.2 Qualitative Results

This section presents the results from the in-depth interviews conducted with the caregivers of children living with HIV. It covers the themes and subthemes generated from the analysis of the transcripts. The results of this section will be discussed in four thematic areas. For each theme, there are subthemes which capture the significant voices reflecting the views or experiences of caregivers of children living with HIV on disclosure of status and its impact on health outcomes in these children. To avoid giving out participants' identity and as a means of ensuring the anonymity of participants' responses, alphanumeric codes were used to identify the participants e.g. P1 representing Participant 1 (see Table 3.1 above). The table below gives a summary of the themes and their corresponding subthemes:

Table 4.1. Summary of themes and subthemes.

Theme	Sub-theme
The Diagnosis of HIV in Children	Reactions to the diagnosis of child's HIV status
	Testing of caregivers
Nuances in Disclosure	Forms of disclosure
	Reasons for non-disclosure
	Reasons for disclosure and disclosure process
Disclosure and Health Outcomes	Emotional reactions to the disclosure of HIV status
	Medication adherence in children with HIV
	Improved physical health due to ART treatment
	Anxiety reduction in caregivers
Challenges and Support Systems for Caregivers	Inadequate finances for caregivers
	Anxieties about lifelong medication adherence
	Psychological distress and burden in caregivers
	Support from religion and spouses

4.2.1 The Diagnosis of HIV in Children

This theme captures how caregivers became aware of the HIV status of their children and how they reacted to the news of the diagnosis. The narratives of all participants point out that the children's frequent illness and hospitalization were some of the reasons that led to the suspicion that something was wrong with the children. The narratives also indicated that the diagnosis of HIV in the children led to the awareness of the HIV status of most of the caregivers. Two sub-themes formed this theme and are discussed below namely; Reactions to the diagnosis of child's HIV status and Testing of caregivers.

Reactions to the Diagnosis of child's HIV status

Majority of the caregivers stated that they found out about the children's status when they were very young and were falling ill frequently which led to hospitalization most of the times. The quotes below illustrate this:

> *"When I got to know, the child was like about four months old. Now she is ten years old. When I gave birth to her, after three months, I noticed that she was getting ill very frequently, so I gave her some medicines and later took her to the hospital. So, they made us do a lot of tests and they found that the child had a disease like this"* [P9, Female, 39years, 10-year-old Daughter]

> *"He was getting sick often. Something little then he will get sick. Today he is sick, tomorrow he is sick. So I took him to Iran Clinic. So they did a lot of lab tests but they said they didn't see anything. So, later on, I said, let us come here. So when we came, they did the HIV test for us and they saw that he had the disease"* [P3. Female, 27 years, 6-year-old Son]

> *Hmm….. Now he is getting to 7 years …when I first got to know he was almost getting to 2 years. When I gave birth to him and he was very small, I noticed that anytime he sleeps, his legs shake or tremble… He became seriously sick and I brought him here to this hospital. When we came here, they kept us at rehab. That was when I got to know.* [P7, Female, 41 years, 7-year-old Son]

From the quotes above, it is obvious that the caregivers noticed some health problems in their children as early as four months and two years and in the quest to access cure for these health problems found that their children had HIV. Without the children falling ill frequently, perhaps these caregivers may not have discovered this diagnosis.

The news of the diagnosis of HIV in these children obviously elicited a lot of intense emotional reactions from the caregivers. The narratives show that almost all the caregivers expressed deep sadness upon hearing the news. Others were saddened and lost hope to the point where they contemplated thoughts of suicide while some expressed deep shock and surprise as reported below.

> *"I was so terrified. It was left with something small like I would have killed myself"* [P1, Female, 47 years, 10-year-old Daughter]

> *"For that one, it wasn't easy. It wasn't easy at all. My heart….if I had pressure or hypertension, it would have come …"* [P2, Female, 34 years, 6-year-old Son]

> *"It wasn't that easy. I felt so bad. I went through a lot of challenges and I thought hmmm (chuckles)…my end had come because of something like this…. So maybe when I die then everything will end"* [P9, Female, 39 years, 10-year-old Daughter]

> *I was surprised but it had happened to me already… I cried so much, I was very sad.* [P7, Female, 41 years, 7-year-old Son].

From the narratives above, it can be seen that the diagnosis of HIV in these children had a toll on caregivers as they did not take the news very lightly. Some were plunged to a state of despair, sorrow, shock, and hopelessness at the news of the diagnosis. It also indicates that caregivers went through very challenging times when they were told about the children's diagnosis. These reactions are not out of the norm as they are typical to the diagnosis of many chronic and incurable diseases like HIV/AIDS.

Although caregivers expressed these deep emotional reactions to the news of the diagnosis, the words of encouragement, education, and support from the counseling departments at the various hospitals helped the situation, particularly for those contemplating suicide. As reported:

> *"It was through teachings and counseling that made me stay but up till now, I feel sad and bad for me and my child…"* [P1, Female, 47 years, 10-year-old Daughter]

> "*… through constant talking and other things….like the education, how it's ongoing, I got to know that it is not something that can kill you. Even someone with malaria can die, so it's not the only thing that can kill someone…"* [P2, Female, 34 years, 6-year-old Son].

Counseling played an important role in helping newly diagnosed patients maintain some emotional balance even after the disclosure of their HIV status or that of their children. The counselors help educate patients and their relatives to understand what the condition was as well as clear some of the myths and erroneous impressions about being diagnosed with HIV.

> *"…..I thought there was no medication or treatment for it…ehee that's how I saw it….But it was later that I found that there is a treatment for it so I started coming for the medication for her*" [P9, Female, 39 years, 10-year-old Daughter]

> *"Because at first, how the thing was, I knew there was no medication to treat it. So when they mentioned the name of the disease I was terrified. I thought so much about it that I even wanted to kill myself. But when I came to the hospital, they told me there are drugs for it and my child can be normal"* [P3, Female, 27years, 6-year-old Son]

The narratives above indicated that these caregivers were ignorant of the fact that there is treatment for HIV. However, through counseling and education from the health professionals, the misconceptions these two caregivers had about HIV were cleared hence they were able to start antiretroviral therapy for themselves and their children.

Testing of Caregivers

Another interesting issue that emanated from the narratives of the caregivers was the fact that a majority of them were unaware of their HIV status until their children were tested and diagnosed. The narratives showed that there was further testing on caregivers and other family members after the children were diagnosed. As such, the diagnosis of the children led to the diagnosis of caregivers and other family members. Almost all caregivers who were the biological parents of the children involved tested positive, indicating that, most of these children were infected perinatally (that is, from mother to child). Therefore, these caregivers started treatment about the same time as their children. Below illustrated this;

> *"… when I was pregnant, they didn't tell me anything. So he was 3 years almost getting to four years when we got to know…… It was my sister that noticed it and took him to the hospital before they did that test and they told her. So when she called me, then I closed my shop, it was late in the afternoon that I went there. But I said the way it is, then let's all go and get tested. And when they did for him and me, they found that we all had it. Then I said his father should also come and get tested. So the three of us have it but his older brother doesn't have it"* [P3, Female, 27 years, 6-year-old Son]

> *"Me, I can say from my side that if I didn't get the disease through my delivery, the operation or surgical knives then it will be from my husband because my pregnancy was normal. I attended antenatal, did all the lab tests but I wasn't told of anything like this until my child was diagnosed"* [P1, Female, 47 years, 10-year-old Daughter]

These narratives above indicate that these caregivers were not infected at the time of pregnancy as they stated going through antenatal testing successfully. This could be an indication that these children were infected through other means of mother to child transmissions like childbirth or breastfeeding other than pregnancy.

One caregiver, on the other hand, stated full awareness of her status but was unconvinced that she had been infected until her child was also diagnosed with HIV.

> *"When I was pregnant, they told me about it but I wasn't sure, I didn't believe it… Yes, they did, they told me but I didn't believe it. I was afraid of what people would say about me if they find out. It was when my child was diagnosed that I realized it was true*" [P7, Female, 41 years, 7-year-old Son].

This caregiver failed to accept the news of her diagnosis which led to the infection of her child. This failure on her part to accept the diagnosis was due to the fear of stigma or being labelled as HIV positive and the negative impressions that society will have about her if others know about her diagnosis.

4.2.2 Nuances in Disclosure

This theme covers the views, opinions, and experiences of caregivers of children living with HIV on the disclosure of status to their children. Respondents were asked if they had disclosed the HIV status of their children to them and their reasons for either disclosing or not disclosing. They were also asked about the health of their children. Three subthemes are discussed under this theme namely; Forms of disclosure, Reasons for non-disclosure and Reasons for disclosure and disclosure process.

Forms of Disclosure

Three forms of disclosure were observed from the narratives of the caregivers. These are non-disclosure, partial disclosure, and full disclosure. Non-disclosure involves caregivers withholding all information about the children's HIV diagnosis from them. Partial disclosure involves caregivers informing their children that they had other conditions other than HIV while full disclosure, on the other hand, involves caregivers telling their children that they had HIV and that the medications were being taken as a treatment for HIV. Some caregivers reported in their narratives that, they had told their children that they had other conditions including poor metabolism, sickle cell, etc. The extracts below illustrates the point:

> *"….I had to explain to him that there is something wrong with your metabolism so you need to take it to boost it and he said ok"* [P6, Male, 40 years, 6-year-old Son]
>
> *"…I have not told him anything. The only thing I have told him is that he has sickle cell and he will have to take the medications till the time he gets married"* [P8, Female, 38years, 11-year-old Son]
>
> *"No, I have not told him anything about it… Oh hmmm, even if I would tell him, I wouldn't say it's that disease or condition"* [P5, Female, 40years, 10-year-old Son]

From the extracts above, it can be noted that these caregivers were not prepared to give their children full disclosure of their HIV status due to one reason or the other hence the use of partial disclosure or a deflected information to ensure that the children continue taking their medication.

Few caregivers, however, gave full disclosure, that is, they mentioned to their children that they had HIV. Below indicate this;

> *"…hmmm…. I told him that we all have AIDS…that he got infected when he was very young. It was a difficult thing to do but I managed I told him the truth"* [P11, Female, 42 years, 12-year-old Son]

> *"Yes, I have. I told him about a year ago that he has the disease and that is the reason why he is taking the medicines every day"* [P14, Female, 42 years, 12-year-old Son]

It was also evident from the narratives nonetheless that disclosure rate among caregivers of children living with HIV was still low. That is, a greater percentage of the caregivers had not disclosed the status of their children to them. Out of the 15 caregivers interviewed, nine had not disclosed while six had disclosed the status of the children to them. The caregivers gave varying reasons for either disclosing or not disclosing as presented in the next subtheme.

Reasons for Non-disclosure

For most caregivers who have not disclosed the HIV status of their children to them, age and maturity were some of the defining factors for not disclosing. They were of the view that the children were not grown or matured enough to be told about their status. Closely linked to this was the argument by most caregivers that the children did not have the mental capacity to understand what the condition means and its implications, hence the reason for not informing their children about their HIV status. The extracts below captures this point:

> *"For him, the way the mind is, I don't know that…… hmm (chuckles)…. you see he is not grown so…… as for the child, a child of six years, what are you going to tell him that will be…..he has not gotten to the stage that he will understand. If he gets to that stage ahaaaa…. So when he gets to that stage then I can tell him*" [P2, Female, 34 years, 6-year-old Son]

"Mmmm how he is, I don't think he will understand what it is even if I tell him. Maybe it is his siblings that will but for him, he won't" [P7, Female, 41 years, 7-year-old Son]

"*Oh, he is not grown so I don't want to tell him anything. So, I have not explained anything to him and he doesn't know that he has it"* [P8, Female, 38 years, 11-year-old Son]

"Oh, now her mind is not matured, she is young but she takes her medication all the time" [P1, Female, 47 years, 10-year-old Daughter].

From the narratives above, it can be noted that these caregivers were more concerned about how matured or how cognitively prepared the children were to understand their diagnosis hence the reason for non-disclosure.

Other caregivers also expressed uncertainties as to how the children will take the news of the disclosure and therefore have not told them about their status. For instance, below says:

"If I tell him, I don't know how he would take it because he doesn't even know the disease called HIV" [P3, Female, 27 years, 6-year-old Son]

"Hmmm, if I tell him, I can't tell how he would react to it. I am really scared of that, which is why I have not told him. Maybe, he'd get angry at me. I don't know so I want to wait a little" [P5, Female, 40 years, 10-year-old Son]

These caregivers are in a dilemma of how their children would react in case they tell them about the diagnosis. The fear of a child having negative emotional reactions prevented these caregivers from disclosing as seen above.

Another pertinent reason given by a majority of caregivers who had not disclosed the HIV status of their children to them was the fear that the child might divulge the information about their HIV status to others. The caregivers feared that they themselves and their children would be stigmatized or ill-treated by friends, family or the community if the information about the child's status goes out hence the non-disclosure. The extracts below captures this;

> *"Hmmm, you see, she is a child and if you are not careful and you tell her she will be telling people about it. You see this disease, if you are in someone's house and you say you have a condition like that, they will even evict you from the house. They will sack you. So she has not gotten there yet."* [P4, Female, 38 years, 10-year-old Daughter]

> *"You see these children are small. So maybe when he's playing with other kids and he will be talking about it with his friends. When he is about 15 years and his mind is a bit matured then I can tell him but for now, no, I can't tell him anything"* [P5, Female, 40 years, 10-year-old Son]

> *"I have seen that she is very young. She doesn't really have that wisdom, so if I tell her she can take it outside, maybe tell her friends. Her mind is not matured"* [P9, Female, 39 years, 10-year-old Daughter]

From the narratives above, these caregivers did not want outsiders to know about their HIV status. They were afraid of the discriminatory treatments that will be meted out to them should others find out that they have HIV. For instance, caregivers above expressed fear of losing her accommodation should her landlord find out about the child's HIV status.

Again, other caregivers expressed some fear of having to disclose the status of their children to them. Some felt they might not be able to disclose to the children and may require the assistance of the health workers or counselors to do so. The narratives below indicate that;

"…when she grows up, what will I tell her? That it was through this or that that she got the disease? Maybe I will bring her to the counselors to talk to her or tell her about it. [P1, Female, 47years, 10-year-old Daughter]

"…sometimes it pains me that when he's grown up to a point I would have to tell him about it, I don't really think about anything like that one, that I would tell him it's because of this that's why you're on medication" [P5, Female, 40 years, 10 year old Son]

From the narratives above, it can be observed that the main reasons for non-disclosure of HIV status among caregivers are age and maturity, inability to understand what the condition means, fear of children telling others about the diagnosis and fear of being stigmatized for the infection.

Caregivers have enquired the age at which they thought it was appropriate to fully disclose to the children. Most of them mentioned late adolescence as the right time to disclose. Below are some of the excerpts that showed this:

"Until he is grown a little, up to like…..even from the counseling they said until he is about 18 years before you can tell him this" [P2, Female, 34years, 6-year-old Son]

"Oh maybe when she is about 18, her mind will be matured a little so you can tell her that this is what is wrong with you" [P4, Female, 38 years, 10-year-old Daughter]

"Oh, now he is young and I don't want any kind of surprises that would affect him and all that. So I think I'll wait till around maybe 12 or 13 there about, to really tell him what it is" [P6, Male, 40 years, 6-year-old Son]

"..if he is grown up like his older brother who is around 12, then I can tell him. As for the older ones they know everything" [P7, Female, 41 years, 7-year-old Son]

These narratives above indicate that caregivers prefer to disclose during early or late adolescence by which time the children will be a bit matured cognitively enough to understand what HIV infection means and its implications.

Reasons for Disclosure and Disclosure Process

For those caregivers who disclosed, one of the main reason for disclosure was the fact that the children kept enquiring and asking questions about the medications they were taking.

> *"…he was asking questions often. First, he asked why he was taking the medication every day. I couldn't tell him anything. Hmmm…then, later on, he asked if he will ever stop taking it because when his friends get sick and they give them medicines, they stop taking it at a point but his never gets finished. It made me very sad, so I just decided to tell him"* [P10, Female, 46 years, 11-year-old Son]

> *"Hmmm…You know she is a very intelligent girl. It got to a point that she was frequently asking a lot of questions; why we keep going to the hospital for more medicine even though she is strong. Why don't I want people to know she takes the medication and a whole lot. Why we keep our folders in a file while other patients don't. At first, I kept lying about it but hmmmm….its hard [pauses]. I didn't know what to say again so decided to let her know…."* [P13, Male, 45 years, 14-year-old Daughter]

The quotes above showed that as the children age into adolescence, they became more concerned and curious about why they are always on medications and started demanding explanations from their parents which prompted them to eventually tell the children about their diagnosis.

Some caregivers also expressed concern about poor adherence in some children which led to the disclosure of status. Caregivers explained that the children were unwilling to take their medication because they felt that they were strong enough to be taken off the medication. For instance;

> *"At a point, he became fed up with taking the medication. He said they were a lot and he had to take them every blessed day which was tiring. I tried to force him into it but later on, I saw that he was throwing the medicines away. So I came to tell the nurse about it and they advised that he was old enough to be told, so they told him that he had HIV…."* [P12, Male, 55 years, 15-year-old Son]

> *"…he was not taking his medicines again. Sometimes I'd have to talk and shout in the house for so long before he goes to take it. You know…. we live in a compound house, and people are around but he will make me talk so much. He felt that he was strong so he doesn't need the medicine again. I was afraid he will fall sick again so I decided to tell him about it"* [P15, Male, 41years, 13-year-old Son]

The narratives show because the children felt strong and fit, they were reluctant to adhere to or continue taking the medications as they did not see the need to continue the medications. Given the repercussions this can have on their health, caregivers decided to disclose to ensure that they understand why they have to continue the medications despite being fit physically.

Other caregivers waited till their children were about transitioning to senior high school before disclosure was made to them. According to the caregivers, because the children were going to boarding school and they would not be available to supervise and make sure they take their medicines, disclosure was made. This was done with the aim of making the children understand why they take the medicines and ensure adherence even in school.

> *"Also, she was about going to SS…You know she already complains sometimes about the medicine, so I was afraid that when she goes to secondary school, she will stop taking it. So few weeks after he wrote her paper, I brought her to the hospital and they sat her down and talked to her"* [P10, Female, 46years, 11-year-old Daughter]

> *"I told him after the B.E.C.E. I knew it wouldn't take long before he leaves for boarding. The nurses said he should be a day student, but he liked the boarding, so I decided to let him know that he has the disease. Mmmm…so that was the reason why I told him"* [P14, Female, 42years, 12-year-old Son]

Since the children were moving to high school or boarding school, these caregivers felt they will not always be around to monitor and make sure that the children take their medication. As a way of ensuring that the children take responsibility for their health and continue the medications even in their absence, caregivers had to disclose.

One caregiver, on the other hand, felt the child was old enough to know about the condition. Also was the concern that the child may discover news about the disease through other means like on the internet hence disclosure was made to avert this.

> *"Oh, I just wanted him to know. He is growing and I thought it was right to let him know rather than him finding out elsewhere which I am sure he will not be happy with…ehee… you know the children of today and internet and all that, so I told him about it"* [P11, Female, 42years, 12-year-old Son]

This caregiver felt that it was her duty to inform her child other than the child finding out on her own which may have negative consequences on the child.

Of the six caregivers whose children knew their HIV status, two did the disclosure themselves and four of them brought their children to the counseling unit at the antiretroviral clinics to be disclosed to. The four stated that they did not know how best to go about the process of disclosure.

> *"I did not know what to say…hmmm, I felt it was too difficult for me. So I spoke to the nurses about it and they said ok, they would do it. So we arranged a meeting and I was there before they told him"* [P15, Male, 41years, 13-year-old Son]

> *"I knew that if I wanted to do it, I would cry …so much in the process. I felt the nurses knew more and can explain it better to her than me so the counseling people told her about it…ahaa but I was there when they told him"* [P10, Female, 46years, 11-year-old Daughter]

The narrative above showed that the disclosure process was difficult for caregivers as they did not know how best to go about it for fears of breaking down emotionally in the process. Also, caregivers did not have the needed information to adequately explain the condition to the children hence the need to fall on the health care providers to disclose.

The two caregivers who disclosed however stated they sought some assistance from the health professionals.

> *"I asked one nurse at the clinic how best to go about it because I wanted to tell him myself...I believe that I'm the best person to inform him not anybody outside, so I called him one dawn and told him everything"* [P12, Male, 55 years, 15-year-old Son]

This caregiver was of the view that it was his duty to inform the child about his diagnosis and therefore sought the needed help from the health care professionals in doing so.

Caregivers who disclosed themselves were probed about what exactly they told their children in the process of disclosure. The two caregivers said they mentioned the condition and the treatment options available to manage the condition.

> *"Hmmmm…. I told him he has a disease called HIV/AIDS and that is the reason why he is taking the medicine every day. I also said that for now, the doctors said that there is no medicine that will make it go completely. So he will take the medicine till he dies…that that's what I said"* [P12, Male, 55 years, 15-year-old Son]

> *"I said to her one dawn that…., you have asked me always why you take these medicines. It is because the doctors found when you were small that you have AIDS. They said it is caused by some virus. And the disease cannot be cured but there are medicines you take and be ok. So that's why you are taking the medication and please keep it a secret because when you tell people they will use it insult and laugh at you"* [P13, Male, 45 years, 14-year-old Daughter].

From the narratives above, disclosure was a one-time event for these caregivers and the focus of the disclosure event was mainly the mention of HIV to the children and the need for strict adherence to medications. Emphasis was also laid by caregivers on the need for the children to keep the diagnosis a secret because of the stigma attached to the condition. The narratives did not indicate any conversations about the child's condition after the disclosure event.

4.2.3 Disclosure and Health Outcomes

This major thematic area covers the narratives of caregivers about their health and that of their children with a particular focus on adherence levels, general physical health, and psychological health and wellbeing. Four sub-themes were derived from the narratives and discussed namely: Emotional reactions to the disclosure of HIV status, Medication adherence in children with HIV, Improved physical health due to ART treatment and Anxiety Reduction in Caregivers.

Emotional reactions to the disclosure of HIV status

Caregivers described the reactions of the children to the news of the diagnosis with particular emphasis on their psychological wellbeing before and after disclosure. Caregivers reported that, after the disclosure was made, some children expressed some emotional distress characterized by feelings of deep sadness for a few weeks but later on observed improvement in the subsequent months. Below says:

> *"I saw that the first three weeks that followed, she was very quiet. My child is very lively, she is most of the time all over the house, laughing and playing with the other children in the house. Hmm, it made me think a lot because when I asked what was wrong, she said was alright. So I really prayed for her but after some time she was back to herself"* [P10, Female, 46years, 11-year-old Daughter]

> *"Those times were difficult for him. After I spoke to him, he was ok but I started seeing that he was always alone. Yes… he no longer wanted to be in the living room with me in the evening to watch TV as he usually does. His younger brother even asked me if he was ok and I didn't know what to say. So I personally called him and talked to him on a number of occasions before I saw some improvement"* [P12, Male, 55 years, 15-year-old Son]

These excerpts indicated that disclosure brought some emotional discomfort to the children. As seen above, caregivers reported feelings of sadness and withdrawal which were uncharacteristic of the children. These reactions to the disclosure were not unexpected owing to the fact that most people react intensely to the news or diagnosis of many incurable diseases like

HIV. The reactions were also due to the fact that the children were beginning to understand, and perhaps accept and come into terms with the implications of having HIV. With reassurance from the caregivers, the children eventually overcame these negative feelings and emotions. This means that the psychological support that children receive after disclosure plays an enormous role in helping the children overcome all negative emotions and also help them in coming to terms with the reality of the condition. As such, disclosure has to be a continuous process and not a one-time event and should be done with the help of trained professionals like psychologists who would continue to provide psychological support for this children even after disclosure is made.

Medication Adherence in Children with HIV

The narratives of the caregivers interviewed indicated that generally there was poor adherence among the children particularly those whose HIV status has not been disclosed to them. They indicated that most of the children found it difficult taking the medication, complained or and expressed feelings of being tired or fed up. Below are the voices that captured this:

> *"…sometimes when you give him the medication to take, he hides and throws it away. Even when you give it to him to take to school and eat before taking it, he throws it away"* [P8, Female, 38 years, 11-year-old Son]

> *"It's hard for him. So sometimes, I use………I have to make it like something that is nice for him. So I have started using honey to mix the medications for him so he will get that taste that it is nice. If not that….he doesn't like taking medications. Yea, that one there are no two ways about that. If he tastes it and it is not nice, he wouldn't take it"* [P2, Female, 34 years, 6-year-old Son]

> *"Oh sometimes, she says, "ahhh, I am taking medications all the time, I won't take it again"* [P1, Female, 47 years, 10-year-old Daughter]

The narratives above are from caregivers who have not disclosed and indicates that non-disclosed children have challenges with adherence as they sometimes refuse to take their medication or throw them away resulting the increased number of missed doses.

Although these caregivers indicated poor adherence in their children, few, however, stated that their children were complaint and took the medications appropriately. This was particularly true for those children who are aware of their status. Caregivers stated that they showed more responsibility towards taking their medication since they knew the reason why they were taking them. Below are the excerpts that indicated this:

> *"He takes the medications. That was one of the main changes I noticed after the counselors had spoken to him. I'm sure he knows that his life depends on it, so I don't talk plenty like previously. Even if it is getting time for us to go for the medicines, he reminds me about it and we all go"* [P12, Male, 55 years, 15-year-old Son]

> *"At first he complained a lot ahaaa….yes but after we told him, he takes it himself and does not miss any dose. Now he knows that taking the medicine is for a reason…"* [P15, Male, 41years, 13-year-old Son]

The narrative of these caregivers shows that disclosure resulted in more responsible health behavior, particularly towards medications. Disclosure enabled children to understand the condition they were suffering from and why the need for lifelong medication hence improved adherence.

Improved physical health due to ART treatment

Also, caregivers reported improved and quite satisfactory physical health in children living with HIV. According to these caregivers, the initiation of the antiretroviral therapy had a significant influence on their physical health and as such are fit and healthy. Quite a number of the caregivers who reported frequent hospitalization before the diagnosis stated that it has reduced drastically. Below are the excerpts that illustrate this:

> *"Oh, his health is very good. When we started taking the medication everything has changed. But at first, he was getting sick very often, something little and then he will be sick. Now everything has changed. His eating and sleeping, everything has changed. At first, he couldn't sleep. He will sweat so much and always he will be crying but everything has come down. I don't see anything again"* [P3, Female, 27years, 6 years Son]

> *"Oh he is better than before because even in those days because of the prolonged cough, he wouldn't eat much, he couldn't play with other kids, he couldn't go out, he was always in the house and all that, he was weak and because of the cough and the pain, he couldn't mingle but since he started taking the medication, he's gotten better: he rides his bike, he goes to play soccer ... since then he's not even complained of a headache and that's almost 11 months, he's not gotten sick, headache, anything, no complain since then"* [P6, Male, 40 years, 6-year-old Son]

> *"Oh her health is ok. Since the day we found out that it was this that was disturbing her, she has never fallen ill. So if we say we are coming to the hospital, this is where we come. But aside we coming for a refill of our medications, she has never fallen ill for me to bring her to the hospital* "[P9, Female, 39 years, 10-year-old Daughter]

It is evident from the narrative above that generally, almost all caregivers reported better physical health for their children after beginning antiretroviral treatment. Only one caregiver, however, complained of dwindling or declining physical health in the child.

"Her health is not so good. She doesn't really have that strength. I don't see her as strong .....She's going down. She keeps going down. She's become slim and she's not putting on. And she gets sick very quickly. Within a short space of time, then she becomes sick"

[P4, Female, 38 years, 10-year-old Daughter]

Anxiety Reduction in Caregivers

The sub-theme discusses the impact of disclosure of status on caregivers themselves. Caregivers were of the view that disclosing the status of the children to them affected some way. Generally, the accounts indicated that disclosure eliminated the anxieties or worries that caregivers had about having to tell the children about their condition. Below says:

"Well, I can say that before he was told, I was afraid of what to tell him. That was one of my greatest problems but now that he is aware, that fear is no longer there. Yes.... That's what I can say" [P15, Male, 41years, 13-year-old Son]

"Oh, first I was worried about what to tell him if he grows up and how he will take it if he eventually knows. Yes, telling him cleared those worries. However, I'm still concerned about the future. So that is the change I can say I have noticed" [P12, Male, 55 years, 15-year-old Son]

"I used to feel that when I tell her, she will blame me for giving her the disease, but after everything, that feeling left, but the problems we have are still there. Nothing has changed that much aside from her knowing. The money issues are still there you know...ahaa..." [P10, Female, 46years, 11-year-old Daughter]

From the narratives above, it can be noted that the anxiety that caregivers had about having to disclose subsided eventually when disclosure was made. This means that disclosure reduced to some extent the distresses faced by caregivers. However, they stated that most of the challenges they encounter particularly those relating to finances and uncertainties about the future of the children continue to persist.

4.2.4 Challenges and Support Systems for Caregivers

This theme explains the experiences caregivers have had in taking care of children with HIV. Particular focus or attention was paid to the challenges they encounter as well as support systems which have helped them cope with the challenges. The accounts show that most caregivers face serious financial challenges, emotional and psychological distress, and burden. Some also expressed concern over the lifelong usage of medication by the children. Support from religion/faith and partners helped caregivers deal with the many challenges they face on a daily basis. Four subthemes are discussed below namely: Inadequate finances for caregivers, Anxieties about lifelong adherence, Psychological distress, and burden in caregivers and Support from religion and spouses.

Inadequate Finances for Caregivers

Although antiretroviral treatment is entirely free in almost all hospitals across the country, almost all caregivers interviewed complained of inadequate financial resources as one of the greatest challenges they encounter in caring for children living with HIV. Below indicated this.

> *"It's difficult. It's really difficult….hmmm (sighs) it's an issue, ….. You will pay rent, you will pay for light and if you don't have that chunk of money to pay for these things…..hmmm, life is just miserable and this disease has added to it. Sometimes if it's time for me to go for my medicines, sometimes it will be left with my last 5 cedis, I have to*

> *pick a car. I go for mine at Mamprobi. I have to pick a car and go there too"* [P4, Female, 38 years, 10-year-old Daughter]

> *"Mmmmm…..financially yeah….. because I have to be coming to the hospital all the time for review and lab tests. Even though there are some of the drugs that are mainly free…. but you have to take transport here. Yeah…. And I think recently they have been giving us some drug for….Septrin but before that, we were buying the Septrin and also there is also the burden of buying blood tonic because he has to be taking it often. So it's a strain financially"* [P6, Male, 40 years, 6-year-old Son]

> *"Financially, now that I'm not working it has really affected me. My money issues are not really good"* [P9, Female, 39 years, 10-year-old Daughter]

From the descriptions above, it is clear that caregivers did not have adequate financial resources to cater for transportation to and from the hospitals, to pay for rent or accommodation and buy some needed medications like blood tonic for the children. The plight of these caregivers is worsened by the fact that some are single parents, hence the upkeep of the children is entirely dependent on them. Below said:

> *"They are three in total but their father died a few years back, so, I am the only taking care of the three of them"* [P4, Female, 38 years, 10-year-old Daughter]

> *"…when the disease came and I told him, he was not bothered and we were all living fine but recently, about 5 years ago and he runs away and left us"* [P1, Female, 47 years, 10-year-old Daughter].

These excerpts show that the caregivers are single-handedly shouldering the responsibility for these children because their partners are unavailable to assist in taking care of the children and this accounts for why these caregivers complain of financial difficulties.

Anxieties about Lifelong Medication Adherence

One key challenge that runs through the accounts of the caregivers was the worry and concern about the children staying on medications for the rest of their lives. Some caregivers expressed the desire or wish that their children would be taken off the medication someday. Others also expressed fear of possible relapse in the future as presented below.

> *"The challenge I can say…, is for any parent to have his child taking medication for the rest of his life. This one is really daunting for me. It weighs you sometimes, you understand"* [P6, Male, 40 years, 6-year-old Son]

> *"…the only thing I worry about is she taking the medication every day ehee…. I've seen that if it were any other different illness, she would have stopped taking the medication. Now that it's this one, I ask myself, how long this child will be able to continue taking this medicine. For me, I have seen that I'm grown. I have come far but I see her as a child"* [P9, Female, 39 years, 10-year-old Daughter]

> *"…I don't really think about anything like that one that I would have to tell him it's because of this that's why you're on medication. So I'm praying that by God's grace it would get to a point where he will stop the medication"* [P5, Female, 40 years, 10-year-old Son].

> *"…it's such that you don't know if in the future there will be a relapse, you never know. If the drugs are….For now, the drugs are working but you never know when there will be relapse"* [P6, Male, 40 years, 6-year-old Son].

These excerpts show the concern, worry, and anxiety that caregivers expressed over their children having to take medications for the rest of their lives. They were of the opinion that these children are young to be subjected to medications for life. Also, there was the concern about whether the children will be able to adhere to the medications for that long and hence the wish that the children will stop taking the medications at some point. Others also had fears about the efficacy of the drugs in managing the condition in the long term.

Psychological Distress and Burden in Caregivers.

Regardless of whether the disclosure was made to the children or not, most caregivers narrated that they experience some psychological distress in caring for children living with HIV. This is characterized by feelings of deep sadness and sorrow at the plight of their children. Below are some of the excerpts:

> *"…if you sleep and think about these things, it makes you sad. And if you want to think about it a lot too, it makes your head ache, so when I think about it a little, then I stop and put it aside"* [P4, Female, 38 years, 10-year-old Daughter]

> *"It makes me sad all the time. And also maybe when I come to the clinic and I see these children like that, it makes me feel bad, and it makes me sorrowful within (sobbing)…"* [P1, Female, 47 years, 10-year-old Daughter]

> *"…it has affected me… there's sadness always within me….ehee. I'm always sad"* [P8, Female, 38 years, 11-year-old Son]

> *"It makes me feel bad. I think a lot. I feel like my life is left behind. Everything of mine is spoilt. The way I want to move to forward, I'm not moving"* [P9, Female, 39 years, 10-year-old Daughter]

These narratives indicate the varying forms of distress experienced by caregivers as a result of the experiences they go through daily. Most of these are feelings of deep sadness and sorrow, headaches, pain and feelings of stagnation and retrogression. This distress reported by caregivers could be precursors to serious mental health challenges in these caregivers if not handled professionally.

Closely linked to the distress experienced by caregivers is the burden of caring for children with HIV. Some caregivers explained that because of their children's condition and fear of people knowing about their status they are not able to seek assistance or help from anyone in taking care of the children. The quote below expressed participants concerns;

> *"Taking care of him is not easy because now you cannot leave him for anyone to take care of him. Even if you are going somewhere, you have to come back early and take care of him because you may not know the person you are leaving him what and you don't know how that person will talk and all that"* [P2, Female, 34 years, 6-year-old Son]

> *"...I can't go anywhere very far and leave her. Because if I go and leave her, she wouldn't be able to take her medication, she's young. So maybe if I travel she'll not be able to take her medication"* [P9, Female, 39 years, 10-year-old Daughter]

The narratives show that caregivers are forced to single-handedly cater for the wellbeing of their children because of fears of others knowing about their condition should they seek assistance. This could significantly contribute to stress in these caregivers and coupled with the aforementioned distresses, could have devastating effects on the health of caregivers.

Some also stated their inability to work, and other family responsibilities as some of the reasons that contribute to the burden of care.

> *"My work issues too, it has made the work some way. ...as any human being, if you are there, you have to work. Because I have my mom there, I have siblings that I'm helping through school and others. Now that my work has gone down, it's making us go through some sufferings….mmmm"* [P9, Female, 39years 10-year-old Daughter]

> *"…now I can't sell again because there is no money. From the time they discharge us from the hospital around December, things have not been moving on well, things are not good again"* [P8, Female, 38 years, 11-year-old Son]

These excerpts are concerns of caregivers about their inability to ply their various trades or work because they have to always be available to take care of their children. Given the fact that they have other family responsibilities, it makes the burden of care very huge.

Support from Religion and Spouses

Caregivers reported that they received support in coping with the challenges they face in performing their caregiving role. They stated faith/religion as the main source of support or help in strengthening and encouraging them to withstand some of the challenges they encounter. The excerpts below illustrate this:

> *"I have been helped by my faith. I believe in the Lord Jesus Christ and I believe …..erhnnmm we are strong concerning every circumstance, we are independent of every circumstance and this is one of them, I am just riding through it winning and winning. Even though they will call it this way, I know I'm winning"* [P6, Male, 40 years, 6-year-old Son]

> *"It's God. The only thing is God. If you worship God, you give everything to him. You continue praying, everything will be fine. So it's only God and prayer that I hold on to"* [P8, Female, 38 years, 11-year-old Son]

The excerpts above indicate the caregiver's faith in God and Jesus Christ, the belief in the power of prayer and the Christian teachings of tenacity in all circumstances provided them with the needed support to sail through their daily challenges.

While some caregivers complained of the unavailability of their partners as a major challenge they encounter, caregivers who were still with their partners stated that they were a great source of support in dealing with the stresses and challenges they face in the care of the children.

> *"…the man I am staying with doesn't have the disease. He is not infected, so sometimes he is the one that even gives me words of encouragement…you see what has helped me is that …., he makes me happy. If you live in happiness you can do everything. If the person disturbs you, that's when you can say that you can't do anything so he makes me happy so I'm not in any difficult situation"* [P5, 40 years, 10-year-old Son]

> *"Ok, what has helped me is my husband. He strengthened me all these while that I was going through all these challenges. He is someone that if he has time, he talks to me. He told me that any challenge that I would go through, it's from God, that I should take it that it is God's test. So things like that give me strength, hope and courage"* [P9, Female, 39 years, 10-year-old Daughter]

Here, we see that the spouses provided these caregivers the needed support, strength and courage to handle their daily challenges. Also, the presence of the spouses and their words of encouragement produced positive emotions and feelings of happiness in these caregivers regardless of their condition.

Some other caregivers also stated receiving support especially financial support from benevolent individuals which helped a long way in easing some of the constraints they faced financially.

> *"Hmm, for my child, the name that he carries….God is really miraculous. Sometimes there's someone there who doesn't even know him when he hears the name and I'm walking with him and they go like, is he there? Take this and give it to him"* [P7, Female, 41 years, 7-year-old Son].

This narrative shows that the assistance of these well-meaning individuals sometimes provided relief in dealing with some of the financial challenges that this caregiver encountered. In summary, it can be said that support from religion, spouses and benevolent individual aided caregivers to cope with their challenges.

4.3 Quantitative Results

4.3.1 Socio-demographic characteristics of Participants

The final sample for this study comprised 155 children living with HIV and their caregivers respectively. The caregivers in the study were within the ages of 22-82 years, with a mean age of 41.60 (*SD* = 10.38). Of the 155 caregivers sampled, 119 (76.8%) were females. A majority of the caregivers had no education at all or just basic education (47.1%) and 30.3% having tertiary education. The children, on the other hand, were within the ages of 6 – 15 years with a mean age 9.55 (*SD* = 2.72). Of this number, 83 (53.5%) were males. A majority of the children were unaware of their HIV status (66.5%) while 33.5% were aware of their status. Details of the demographic information of the caregivers and children are presented in Table 4.2 below:

Table 4.2 Socio-demographic Information of Caregivers and Children (N = 155)

Variables	*Number*	*Percentage*
Gender of Caregivers		
Male	36	23.2
Female	119	76.8
Caregivers' Age (*M*= 41.60; *SD*= 10.38)		
18-40	82	52.9
41-60	64	41.3
60+	9	5.8
Caregivers' Education		
No Education	11	7.1
Primary Education	62	40.0
Secondary Education	35	22.6
Tertiary Education	47	30.3
Caregivers' Relationship with Child		
Biological Parent	85	54.8
Extended Family	48	31.0
Guardian	22	14.2
Disclosure of Status		
Disclosed	52	33.5
Non-disclosed	103	66.5
Child's Age (*M*= 9.55; *SD* = 2.72)		
6-10	95	61.3
11-15	60	38.7
Gender of Child		
Male	83	53.5
Female	72	46.5
Child's Education		
Primary Education	144	92.9
Secondary Education	11	7.1

5.3.2 Relationship among study variables

Person Product Moment Correlation test was computed among all study variables to establish the relationship between the study variables. This is a prerequisite for conduction regression or mediation or moderation analysis. The correlation matrix was generated as shown in Table 4.3 below indicating all the significant relationship among the study variables with asterisks (*).

Table 4.3 Correlation Matrix of Various Study Variables

		1	2	3	4	5
1.	Disclosure of Child's HIV Status	1				
2.	Length of Disclosure	-.76**	1			
3.	MACHIV	-.53**	.48**	1		
4.	PWCHIV	-.63**	.58**	.60**	1	
5.	CB	.17*	-.13	-.06	.02	1
6.	PHC	.08	-.01	-.07	.01	.61**

NOTE: MACHIV = Medication Adherence in Children living with HIV, PWCHIV = Psychological Wellbeing in Children living with HIV, CB = Caregiver Burden, PHC = Psychological Health in Caregivers.

*Note: * p < .05, ** p < .01 (one-tailed)*

Findings in Table 4.3 above indicated that there was a significant relationship between disclosure and medication adherence in children living [*r* (155) = -.53, *p*<.01], disclosure and psychological wellbeing in children living with HIV [*r* (155) = -.63, *p*<.01], disclosure and caregiver burden [*r* (143) = .17, *p*<.05], as well as disclosure and length of disclosure [*r* (155) = -.76, *p*<.01]. A significant relationship was also found between length of disclosure and medication adherence [*r* (155) = .48, *p* < .01] and psychological wellbeing [*r* (154) = .58, *p*<.01]. Additionally, a significant relationship between medication adherence and psychological wellbeing in children living with HIV was observed [*r* (154) = .60, *p* < .01]. Caregiver burden was found to be significantly associated with psychological health in caregivers of children living with HIV [*r* (135) = .61, *p*=.01].

4.3.3. Hypothesis One and Two

The first hypothesis stated that *"Children whose HIV status have been disclosed will report better antiretroviral adherence than those whose HIV status have not been disclosed"* and the second that *"Children whose HIV status have been disclosed will report better psychological wellbeing outcomes than those whose HIV status have not been disclosed."* To test these two hypotheses, a one-way between-groups multivariate analysis of variance (MANOVA) was employed. Total medication adherence and psychological wellbeing scores were entered as the dependent variables and disclosure of status as the fixed factor or independent variable. The Levene test for equality of Variances showed that the two dependent variables had significant levels below .05 indicating that, the assumption of the equality of variances for scores in the dependent variables were violated. Accordingly, the Pillai's Trace (*V*) multivariate test of significance (see Table 4.4) was reported with a stringent alpha of .01 as suggested by Pallant (2016) and Tabachnick and Fidell (2013). Results showed that there was a statistically significant difference between children whose HIV status have been disclosed and those whose status have not been disclosed on the combined dependent variables, F (2, 151) = 57.3, $p < .001$; $V = .43$; partial eta squared = .43. This means that children whose HIV status have been disclosed differed significantly from those whose status have not been disclosed on medication adherence and psychological wellbeing scores.

The results for each dependent variable was considered independently and both medication adherence and psychological wellbeing reached statistical significance, using a Bonferroni adjusted alpha level of .025. Both medication adherence [F (1, 152) = 60.09, $p < .001$, $\eta^2 = .28$] psychological wellbeing [F (1, 152) = 99.09, $p < .001$, $\eta^2 = .40$] were significant (see Table 4.5). An examination of the mean scores showed that children whose HIV status have been disclosed reported better medication adherence ($M = 7.17$, $SD = 1.88$) than those whose status have not been disclosed ($M = 5.03$, $SD = 1.48$). Similarly, children whose status have been disclosed reported better psychological wellbeing ($M = 43.37$, $SD = 6.75$) than those whose status have not been disclosed ($M = 33.97$, $SD = 4.81$). This goes to confirm hypothesis one and two that children whose HIV status have been disclosed have better medication adherence and psychological wellbeing than those whose status have not been disclosed. This means that disclosure resulted in better adherence and psychological wellbeing in children whose status have disclosed compared to those whose status have not been disclosed. Summary of the MANOVA and Univariate results are shown in Table 4.4 and 4.5 below:

Table 4.4 MANOVA tests for group differences between disclosed and non-disclosed children on medication adherence and psychological wellbeing

MANOVA Test	**Value**	***F***	***df***	***p***	η^2
Pillai's trace (*V*)	.43	57.30	2	<.001	.43
Wilks' Lambda (λ)	.57	57.30	2	<.001	.43
Hotelling's trace (*T*)	.76	57.30	2	<.001	.43
Roy's largest root (*Θ*)	.76	57.30	2	<.001	.43

Table 4.5 Table of significant univariate effects of disclosure on medication adherence and psychological wellbeing

DV	***df***	***df* error**	***F***	***p***	η^2	**Disclosure**	***M***	**99.9% CI**	
								Lower	**Upper**
Medication Adherence	1	151	60.09	<.001	.28	Yes	7.17	6.73	7.62
						No	5.03	4.71	5.35
Psychological Wellbeing	1	151	99.09	<.001	.40	Yes	43.36	41.85	44.88
						No	33.97	32.89	35.05

4.3.4 Hypotheses three and four

Hypothesis three stated that "*Caregivers who have disclosed the HIV status of their children will have better psychological health than caregivers who have not disclosed*" and four that "*Caregivers who have disclosed the HIV status of their children will have lesser caregiver burden than caregivers who have not disclosed*". These hypotheses were tested using a one-way between-groups multivariate analysis of variance (MANOVA). Total scores for caregiver burden and psychological health were entered as the dependent or outcome variables and disclosure of status as the fixed factor or independent variable. No assumption was violated per the outcome, therefore the Wilks' Lambda (λ) multivariate test of significance was reported.

The results indicated that there was no statistically significant difference between caregivers who have disclosed the HIV status of their children and those who have not disclosed on the combined dependent variables, F (2, 132) = 1.51, p = .223; λ = .98; η^2= .02. (See Table 4.6) This means that caregiver burden and psychological health of caregivers who did not disclose did not differ from caregivers who disclosed the HIV status of their children. Although an inspection of the means showed that caregivers who have disclosed had slightly lesser scores on caregiver burden (M = 30.48, SD = 1.86) compared to those who have not disclosed (M = 34.33, SD = 1.25), this did not reach any statistical significance (See Table 4.7). Non-disclosed caregivers on the contrary to hypothesis three had higher scores on psychological health (M = 24.14, SD = 1.12) than disclosed caregivers (M = 22.55, SD = 1.66) yet this difference was also insignificant as observed in Table 4.7 below. Hence hypotheses two and three were not supported.

Table 4.6 MANOVA tests for group differences between caregivers who have disclosed and those who have not on caregiver burden and psychological health.

MANOVA Test	**Value**	**F**	***df***	***p***	**η^2**
Pillai's trace (*V*)	.02	1.52	2	.22	.02
Wilks' Lambda (λ)	.98	1.52	2	.22	.02
Hotelling's trace (*T*)	.02	1.52	2	.22	.02
Roy's largest root (*Θ*)	.02	1..52	2	.22	.02

Table 4.7 Table of univariate effects of disclosure on caregiver burden and psychological health

DV	***df***	***df* error**	***F***	***p***	**η^2**	**Disclosure**	***M***	**95% CI**	
								Lower	**Upper**
Caregiver Burden	2	132	2.95	.22	.02	Yes	30.48	26.79	34.16
						No	34.33	31.56	36.80
Psychological Health	2	132	.63	.22	.005	Yes	22.55	19.26	25.83
						No	24.10	21.93	36.35

4.3.5 Hypothesis five

This hypothesis stated that *"Duration of disclosure will mediate the relationship between disclosure and medication adherence of children living with HIV"*. To test if the association between disclosure and medication would be mediated by how long a child has known, a mediational regression analysis was performed using the Model 4 of the PROCESS macro version 3.3 created by Hayes (2012) with a recommended bias-corrected bootstrap confidence interval of 95% and bootstraps set at 5,000. In the analysis, medication adherence in children living with HIV was entered as the outcome variable.

The first regression model was significant, $R^2 = .57$, $F(1, 153) = 204.46$, $p < .001$ (See Table 4.8) and showed that duration of disclosure is predicted by disclosure of status ($B = -19.03$, $p < .001$). In the second model which reflects the direct effect of disclosure of status on medication adherence accounting for the mediator, results showed that the model was again significant, $R^2 = .30$, $F(2, 152) = 31.99$, $p < .001$ with disclosure of status significantly predicting medication adherence ($B = -1.60$, $p = .001$); however, duration of disclosure did not predict medication adherence ($B = .03$, $p = .11$). For the total effect output which reflects the effect of disclosure of status on medication adherence without accounting for the mediator (duration of disclosure), it was shown that the model was significant, $R^2 = .28$, $F(1, 153) = 60.70$, $p < .001$, and medication adherence was significantly influenced by disclosure of status ($B = -2.14$, $p < .001$). This means that disclosure predicts adherence to medication in children with HIV. The indirect effect of the relationship between disclosure of status and medication adherence as mediated by the duration of disclosure, however, was statistically not significant because the estimated confidence interval included zero (95% CI: -.61 to .10) as indicated in Table 4.8 below. This means that the relationship between disclosure and adherence cannot be explained by the duration of the disclosure. Therefore, the hypothesis that the relationship between disclosure and medication adherence is mediated by duration of time after disclosure was rejected.

Table 4.8 Mediational analysis of disclosure and medication and psychological wellbeing via duration of disclosure

	Medication Adherence			Psychological Wellbeing		
	(n = 155)			(n = 154)		
	B	(SE *B*)	*p*	*B*	(SE *B*)	*p*
Constant	38.13	2.30	<.001	38.13	2.31	<.001
DD	.03	.02	.10	.14	.06	<.01
Disclosure predicting DD	-19.03	1.33	.<001	-19.03	1.33	<.001
Direct Effect of Disclosure	-1.63	.42	<.001	-6.63	1.41	<.001
Total Effect of Disclosure	-2.14	.27	<.001	-9.39	.94	<.001
Indirect effect of Disclosure via DD on DVs;	-.51	.34		-2.76	1.17	
95% CI; (*B* [SE *B*])	(-1.17 [.18])			(-5,05 [-.41])		
R^2	.30			.42		

Note: DD = Duration of Disclosure

4.3.6 Hypothesis Six

Hypothesis six stated that *"Duration of disclosure will mediate the relationship between disclosure and psychological wellbeing of children living with HIV"*. This hypothesis was also tested using Model 4 of the PROCESS macro version 3.3 by Hayes (2012) with a confidence interval of 95% and bootstraps set at 5,000. Psychological wellbeing in children living with HIV was entered as the outcome variable with disclosure of status as the independent variable and length of disclosure as the mediating variable.

The output indicated that first regression model was significant, $R^2 = .57$, $F(1, 152) = 202.44$, $p < .001$ (See Table 4.8), and showed that duration of disclosure is predicted by disclosure of status ($B = -19.03$, $p < .001$). The second model reveals the direct effect of disclosure of status on psychological wellbeing taking into consideration the mediator and the output showed that the model was again significant, $R^2 = .42$, $F(2, 151) = 54.73$, $p < .001$ with disclosure of status ($B = -6.63$, $p = .001$) and duration of disclosure ($B = .14$, $p = .01$) significantly predicting psychological wellbeing. The total effect model output which indicated the effect of disclosure of status on psychological wellbeing without the mediator (duration of disclosure) showed that the model was significant, $R^2 = .39$, $F(1, 152) = 99.09$, $p < .001$ and psychological wellbeing was significantly influenced by disclosure of status ($B = -9.39$, $p < .001$). The indirect effect of the relationship between disclosure of status and psychological wellbeing as mediated by the duration of disclosure was statistically significant. This is because the estimated confidence interval was totally below zero (95% CI: -5.05 to -.41). This means that the relationship between disclosure and psychological wellbeing is explained by the duration of the disclosure. Hence the hypothesis that the relationship between disclosure and psychological wellbeing in children living with HIV is mediated by the duration of disclosure was confirmed. Table 4.8 above gives a summary of the mediation analysis.

4.3.7 Hypothesis Seven

This hypothesis stated that *"Age will predict disclosure of status in children living with HIV"* In testing this hypothesis, hierarchical regression was performed with disclosure of HIV as the dependent or outcome variable and child's age as the predictor. The caregiver's demographic variables —age, gender, education, and relationship with the child were entered in the first model, followed by the other demographic variables of the child—gender and education—which was entered in the second block. The purpose of this was to control their effects before entering the main predictor – child's age into the last block.

The results from the regression (see Table 4.9) revealed that the first model in Disclosure of Status having caregiver's characteristics as predictors was significant F (4, 150) = 3.05, p = .019; R^2 =.08, with caregivers sex (β = .19, p = .025) and relationship with child (β = .18, p = .041) making a statistically significant contribution while caregivers age (β = -.15, p = .071) and education (β = -.04, p = .625) were not a significant contributor. Model 2 which included other demographic variables of the children- sex and education and controlled for the effects of the caregivers demographic variables was equally significant, ΔR^2 = .12, F (6, 148) = 6.03, $p < .001$ with only child's education (β = -.36, $p < .001$) explaining statistically significant amount of variance in disclosure of status whereas child's age not a significant contributor (β = -.04, p = .57). The last model which was of interest to the researcher's was significant, ΔR^2 = .17, F (7, 147) = 12.37, $p < .001$. Child's age after controlling for demographics of caregivers and child was a significant predictor of disclosure of status in children living with HIV and accounted for unique variance in disclosure (β = -.47, p < .001, Adj. R^2 = .34). This means that holding other variables constant, the chance of disclosure increase 17 times by the age of the child and this explains 34% of the variance in disclosure. This goes to confirm the hypothesis that age predicts disclosure of status in children living with HIV.

Table 4.9 Hierarchical regression of child's age as a predictor of disclosure of status in children with hiv while controlling demographic variables in caregivers and children.

Model		*B*	(SE *B*)	*β*	R^2	ΔR^2	*F*	*p*
1					.07		3.05	<.05
	(Constant)	1.432	.268					
	Caregiver's Age	-.007	.004	-.15				
	Caregiver's Sex	.209	.092	.19*				
	Caregiver's Education	-.021	.043	-.04				
	Caregivers Relationship with the child	.116	.056	.18*				
2					.20	.12	6.03	<.001
	(Constant)	2.118	.296					
	Caregiver's Age	-.004	.004	-.10				
	Caregiver's Sex	.201	.087	.18				
	Caregiver's Education	.025	.042	.05				
	Caregivers Relationship with the child	.064	.055	.10				
	Child's Sex	-.042	.073	-.04				
	Child's Education	-.663	.141	-.36**				
3					.37	.17	12.37	<.001
	(Constant)	2.757	.281					
	Caregiver's Age	-.005	.003	-.10				
	Caregiver's Sex	.082	.080	.07				
	Caregiver's Education	.029	.038	.06				
	Caregivers Relationship with the child	.061	.048	.09				
	Child's Sex	-.020	.065	-.02				
	Child's Education	-.356	.134	-.19				
	Child's Age	-.081	.013	-.46**				

4.3.8 Summary of Quantitative Findings

This study basically tested seven main hypotheses to examine the impact of disclosure of status to children living with HIV on health outcomes in these children (i.e. medication adherence and psychological wellbeing) and their caregivers (i.e. caregiver burden and psychological health). The findings of the present study are listed below:

1. Disclosure of status in children living with HIV led to better health outcomes in the children as indexed by higher scores on medication adherence and psychological wellbeing in children whose HIV status have been disclosed that those whose status have not been disclosed.
2. There was no statistically significant difference in caregiver burden among caregivers who disclosed and those who did not disclose as both indicated high levels of burden.
3. Disclosure of status did not improve the psychological health of caregivers of children living with HIV because there was no statistically significant difference between those caregivers who disclosed the status of children living with HIV and those who have not disclosed on psychological health scores.
4. The relationship between disclosure of status and psychological wellbeing in children living with HIV was mediated by the duration of disclosure (how long the children have been aware of their status).
5. The relationship between disclosure of status and medication adherence in children living with HIV was not mediated by the duration of the disclosure.
6. Age was a significant predictor of disclosure of status in children living with HIV.

3.4.9 Observed Model for Quantitative Findings

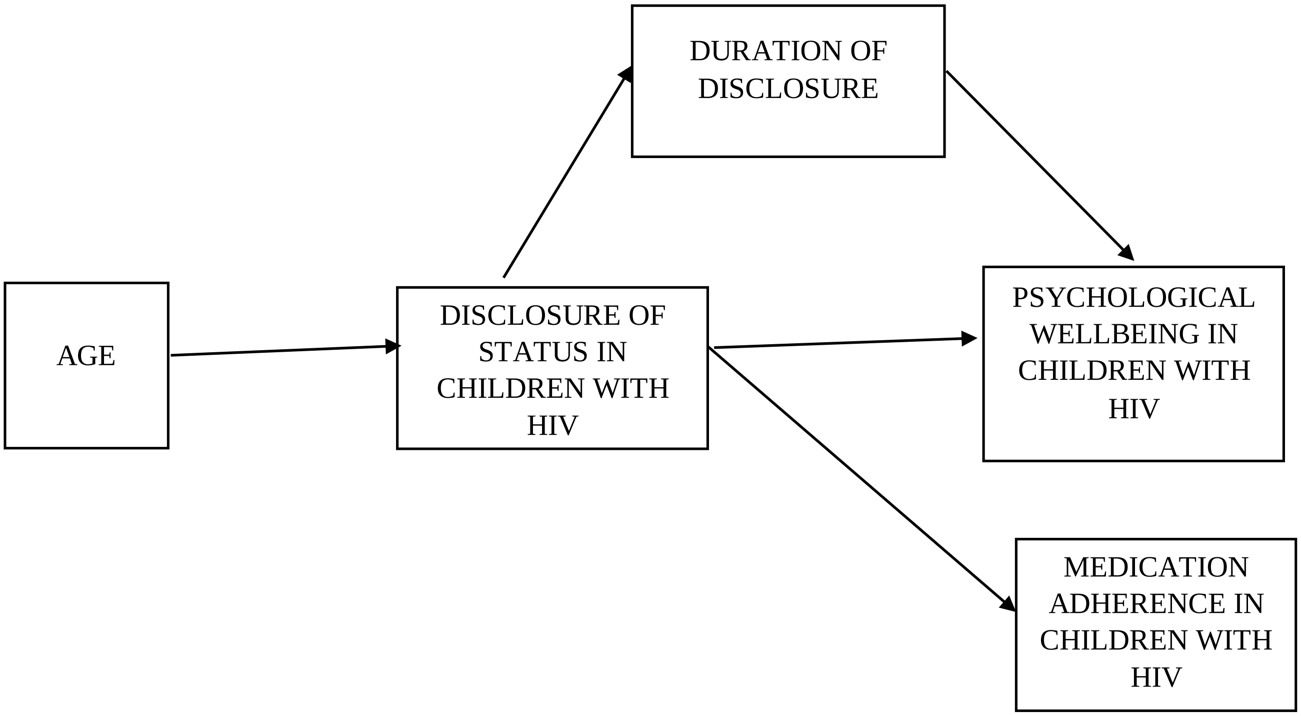

Figure 2 . Figure depicting the observed relationships between study variables

CHAPTER FIVE

DISCUSSION

5.1 Introduction

Both the qualitative and quantitative findings of this study are discussed in this chapter with references to existing literature. In discussing the key findings, contextual explanations are provided for the different outcomes in the children and their caregivers. The implications of these findings are also discussed with recommendations for future research and clinical practice. The chapter ends with limitations, recommendations, and conclusion.

5.2 Diagnosis of HIV in Children living with HIV

In this study, it was found that for the majority of the children, the diagnosis of HIV occurred during infancy owing to frequent illnesses and hospitalizations. The caregivers noticed symptoms in their children as young as four and six months. This confirms studies (e.g. Burchett & Pizzo, 2003; Sütçü et al., 2017) which found that most children infected with HIV present in the first few months of life or the infantile period. Also, findings indicated that the diagnosis of the children led to further testing of caregivers, particularly those who were the biological parents of these children most of whom did not know that they were also infected until their children were diagnosed. These findings show that these children were infected perinatally or through mother to child infection as evidenced by other studies (Kassa, 2018; Lentoor, 2017; Wudineh & Damtew, 2016). These studies found that a majority of the children living with HIV below the age of 15 years are infected mainly through mother to child transmission during pregnancy, childbirth or breastfeeding. For example, Wudineh and Damtew (2016) in their study found that a third of children born to HIV infected mothers are infected with HIV through mother to child transmission.

One plausible reason why caregivers particularly the biological parents or mothers were not aware of their status could be the fact that they had side-stepped antenatal testing or failed to accept their diagnosis even when they were told, as observed in the narratives of some caregivers.

According to the World Health Organization and Ministry of Health, Ghana, standard guidelines for the prevention of mother to child transmission (PMTCT) (Ministry of Health, 2014; WHO, 2016), HIV testing is part of the routine tests conducted as part of the initial and subsequent antenatal care services for all pregnant women who report to the hospitals across the country. Hence, the inability of caregivers to be aware of their status could be due to the fact that they skipped antenatal testing or failed to accept the diagnosis. The lack of acceptance on the part some of the caregivers may also be a result of the stigma and other negative connotations that surround HIVinfection in the African context particularly (Treves-Kagan et al., 2016). According to studies, stigma, and discrimination related with HIV is one of the major reasons why people avoid HIV testing or avoid seeking care (Treves-Kagan et al., 2016; Young & Bendavid, 2010; Young & Zhu, 2012). For instance, in the study by Young and Bendavid (2010), stigmatization was found to be positively related to and affected HIV testing decisions and behaviour among people living with HIV. These studies provide support for the reasons why most caregivers (especially the biological parents) were unaware of their HIV status as at the time their children were diagnosed.

5.3 Disclosure of Status to Children living with HIV

Full disclosure of status to children living with HIV has been found to be a challenge for most caregivers in sub Saharan African countries and studies have indicated low prevalence rate of disclosure across countries in the sub-region (Baker et al., 2018; Finnegan et al., 2019; Gyamfi et al., 2017; Kallem et al., 2011; Turissini et al., 2013). In this study, the qualitative findings indicated that the rate or prevalence of disclosure was just one third among caregivers interviewed whereas the quantitative indicated that less than one-third of the children had full disclosure. Although these rates are still low, they are slightly higher compared to those reported in Kenya (Turissini et al., 2013), the Dominican Republic (Beck-Sagué et al., 2015), Zimbabwe (Finnegan et al., 2019) and in Ghana by Gyamfi et al. (2017) in a previous study. A reason for this low rate of disclosure could be due to the fact that most of the children that took part in this study were younger as observed in the mean age of the children which was, less than ten years.

The majority of caregivers who did not disclose the status of their children in the qualitative study indicated that the children were not old or matured enough to be told about their diagnosis, hence the reason for non-disclosure. When asked to suggest the right age at which to fully disclose, some stated early or late adolescence as the right age at which they can disclose since by then the children will be developed cognitively to understand what HIV is and its implications. This finding supports previous literature on disclosure e.g. Baker et al. (2018), DeSilva et al. (2018), and Gyamfi et al. (2017) which have reported that, older children, particularly adolescents are more likely to be disclosed to than younger ones or non-adolescents whom caregivers perceive as not matured enough cognitively to understand their condition.

5.3 Factors Promoting Disclosure and Non-Disclosure in Children living with HIV

The study revealed that age or maturity, fear of the child not keeping the diagnosis confidential, fear of societal rejection, stigma and ill-treatment as the main reasons for caregivers not disclosing the HIV status of their children to them. Caregivers who did not disclose were of the view that their children were not grown enough or matured enough to be told about their condition. This is particularly true for the younger children or non-adolescents. Closely tied to the age factor was the concern that children were not cognitively developed enough to grasp the explanations of HIV, what is it, how it is transmitted and its implications and impact on the family, hence the need to refrain from disclosing till the children were older enough to understand before they are told. This supports previous studies (Beck-Sagué et al., 2015; Gyamfi et al., 2017; Vreeman et al., 2014). For instance, Beck-Sagué et al. (2015) found in the Dominican Republic that caregivers of younger children did not disclose because the caregivers felt they had not gotten to the stage where they could understand and cope effectively with their condition.

This means that age is a factor that determines whether caregivers would disclose or not. The effect of age as a predictor of disclosure was tested in the quantitative study controlling for other demographic variables of both children and their caregivers and this was significant explaining seventeen percent of the total difference in disclosure rates. This indicates that older children were more likely to know about their sero status than younger children. Similar findings have been documented in previous studies (Kallem et al., 2011; Mumburi et al., 2014; Pinzón-iregui et al., 2013; Vreeman et al.,2013).

Also, the findings of this study indicated that caregivers feared their children will tell others about their diagnosis when they disclose their status to them. They were of the view that the children were young and naïve and could spill the bin unknowingly to other children through conversations without knowing the implications. Linked to the fear of others knowing about the condition of the family was also the fear of stigma, discrimination and ill-treatment by family, friends and the society at large when others get to know of their condition which these caregivers were not prepared for. Some expressed fears of rejection by family, eviction from their homes and also the fear of losing their jobs. These findings are consistent with prior studies from sub-Saharan Africa on stigma and disclosure (Beck-Sagué et al., 2015; Gyamfi et al., 2017; Madiba & Mokgatle, 2017; McHenry et al., 2017; Ostrom, Serovich, Lim, & Mason, 2006). For instance Gyamfi et al. (2017) found in a prior study in Ghana that, because of the belief that HIV is caused by supernatural powers as punishment for wrongdoing, it leads to negative attributions and labeling, hence most caregivers decide not to disclose the status of their children in order to avoid such labeling and rejection from community members. It is obvious that the larger societal factor of stigma greatly affects the decision of whether to disclose or not to disclose the HIV status of children to them among caregivers hence supporting the social influence theory of disclosure. Again, these reasons explained above are costs or negative outcomes that caregivers believe outweighs the benefits that disclosure could bring hence the need to withhold disclosure and also reinforcing the consequences theory of disclosure.

Disclosure on the hand was mainly necessitated by three main factors, namely, curiosity and questioning by children on the need for medications, poor adherence to antiretroviral treatment and transition to high school or boarding school. Findings from this study showed that most caregivers were compelled to disclose because their children were questioning why they are on medication and to address their concerns, the caregivers thought it prudent to disclose. As indicated in the qualitative findings, the concern about always taking medications was raised by the children because they felt they were not physically ill to be on medications every day. Also, some practices at the antiretroviral clinics raised eyebrows and made the children curious: this included keeping folders in a rubber files which was not the same for other patients. This means that actions intended to protect people with HIV from being recognized or identified at the various clinics could rather lead to curiosity and suspicion. These findings support prior studies on the reasons for disclosure (Beck-Sagué et al., 2015; Lorenz et al., 2016). A probable reason for this result is that, as children age and mature cognitively, they begin to question the status quo to understand the reasons behind certain actions and behaviours hence the curiosity and inquisitiveness.

Also, this study revealed that some children became non-adherent and stopped medicating completely, which prompted caregivers to disclose. This was so because in most cases, caregivers did not explain to these children why they were on medication daily. Without this explanation, some of these children did not see the need to continue the medication and therefore stopped taking the medications altogether or were missing doses. These findings have been documented in previous studies (Baker et al., 2018; DeSilva et al., 2018; Gyamfi et al., 2017). For instance, in Peru, Baker et al. (2018) found that frustrations about non-adherence to medication compelled caregivers and health care providers' to disclose the status of children living with HIV.

Again, others felt the need to disclose because their children were transitioning from basic to high school or boarding school, and as a means of ensuring that their children continue taking the medication even when in school, disclosure was made. The motivation behind this was perhaps the fact that caregivers felt that the children may not adhere to medications in their absence and also because they may no longer be available to supervise the children to take their medications regularly and on time. Hence, the need for disclosure to make children understand why they are on medication. This finding is unique to this study and the Ghanaian context as this has not been documented in prior studies.

From the findings discussed above, it can be observed that there is the interplay of both individual factors such as the child's age or maturity, the need for adherence, transition into higher educational levels and societal factors such as stigma, fear of rejection and ill-treatment. These individual and societal factors singularly determined or combined to determine whether or not caregivers would disclose or not disclose the HIV status of their children. Depending on which was of significance to the caregiver at the point in time, determined whether disclosure was made to the child or not.

5.4 Disclosure and Health Outcomes in Children living with HIV

Findings from both the qualitative and quantitative studies showed that disclosure of status led to better and improved health outcomes in children living with HIV. In the quantitative study, findings showed that children whose HIV status had been disclosed had satisfactory adherence and compared to children whose status have not been disclosed as children who knew their status had higher adherence compared to those who did not know their status. This finding supports prior studies that found that disclosure positively affected medication adherence in children living with HIV (Britto, Mehta, Thomas & Shet, 2016; Bulali et al., 2018; Pinzón-iregui et al., 2013; Ramos et al., 2018). It, however, contradicts the study by Naidoo and McKerrow (2015) which found disclosure did not improve medication adherence as indexed by reduced viral load or increased CD4 cell count. A likely reason that may account for the different results is the method for measuring adherence in the children. While this study used a self-report measure for adherence, the study by Naidoo and McKerrow (2015) used clinical tests of viral load and CD4 count and a measure of adherence.

From the qualitative study, caregivers explained that disclosure made children more responsible towards taking their medication than when they were not aware of their status. Another reason why adherence was better in children whose status have been disclosed was that disclosure enabled the children to understand the reason for being on medications and hence resulted in a greater willingness to adhere to medications. This has been documented in earlier studies (Gyamfi et al., 2015; Kunapareddy et al., 2014; Vreeman et al., 2010; Perez & Leroy, 2009). For instance, Perez and Leroy (2009) explained that disclosure resulted in an increased motivation in the children as they now understand the need for adherence. Disclosure again helped these children to accept their HIV status, and come to terms with the fact that one of the key issues to a healthy life for them is to continuously take the antiretroviral medications. A possible reason that could further explain the improved adherence in children who knew their status was that disclosure gave them knowledge about the positive effect of antiretroviral therapy and resulted in a greater commitment to continue adherence. These reasons given above are rewards or positive benefits that caregivers believed would result from disclosure hence the supporting the consequence theory of disclosure. Children whose status had not been disclosed on the hand were reported to have problems with adherence as caregivers explained that they complained about the medications most of the time, were unwilling to take them and sometimes threw medications away.

On the impact of disclosure of status on psychological wellbeing, the quantitative study found that disclosure did not affect the wellbeing of children who knew their HIV status negatively as most caregivers were worried about. The study found that children whose HIV status had been disclosed had better psychological wellbeing than those children whose status have not been disclosed. This supports findings from earlier studies (Adefalu et al., 2017; Pinzón-iregui et al., 2013; Santamaria et al., 2011). Santamaria et al. (2011) for example, found disclosure did not affect the psychological functioning of children living with HIV as children who knew their HIV status reported less anxiety, depression and internalizing behaviour compared to children who did not know their HIV status.

There are a number of explanations as to why this is so. First, it is possible that disclosure eliminated all anxieties, tensions, and suspicions that existed between children and their caregivers due to the absence of communication about the children’s condition. With the disclosure of status, these negative thoughts and emotions were eliminated hence there was improved psychological wellbeing. The qualitative results confirms this as caregivers reported that their anxieties were eliminated as a result of disclosure. Secondly, disclosure also enabled the children to come to terms with their condition, to understand and accept comprehensive care and support from health professionals and caregivers in managing the condition leading to improved psychological wellbeing. This, therefore, provides evidence to debunk the notion that disclosure affects the mental or psychological wellbeing of children negatively.

5.5 Duration Of Disclosure And Health Outcomes In Children With HIV

A unique finding from this study was that the duration of disclosure (how long a child has been aware of his/her HIV status) mediated or explained the relationship between disclosure and psychological wellbeing. This addresses or explains the inconsistencies in the literature regarding disclosure and psychological wellbeing or health. The qualitative study revealed that, children who had been disclosed to experience some emotional reactions to the news of the infection as expressed in feelings of sadness, quietness, and withdrawal. These negative emotions were however alleviated as the children were able to adjust and bounce back in a few months and did not exhibit any of such emotions afterwards. It suggests that the longer children are aware of their HIV status, the more they are able to accept and adjust to it hence reducing significantly the negative emotions that come with disclosure. This was tested in a mediation analysis in the quantitative study and the result supported that of the qualitative study. Results indicated that the duration of disclosure significantly mediated the relationship between disclosure and psychological wellbeing.

A plausible reason for this finding is that the children were able to develop effective coping mechanisms as time went on to help them deal with the negative emotions they experience as a result of the disclosure. Also, with time these children are able to harness the support of family and health care professionals in dealing with the negative emotions that come with disclosure. For instance, in the qualitative study, caregivers indicated they provided the children with emotional support after disclosure and this helped the children with time to overcome the mood changes and other emotions that was present in the children after disclosure was made.

Duration of disclosure, however, did not mediate the relationship between disclosure and medication adherence. This could be due to the fact that the children had already formed adherence habits from childhood and as such the duration of disclosure could not have influenced adherence in these children. Also, there may be other individual (misconceptions, forgetfulness, medication side effects), social (social support), and structural (poverty, limited supply of antiretroviral drugs, stigma, and discrimination) factors that could affect adherence in children with HIV.

5.6 Disclosure and Health Outcomes in Caregivers

Disclosure is believed to have a positive impact on the health of caregivers. In this study, the qualitative results showed that disclosure relieved caregivers of the anxieties they had about having to disclose. However, they reported that the challenges they faced, particularly, financial difficulties due to unemployment and anxieties about lifelong medication in the children continued to persist. This means that the challenges or burdens faced by caregivers of children living with HIV are very daunting regardless of whether they have disclosed or not.

The quantitative findings confirmed this as there was no statistically significant difference between caregivers who disclosed and those who did not disclose on the two health outcome measures- caregiver burden and psychological health. This means that disclosure did not significantly lesson burden in caregivers nor did it improve their health significantly. This is contrary to a previous study by Gyamfi et al. (2015) where it was reported that caregivers believed that disclosure resulted in improved mental and psychological health.

A possible explanation for this finding is the fact a majority of caregivers still entertain fears that the children will divulge the news of their status to others. Also, the fear of stigmatization coupled with the many financial and social challenges almost all caregivers encounter could probably explain why disclosure did not influence psychological health and burden in caregivers. This is because these challenges were some of the important concerns raised by caregivers in the qualitative study.

5.7 Challenges and Support Systems of Caregivers of children living with HIV

Findings from this study indicated that caregivers of children living with HIV face a lot of challenges in performing their caregiving role. Prominent among these are financial constraints, anxieties about lifelong medication in the children, psychological distress and the burden of care. Although antiretroviral treatment is free in Ghana, caregivers reported financial challenges related to inadequate resources to cater for accommodation or rent, educational needs of the children as well as providing means of transport to the hospital for regular reviews. This supports previous studies (Bejane et al., 2013; Mafune, Lebese & Nemathaga 2017; Osafo, et al., 2017; Pacheco et al., 2016) which also found that financial difficulties were the greatest challenges faced by caregivers of children living with HIV. For instance, Osafo et al. (2017) found in Uganda that caregivers had difficulties providing food for their children due to financial constraints. These financial challenges could be explained by the fact that most of the caregivers are unemployed or are unable to ply their various trades because of the burden of having to care for their children as was reported in the qualitative findings and hence the financial constraints.

Another challenge expressed by caregivers is the anxiety, worry, and concern about their children being on medication for a lifetime. Most caregivers communicated their worry about their children taking the antiretroviral medications for the rest of their lives which they felt was going to be difficult for them because they are young. This is consistent with the study by Iacob et al. (2017) where it was found that lifelong treatment causes feelings of restraint leading to non-adherence. This resulted in some caregivers expressing the wish for children to be taken off the medications because of some the reactions that the children have due to the medications.

Again, caregivers in this study were burdened with care. As observed in the qualitative component, caregivers expressed concerns about the difficulty of having to combine work with caregiving roles. Some stated their inability to seek help (such as getting house helps) in caring for their children. Caregivers explained that they could not trust these helps not to spread the news of their diagnosis or that of their children. Therefore, they avoided this option and chose to care for the children alone. The burden of care in these caregivers was compounded by the fact that most of their partners were unavailable. Additionally, some caregivers had other family responsibilities such as caring for siblings and parents which also add up to their burden of care. These findings were confirmed in the quantitative component as both disclosed and non-disclosed caregivers scored very high on caregiver burden. These findings support earlier studies (Hayfron-Benjamin et al., 2018; Lentoor, 2017; Osafo et al., 2017). For instance, Lentoor (2017) found in South Africa that frequent medical appointments, unexpected hospitalizations, in addition to the day-to-day caregiving needs of the children contributed a huge burden to caregivers.

Lastly, this study found that caregivers reported some form of distress as a result of caring for the wellbeing of their children. This was characterized by feelings of sadness, frequent headaches due to thinking about the condition and sleepless nights. It is important to note that these distresses were experienced by both disclosed and non-disclosed caregivers. This finding is consistent with prior studies (Asadullah et al., 2017; Lentoor, 2017; Osafo et al., 2017). An explanation for why caregivers experience these distresses could be due to the challenges described above namely financial constraints, fears about lifelong adherence as well as the burden of care. These all come together to contribute to the distress reported by the caregivers because these demands could put a strain on caregivers psychologically.

Although caregivers face these numerous challenges, they received some form of support which aided them in dealing with the hurdles that caregiving comes with. Most caregivers reported religious coping, the belief and trust in a supreme being (God), in helping them through the many difficulties they face and view life with a positive attitude. Few of the caregivers who had their partners available also received a great deal of support and encouragement in dealing with the challenges they encounter daily. Lastly, caregivers also received financial support sometimes from some benevolent individuals within their various communities and this sometimes aided them to deal particularly with their financial challenges. These findings have also been reported in studies by Lentoor (2017) and Osafo et al. (2017). For instance, Lentoor (2017) found in South Africa that caregivers drew strength from their faith and this was essential accepting and coping with the child’s diagnosis of HIV and well as the challenges that it comes with. Osafo et al. (2017) also reported spiritually focused coping among caregivers of children living with HIV in Uganda.

In summary, this study has contributed significantly to our understanding of the influence of disclosure of HIV status on health outcomes in both children living with HIV and their caregivers. The study found that age was a significant predictor of disclosure. Poor adherence, curiosity, and transition to boarding school were the other reasons that encouraged disclosure in caregivers. On the other hand, fear of child not keeping diagnosis confidential, younger age, and fear of how children would react to disclosure discouraged the disclosure of status. Disclosure of status to children living with HIV improved medication adherence and psychological wellbeing in the children in children who knew their status compared to those who did not know. Disclosure, however, did not have any effect on caregiver outcomes (psychological health and caregiver burden). The duration of disclosure mediated the relationship between disclosure and psychological wellbeing of children with HIV but not disclosure and medication adherence. Caregivers reported challenges including financial and work challenges as well as unavailability of partners. However, support from faith or religious, partners and benevolent individuals helped caregivers to cope with these challenges.

5.8 Limitations of the Study

Notwithstanding the contributions of this study on the impact of disclosure of status on health outcomes in children living with HIV and their caregivers, there were some limitations of the study. Hence, there is a need to interpret the results of this study carefully, taking into account the following limitations. First of all, the study used a cross-sectional design which allows only associations to be drawn between a predictor variable and the outcome variables. Therefore, causation cannot be inferred from the results of this cross-sectional study. A greater percentage of the finding from this study, however, is in alignment or support with previous literature and hence the observed relationships in this study should not be overlooked. Secondly, using non-probability sampling methods did not allow for participants to be selected at random. That is, participants were subjectively selected for the study and this is susceptible to biases as it hinders in a way, the ability to draw inferences or generalize about the population under study (Sharma, 2017; Showkat & Parveen, 2017).

In addition, participants recruited for the study were relatively homogenous. Careful scrutiny of the demographic characteristics shows that a majority of the caregivers were mothers, had basic education and were the biological parents of the children while a majority of the children recruited for the study were males and mostly in basic schools. This makes it difficult in generalizing the results to caregivers who are fathers and children who are females particularly those in secondary institutions. Also, it will be difficult generalizing findings to other parts of the country since the study was conducted only within the Greater Accra Region where for instance standard of living may be higher than other parts of Ghana.

Lastly, the use of self-report measures in assessing both predictor and outcome variables is a shortcoming for the present study. Despite the fact that the measures were chosen for their sound psychometric properties, self-reports are characterized sometimes with some predispositions or biases such as social desirable responses, speculating or random responses, etc. (Demetriou, Uzun, & Essau, 2015; Lucas, 2018; Rosenman, Tennekoon, & Hill, 2011).

5.9 Recommendations for Future Research

Based on the limitations enumerated above, the following recommendations are suggested for future studies. First, it is recommended that future studies adopt a longitudinal study design to examine the impact of disclosure on health outcomes pre and post-disclosure. It would allow the impact of disclosure on health outcomes to be studied over time and help understand the cause and effect relationship between disclosure of status and health outcomes in children with HIV.

Second, future quantitative studies should make use of probability sampling as this allows random selection of participants and ensures that the sample is representative of the population. Also, random sampling ensures that the sample recruited is heterogeneous and would allow for greater ability to generalize finding to other settings and the total population. It is also recommended that future studies should include multiple measures other than self-report measures to counter or check for some of the biases that self-report measures are prone to. For example, medication adherence could be measured using both self-report measures as well clinical tests such as CD4 tests and viral load test as well pill count or pharmacy count.

Again, future studies should examine the impact of disclosure on other outcomes such as reproductive health behaviours including risky sexual behaviours. This is because there is a reason to believe that most children have early sexual debuts and engage in sexually risky behaviours at an early age. Finally, future qualitative studies should target the experiences of both children who know their status and those who do not as most qualitative studies that have been conducted in Ghana have focused mainly on the experiences of caregivers.

5.10 Implications for Clinical Care and Practice

The findings of the study have some implication for practice and clinical care. To begin, there is the need for the Ministry of Health and the Ghana Health Service to formulate and implement policies to improve the kind of care that is provided for children living with HIV as well as their caregivers particularly with regards to psychological care.

Health care professionals should encourage the disclosure of status among caregivers of children living with HIV as the present study has indicated that disclosure has a significant positive impact on medication adherence and psychological health. This is because it makes children understand the need for medication and are motivated to take more responsibility for their own health. Also, there is the need for a national disclosure framework to be developed by the Ministry of Health in conjunction with the Ghana Health Service and other stakeholders as recommended by the World Health Organization since Ghana is yet to have a national disclosure framework. This will provide health care professionals and caregivers with guidelines on how and when to disclose the HIV status of children to them. It will also be very valuable as the role that each stakeholder (health care professionals, caregivers, etc) plays in the disclosure process will be clearly delineated.

In developing this disclosure framework, there is also the need to take into account some contextual factors that prohibit and enhance disclosure as established by research. For instance, age should be one of the factors to be considered in developing a national disclosure framework. Also, the role psychologists and counselors are strengthened in developing the disclosure framework because the study revealed that their role is needed role in dealing with some of the psychological aftermaths of disclosure.

Also, there is a need for organizations like the Ghana AIDS Commission and the National AIDS Control Programme to formulate policies to reduce stigma against children with HIV as well as their families. This is because the impact of stigma permeates all facets of life of people living with HIV and their families such as disclosure, medication adherence as well as psychological wellbeing and burden of care. Lastly, care for children living with HIV should include psychological care not only for the children but also for the caregivers since they carry a greater percentage of the burden particular with regards to the care and wellbeing of these infected children.

5.11 Conclusion

This study revealed disclosure rates are still low with caregivers citing the child’s age, immaturity, fear of others knowing about the condition and stigma as some the barriers to disclosure while non-adherence, curiosity, and transition into high school were the factors that facilitated disclosure. Finding also showed that disclosure improved medication adherence and psychological wellbeing of children living with HIV. However, disclosure did not have any significant impact on the health outcomes of the caregivers. Disclosure should be encouraged in children living with HIV since it did not have any negative psychological consequences in children. Additionally, there is a need to incorporate psychological care for both children living with HIV and their caregivers since caregivers presented with a lot of burdens and psychological distresses.

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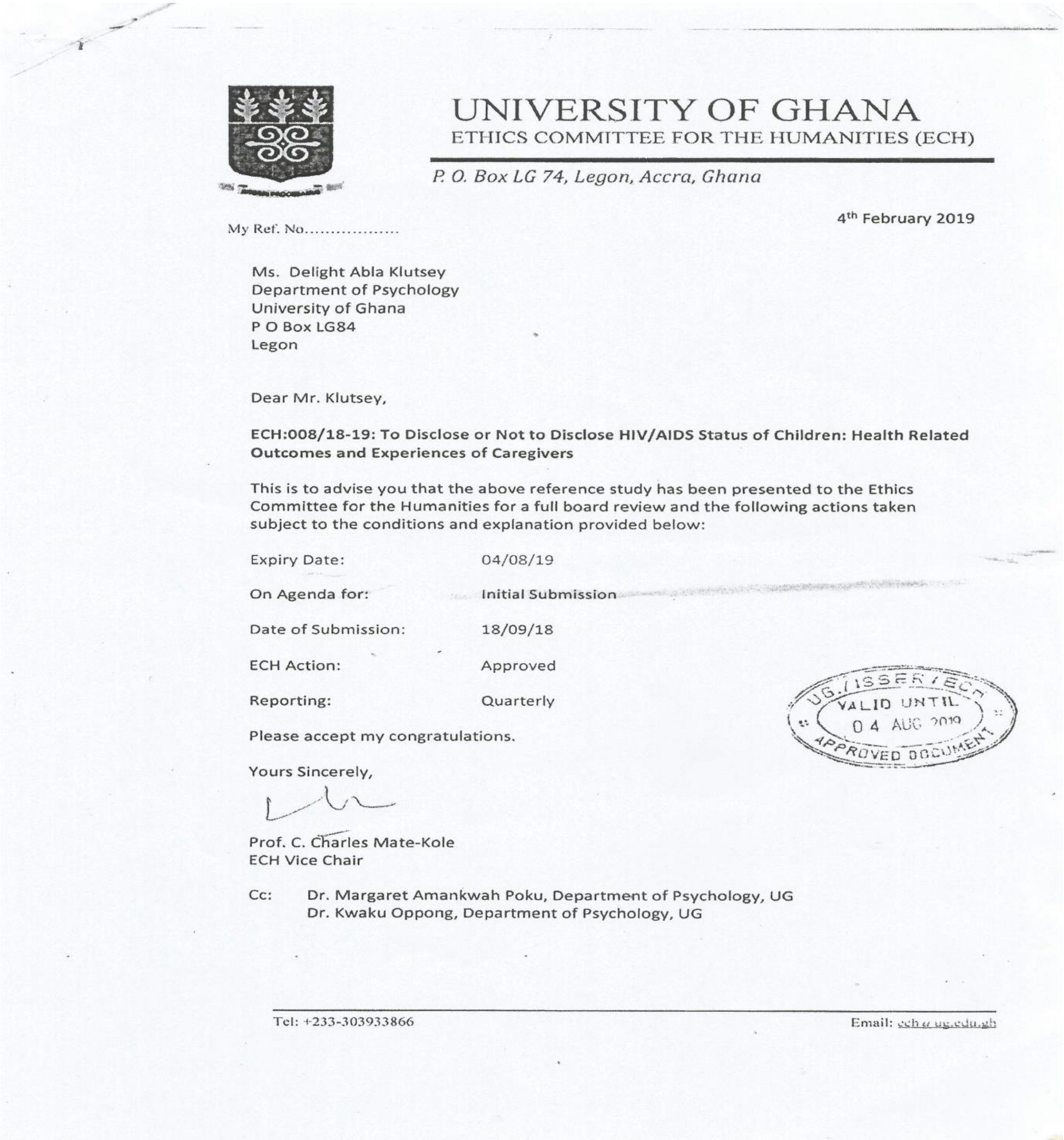
APPENDICES

Appendix A- Ethical Clearance from Ethics Committee for the Humanities (ECH)



UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)
P. O. Box LG 74, Legon, Accra, Ghana

4th February 2019

My Ref. No.................

Ms. Delight Abla Klutsey
Department of Psychology
University of Ghana
P O Box LG84
Legon

Dear Mr. Klutsey,

ECH:008/18-19: To Disclose or Not to Disclose HIV/AIDS Status of Children: Health Related Outcomes and Experiences of Caregivers

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities for a full board review and the following actions taken subject to the conditions and explanation provided below:

Expiry Date:	04/08/19
On Agenda for:	Initial Submission
Date of Submission:	18/09/18
ECH Action:	Approved
Reporting:	Quarterly

UG./ISSER/ECH
VALID UNTIL
04 AUG 2019
APPROVED DOCUMENT

Please accept my congratulations.

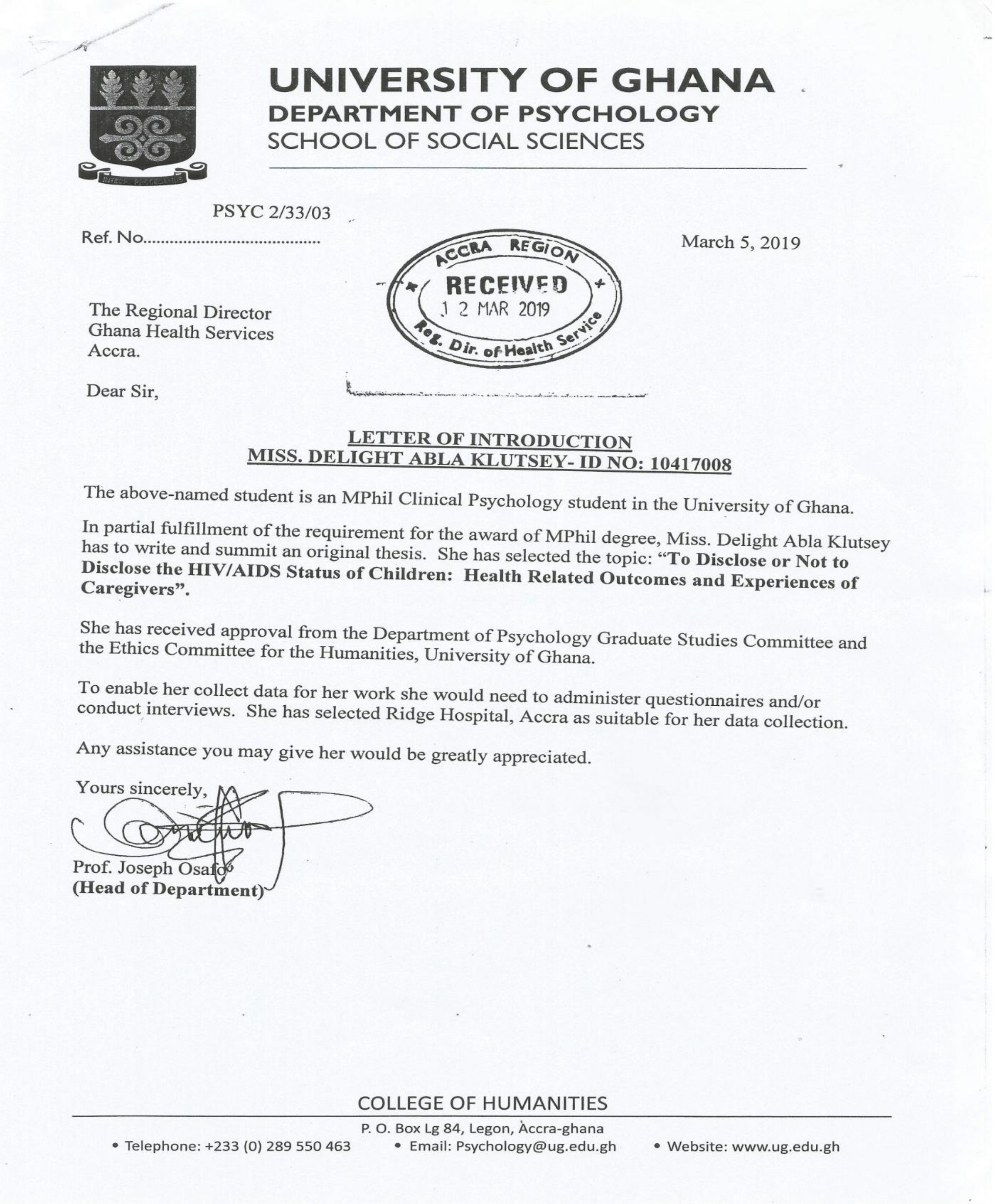
Yours Sincerely,

Prof. C. Charles Mate-Kole
ECH Vice Chair

Cc: Dr. Margaret Amankwah Poku, Department of Psychology, UG
Dr. Kwaku Oppong, Department of Psychology, UG

Tel: +233-303933866
Email: ech@ug.edu.gh

Appendix B - Introductory Letter from the Department of Psychology



UNIVERSITY OF GHANA
DEPARTMENT OF PSYCHOLOGY
SCHOOL OF SOCIAL SCIENCES

Ref. No. PSYC 2/33/03

March 5, 2019

ACCRA REGION
RECEIVED
12 MAR 2019
Reg. Dir. of Health Service

The Regional Director
Ghana Health Services
Accra.

Dear Sir,

LETTER OF INTRODUCTION
MISS. DELIGHT ABLA KLUTSEY- ID NO: 10417008

The above-named student is an MPhil Clinical Psychology student in the University of Ghana.

In partial fulfillment of the requirement for the award of MPhil degree, Miss. Delight Abla Klutsey has to write and summit an original thesis. She has selected the topic: **"To Disclose or Not to Disclose the HIV/AIDS Status of Children: Health Related Outcomes and Experiences of Caregivers".**

She has received approval from the Department of Psychology Graduate Studies Committee and the Ethics Committee for the Humanities, University of Ghana.

To enable her collect data for her work she would need to administer questionnaires and/or conduct interviews. She has selected Ridge Hospital, Accra as suitable for her data collection.

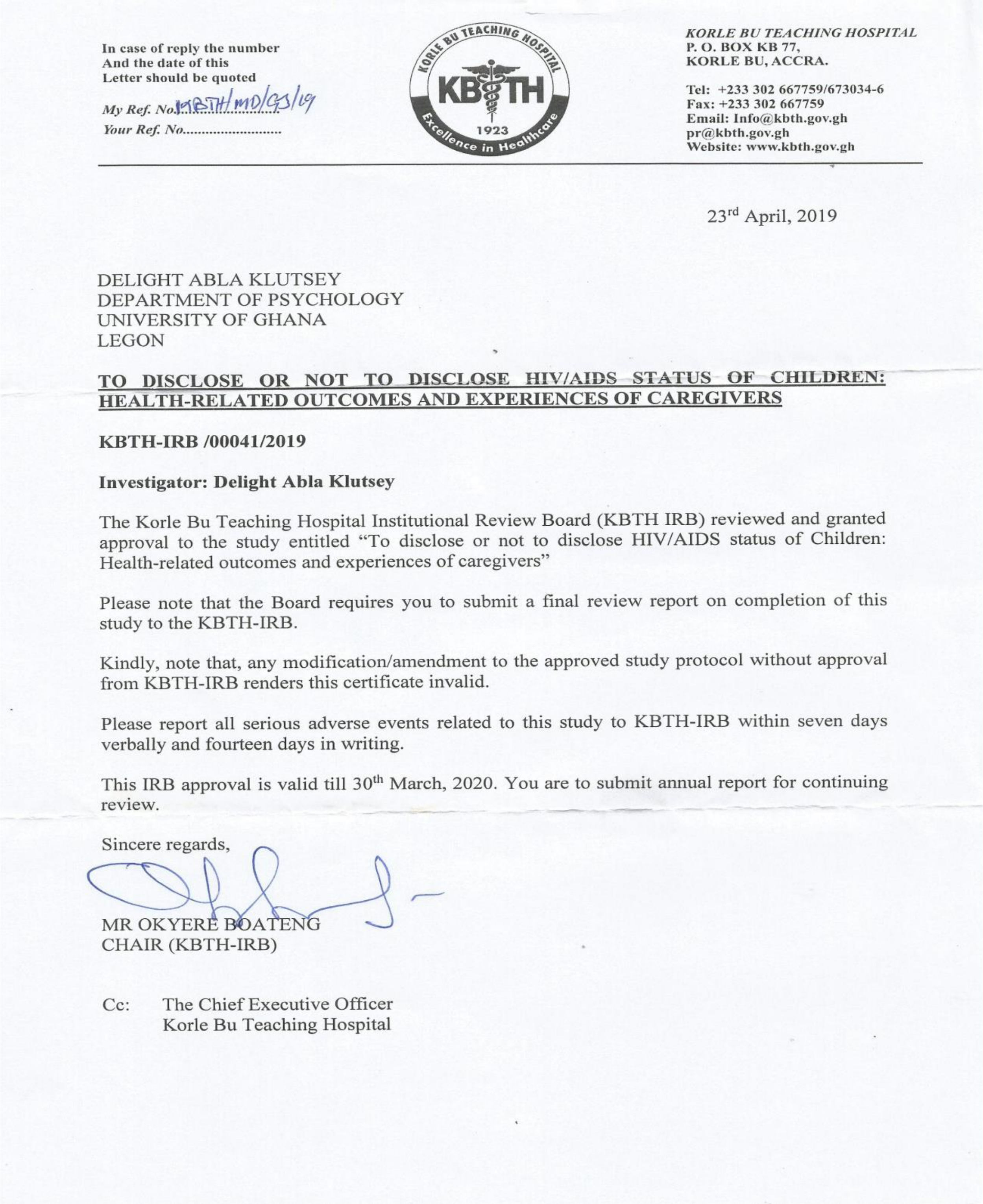
Any assistance you may give her would be greatly appreciated.

Yours sincerely,

Prof. Joseph Osafo
(Head of Department)

COLLEGE OF HUMANITIES
P. O. Box Lg 84, Legon, Accra-ghana
• Telephone: +233 (0) 289 550 463 • Email: Psychology@ug.edu.gh • Website: www.ug.edu.gh

Appendix C- Ethical Clearance from the Korle Bu Teaching Hospital



In case of reply the number
And the date of this
Letter should be quoted

My Ref. No. KBTH/MD/G3/19
Your Ref. No...........................

KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

23rd April, 2019

DELIGHT ABLA KLUTSEY
DEPARTMENT OF PSYCHOLOGY
UNIVERSITY OF GHANA
LEGON

TO DISCLOSE OR NOT TO DISCLOSE HIV/AIDS STATUS OF CHILDREN: HEALTH-RELATED OUTCOMES AND EXPERIENCES OF CAREGIVERS

KBTH-IRB /00041/2019

Investigator: Delight Abla Klutsey

The Korle Bu Teaching Hospital Institutional Review Board (KBTH IRB) reviewed and granted approval to the study entitled "To disclose or not to disclose HIV/AIDS status of Children: Health-related outcomes and experiences of caregivers"

Please note that the Board requires you to submit a final review report on completion of this study to the KBTH-IRB.

Kindly, note that, any modification/amendment to the approved study protocol without approval from KBTH-IRB renders this certificate invalid.

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

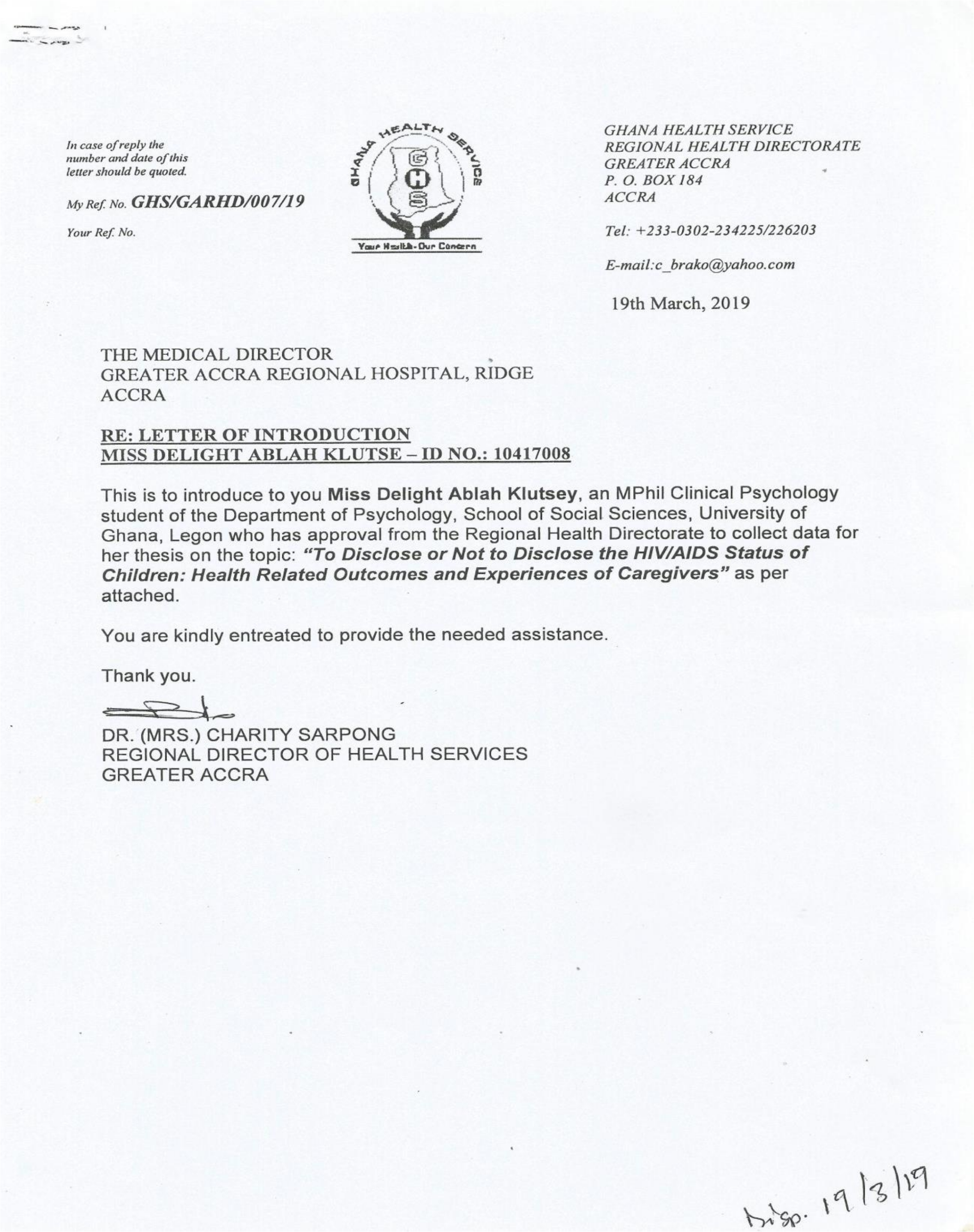
This IRB approval is valid till 30th March, 2020. You are to submit annual report for continuing review.

Sincere regards,

MR OKYERE BOATENG
CHAIR (KBTH-IRB)

Cc: The Chief Executive Officer
Korle Bu Teaching Hospital

Appendix D - Ethical Clearance from the Ghana Health Service- Greater Accra Regional Directorate



In case of reply the
number and date of this
letter should be quoted.

My Ref. No. ***GHS/GARHD/007/19***

Your Ref. No.

GHANA HEALTH SERVICE
REGIONAL HEALTH DIRECTORATE
GREATER ACCRA
P. O. BOX 184
ACCRA

Tel: +233-0302-234225/226203

E-mail:c_brako@yahoo.com

19th March, 2019

THE MEDICAL DIRECTOR
GREATER ACCRA REGIONAL HOSPITAL, RIDGE
ACCRA

RE: LETTER OF INTRODUCTION
MISS DELIGHT ABLAH KLUTSE – ID NO.: 10417008

This is to introduce to you **Miss Delight Ablah Klutsey**, an MPhil Clinical Psychology student of the Department of Psychology, School of Social Sciences, University of Ghana, Legon who has approval from the Regional Health Directorate to collect data for her thesis on the topic: ***"To Disclose or Not to Disclose the HIV/AIDS Status of Children: Health Related Outcomes and Experiences of Caregivers"*** as per attached.

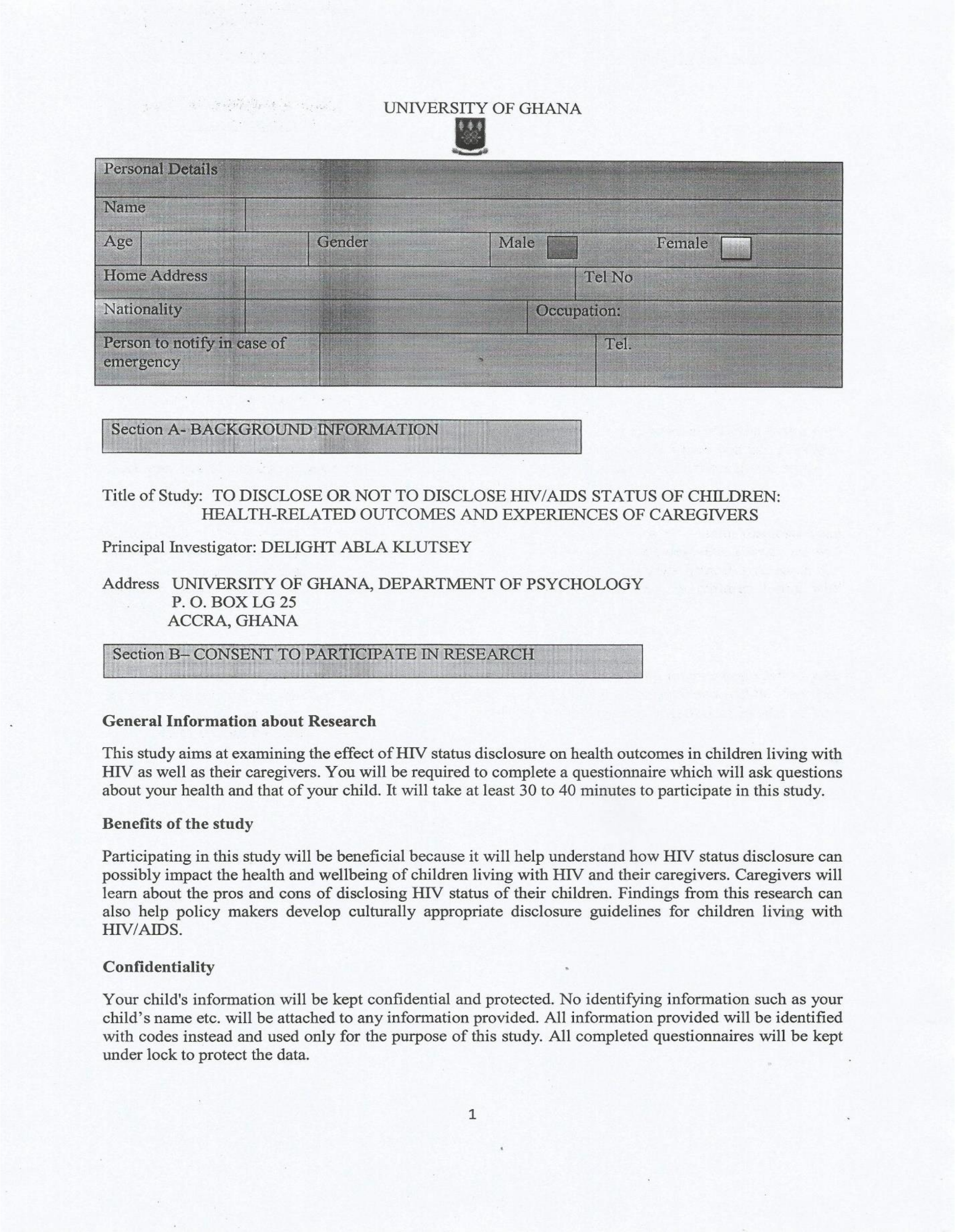
You are kindly entreated to provide the needed assistance.

Thank you.

DR. (MRS.) CHARITY SARPONG
REGIONAL DIRECTOR OF HEALTH SERVICES
GREATER ACCRA

Disp. 19/3/19

Appendix E- Questionnaires



UNIVERSITY OF GHANA

Personal Details				
Name				
Age		Gender	Male ☐	Female ☐
Home Address		Tel No		
Nationality		Occupation:		
Person to notify in case of emergency		Tel.		

Section A- BACKGROUND INFORMATION

Title of Study: TO DISCLOSE OR NOT TO DISCLOSE HIV/AIDS STATUS OF CHILDREN: HEALTH-RELATED OUTCOMES AND EXPERIENCES OF CAREGIVERS

Principal Investigator: DELIGHT ABLA KLUTSEY

Address UNIVERSITY OF GHANA, DEPARTMENT OF PSYCHOLOGY
P. O. BOX LG 25
ACCRA, GHANA

Section B– CONSENT TO PARTICIPATE IN RESEARCH

General Information about Research

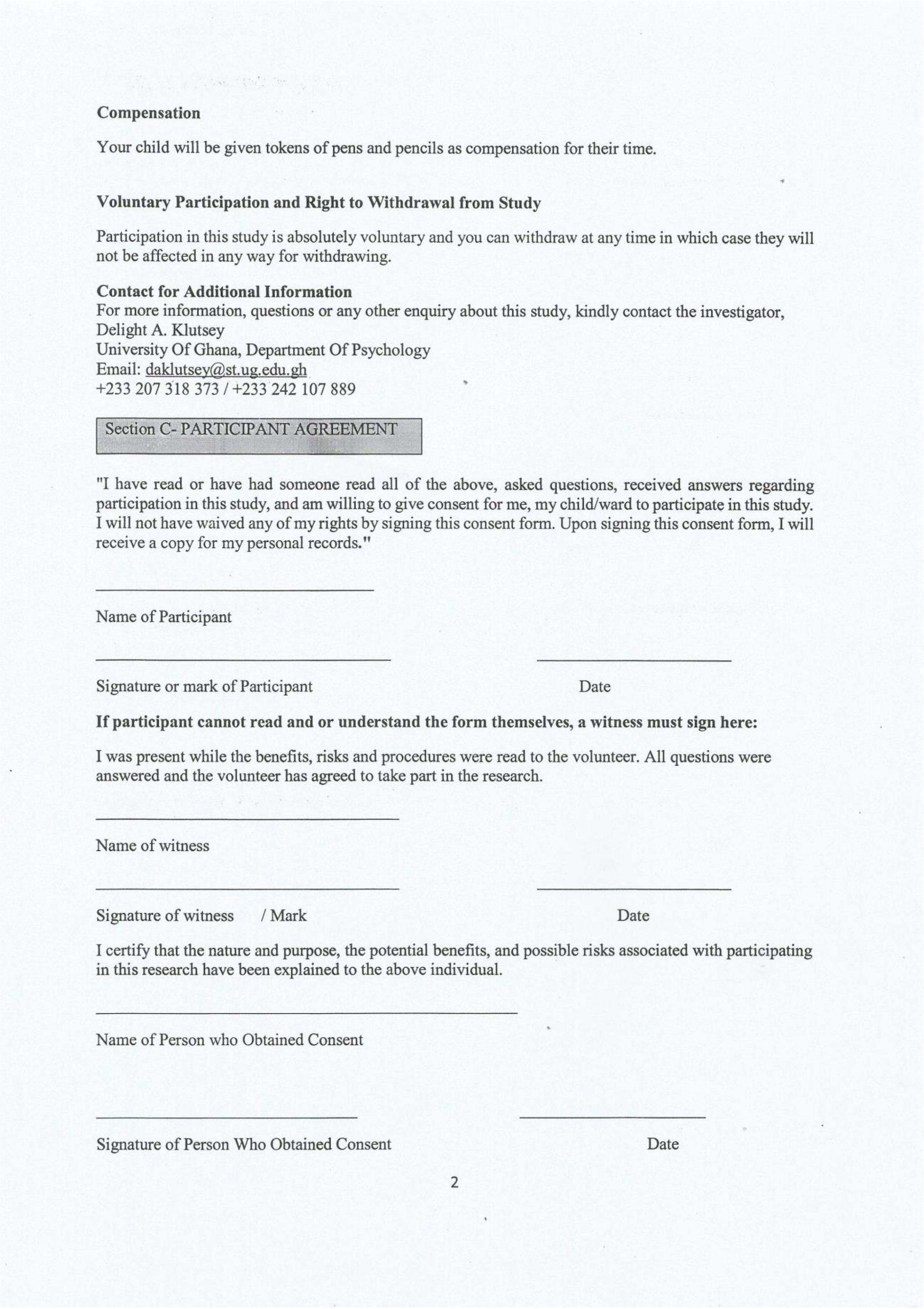
This study aims at examining the effect of HIV status disclosure on health outcomes in children living with HIV as well as their caregivers. You will be required to complete a questionnaire which will ask questions about your health and that of your child. It will take at least 30 to 40 minutes to participate in this study.

Benefits of the study

Participating in this study will be beneficial because it will help understand how HIV status disclosure can possibly impact the health and wellbeing of children living with HIV and their caregivers. Caregivers will learn about the pros and cons of disclosing HIV status of their children. Findings from this research can also help policy makers develop culturally appropriate disclosure guidelines for children living with HIV/AIDS.

Confidentiality

Your child's information will be kept confidential and protected. No identifying information such as your child's name etc. will be attached to any information provided. All information provided will be identified with codes instead and used only for the purpose of this study. All completed questionnaires will be kept under lock to protect the data.



Compensation

Your child will be given tokens of pens and pencils as compensation for their time.

Voluntary Participation and Right to Withdrawal from Study

Participation in this study is absolutely voluntary and you can withdraw at any time in which case they will not be affected in any way for withdrawing.

Contact for Additional Information

For more information, questions or any other enquiry about this study, kindly contact the investigator,
Delight A. Klutsey
University Of Ghana, Department Of Psychology
Email: daklutsey@st.ug.edu.gh
+233 207 318 373 / +233 242 107 889

Section C- PARTICIPANT AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

Name of Participant

Signature or mark of Participant Date

If participant cannot read and or understand 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.

Name of witness

Signature of witness / Mark Date

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.

Name of Person who Obtained Consent

Signature of Person Who Obtained Consent Date

2

A. USAID - AMPATH CAREGIVER HIV DISCLOSURE QUESTIONNAIRE

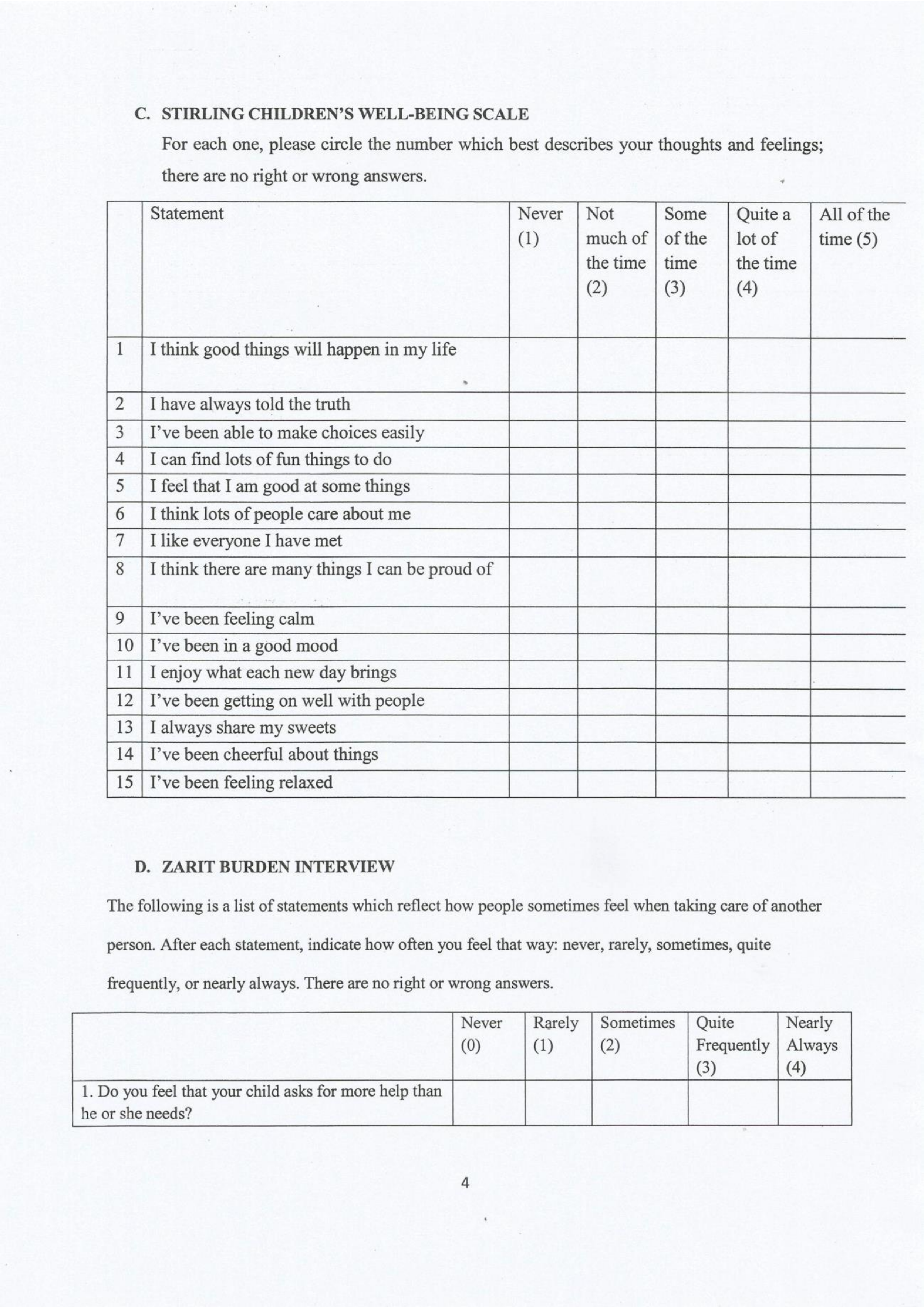
Kindly answer Yes or No to the following Questions

1. Does the child know that he or she comes to the Clinic for HIV care? Yes ☐ No ☐
2. Does the child know he or she has HIV? Yes ☐ No ☐
3. Does the child know that the name of his or her illness is HIV? Yes ☐ No ☐
4. Does the child know he or she is taking medicine for HIV? Yes ☐ No ☐
5. Does the child understand what HIV is? Yes ☐ No ☐

B. MEDICATION ADHERENCE RATING SCALE; MARS

Kindly respond to the statements below by circling the answer which best describes your behaviour or attitude towards their medication ***during the past week***.

Question	**Yes**	**No**
1 Do you ever forget to take your medication?		
2 Are you careless at times about taking your medication		
3 When you feel better, do you sometimes stop taking your medication?		
4 Sometimes if you feel worse when you take the medication, do you stop taking it?		
5 I take my medication only when I am sick		
6 It is unnatural for my mind and body to be controlled by medication		
7 I know why I am on medication		
8 By staying on medication, I can prevent getting sick.		
9 I feel weird, or strange being on medication		
10 Medication makes me feel tired and slow		



C. STIRLING CHILDREN'S WELL-BEING SCALE

For each one, please circle the number which best describes your thoughts and feelings; there are no right or wrong answers.

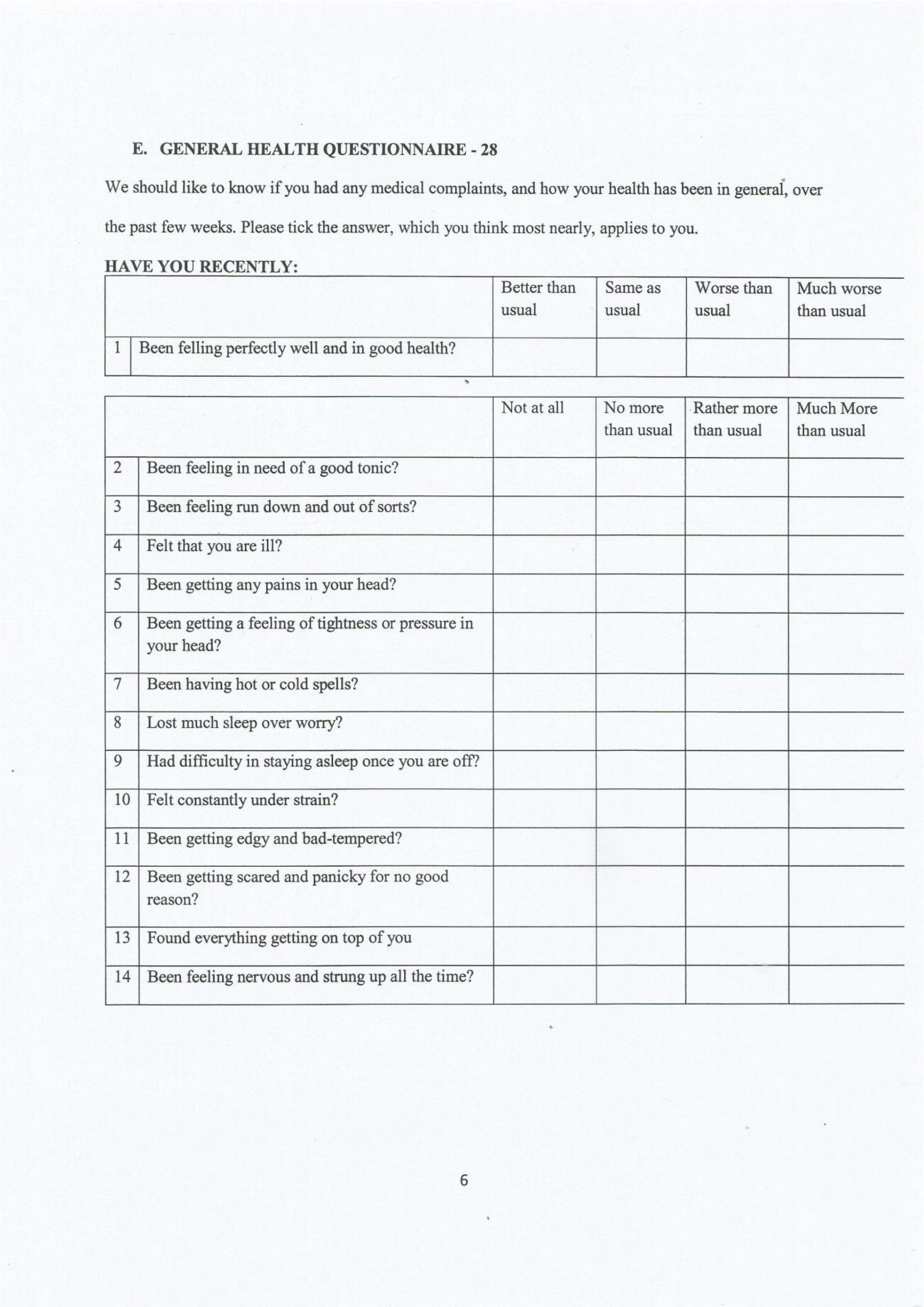
	Statement	Never (1)	Not much of the time (2)	Some of the time (3)	Quite a lot of the time (4)	All of the time (5)
1	I think good things will happen in my life					
2	I have always told the truth					
3	I've been able to make choices easily					
4	I can find lots of fun things to do					
5	I feel that I am good at some things					
6	I think lots of people care about me					
7	I like everyone I have met					
8	I think there are many things I can be proud of					
9	I've been feeling calm					
10	I've been in a good mood					
11	I enjoy what each new day brings					
12	I've been getting on well with people					
13	I always share my sweets					
14	I've been cheerful about things					
15	I've been feeling relaxed					

D. ZARIT BURDEN INTERVIEW

The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
1. Do you feel that your child asks for more help than he or she needs?					

2. Do you feel that, because of the time you spend with your child, you don't have enough time for yourself?					
3. Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed about your child's behavior?					
5. Do you feel angry when you are around your child?					
6. Do you feel that your child currently affects your relationship with other family members?					
7. Are you afraid about what the future holds for your child?					
8. Do you feel that your child is dependent upon you?					
9. Do you feel strained when you are around your child?					
10. Do you feel that your health has suffered because of your involvement with your child?					
11. Do you feel that you don't have as much privacy as you would like, because of your child?					
12. Do you feel that your social life has suffered because you are caring for your child?					
13. Do you feel uncomfortable having your friends over because of your child?					
14. Do you feel that your child seems to expect you to take care of him or her as if you were the only one he or she could depend on?					
15. Do you feel that you don't have enough money to care for your child, in addition to the rest of your expenses?					
16. Do you feel that you will be unable to take care of your child much longer?					
17. Do you feel that you have lost control of your life since your child's condition?					
18. Do you wish that you could just leave the care of your relative to someone else?					
19. Do you feel uncertain about what to do about your child?					
20. Do you feel that you should be doing more for your child?					
21. Do you feel that you could do a better job caring for your child?					
22. Overall, how burdened do you feel in caring for your child?					



E. GENERAL HEALTH QUESTIONNAIRE - 28

We should like to know if you had any medical complaints, and how your health has been in general, over the past few weeks. Please tick the answer, which you think most nearly, applies to you.

HAVE YOU RECENTLY:

		Better than usual	Same as usual	Worse than usual	Much worse than usual
1	Been felling perfectly well and in good health?				

		Not at all	No more than usual	Rather more than usual	Much More than usual
2	Been feeling in need of a good tonic?				
3	Been feeling run down and out of sorts?				
4	Felt that you are ill?				
5	Been getting any pains in your head?				
6	Been getting a feeling of tightness or pressure in your head?				
7	Been having hot or cold spells?				
8	Lost much sleep over worry?				
9	Had difficulty in staying asleep once you are off?				
10	Felt constantly under strain?				
11	Been getting edgy and bad-tempered?				
12	Been getting scared and panicky for no good reason?				
13	Found everything getting on top of you				
14	Been feeling nervous and strung up all the time?				

		More so than usual	Same as usual	Rather less than usual	Much less than usual
15	Been managing to keep yourself busy and occupied?				

		Quicker than usual	Same as usual	Longer than usual	Much longer than usual
16	Been taking longer over the things you do?				

		Better than usual	About the same	Less than usual	Much less than usual
17	Felt on the whole you were doing things well?				

		More satisfied	About the same	Less satisfied	Much less satisfied
18	Been satisfied with the way you've carried out your task??				

		More so than usual	Same as usual	Less useful than usual	Much less useful
19	Felt that you are playing a useful part in things?				

		More so than usual	Same as usual	Less so than usual	Much less capable
20	Felt capable of making decisions about things?				

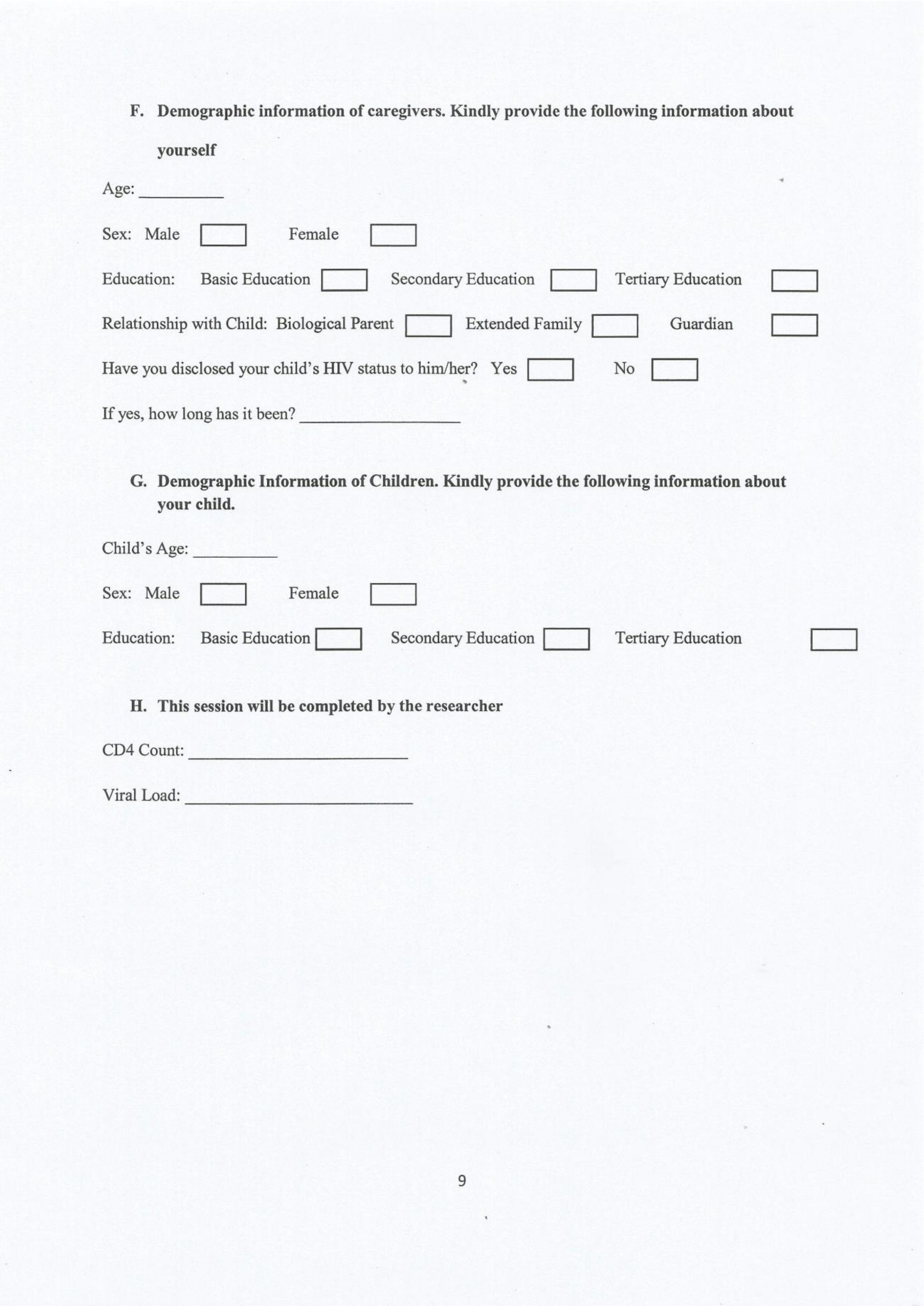
		More so than usual	Same as usual	Less so than usual	Much more than usual
21	Been able to enjoy your normal day to day activities?				

		Not at all	No more than usual	Rather more than usual	Much More than usual
22	Been thinking of yourself as a worthless person?				
23	Felt that life is entirely hopeless?				
24	Felt that life isn't worth living?				

		Definitely Not	I don't think so	Has crossed my mind	Definitely, have
25	Thought of the possibility that you might take away with yourself?				

		Not at all	No more than usual	Rather more than usual	Much More than usual
26	Found at times you couldn't do anything because your nerves were too bad?				
27	Found yourself wishing you were dead and away from it all?				

		Definitely Not	I don't think so	Has crossed my mind	Definitely, have
28	Felt that the ideas of taking your own life kept coming to your mind?				



F. Demographic information of caregivers. Kindly provide the following information about yourself

Age: __________

Sex: Male ☐ Female ☐

Education: Basic Education ☐ Secondary Education ☐ Tertiary Education ☐

Relationship with Child: Biological Parent ☐ Extended Family ☐ Guardian ☐

Have you disclosed your child's HIV status to him/her? Yes ☐ No ☐

If yes, how long has it been? ___________________

G. Demographic Information of Children. Kindly provide the following information about your child.

Child's Age: __________

Sex: Male ☐ Female ☐

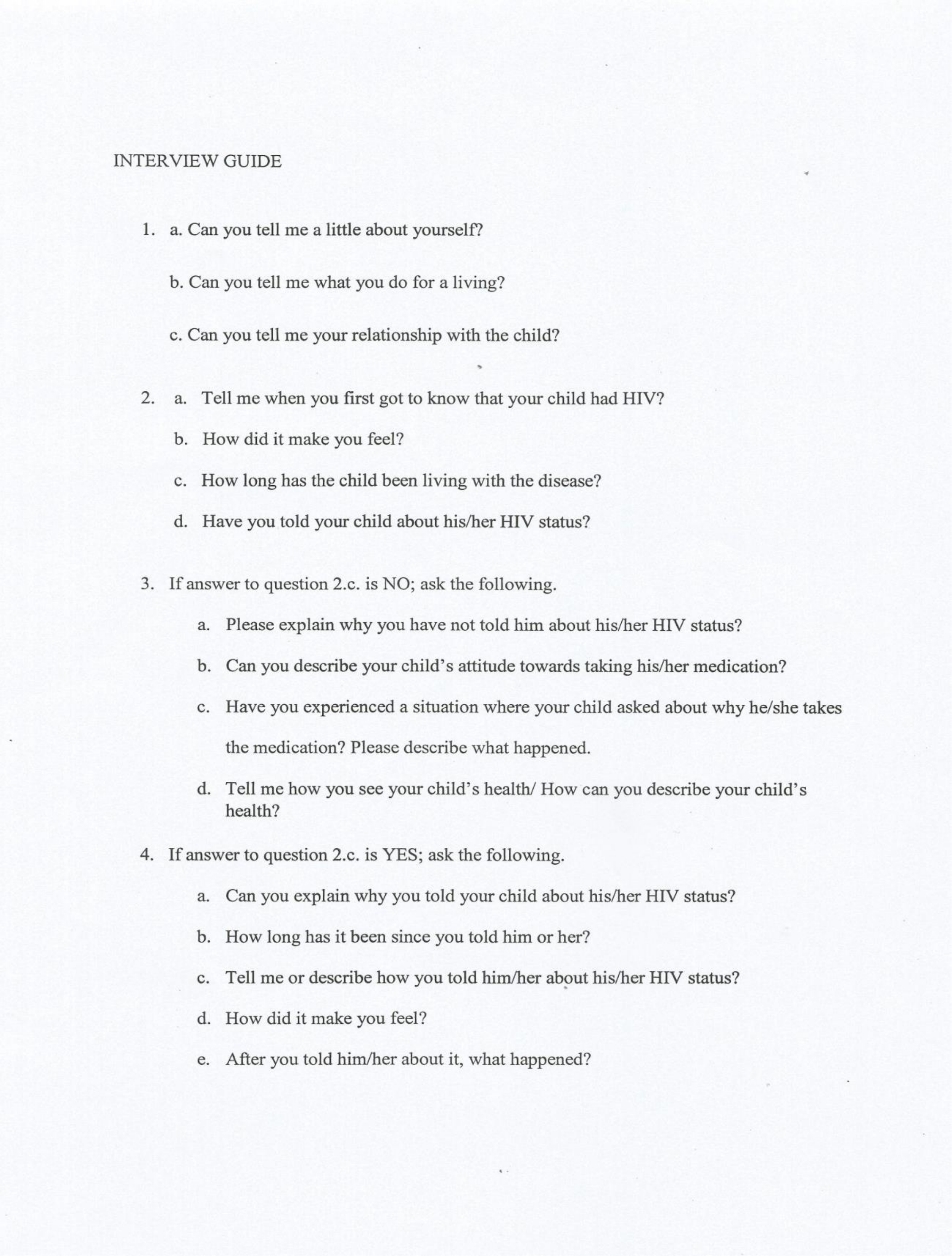
Education: Basic Education ☐ Secondary Education ☐ Tertiary Education ☐

H. This session will be completed by the researcher

CD4 Count: __________________________

Viral Load: ___________________________

Appendix F – Semi-Structured Interview Guide



INTERVIEW GUIDE

1. a. Can you tell me a little about yourself?

   b. Can you tell me what you do for a living?

   c. Can you tell me your relationship with the child?

2. a. Tell me when you first got to know that your child had HIV?
   b. How did it make you feel?
   c. How long has the child been living with the disease?
   d. Have you told your child about his/her HIV status?

3. If answer to question 2.c. is NO; ask the following.
   a. Please explain why you have not told him about his/her HIV status?
   b. Can you describe your child's attitude towards taking his/her medication?
   c. Have you experienced a situation where your child asked about why he/she takes the medication? Please describe what happened.
   d. Tell me how you see your child's health/ How can you describe your child's health?

4. If answer to question 2.c. is YES; ask the following.
   a. Can you explain why you told your child about his/her HIV status?
   b. How long has it been since you told him or her?
   c. Tell me or describe how you told him/her about his/her HIV status?
   d. How did it make you feel?
   e. After you told him/her about it, what happened?

    f. Describe how you see your child's attitude towards taking his or her medication before and after you had told him/her about his/her HIV status?
    g. Tell me how you see your child's health before and after you had told him/her about his/her HIV status.
    h. Has anything changed? Tell me how?

5. a. Describe how the experience has been like caring for a child with HIV?
    b. Tell me some of challenges you face if any, caring for the child?
    c. Can you tell some of things that have helped you perform your caregiving role?
    d. Tell me if caring for this child has affected you in any way. Physically, emotionally, financially or ….?
6. If answer to question 2.c. was YES; ask the following.
    a. Describe the impact that disclosure of the child HIV status has had on you personally.
    b. Describe how disclosure has impacted the relationship between you and your child.
7. Is there anything else, you would like to tell me about?