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EXPERIENCES OF CAREGIVERS ON DISCLOSURE OF CHILDHOOD HIV POSITIVE STATUS TO AFFECTED CHILDREN IN THE HO MUNICIPALITY

BY

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DECLARATION

I, Celestine Yakanu, hereby declare that this thesis is my own original research I undertook as part of the requirement for the award of MPhil in Nursing except where otherwise indicated. This research has been undertaken with the guidance and supervision of Dr. Mary Ani-Amponsah and Dr. Gladys Dzansi both of the School of Nursing and Midwifery, University of Ghana, Legon. I also declare that I have not previously submitted any part or entire work contained in this thesis to any other university to obtain any degree.

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ABSTRACT

Disclosure of HIV positive status to children who acquired the infection perinatally is very crucial in their management and has been shown to have numerous benefits. However, HIV status disclosure rates to children living with HIV are still low in low-and middle-income countries. This study explored the experiences of caregivers regarding disclosure of HIV positive status to their children (6-12years) using the Theory of Planned Behaviour. In-depth interviews were conducted with 13 caregivers from two health facilities in the Ho municipality. Participants were selected using a purposive sampling technique. The audio-recorded interviews were transcribed, coded, and analysed using thematic analysis. The findings revealed that caregivers possessed negative attitudes towards HIV status disclosure to children. Most caregivers expressed fear of negative psychological reactions from the children and the ability of children to maintain secrecy. Most caregivers perceived disclosure as a discreet event and so they are delaying disclosure to an older age. Caregivers also reported that they perceived negative normative influence from significant others to disclose. The major barriers identified to be inhibiting disclosure to the children are fear of stigma, discrimination, low self-efficacy, inadequate knowledge on HIV, school-related factors, lack of disclosure teaching and lack of child-focused care at the clinics. Most caregivers said they need nurses' support to be able to disclose. They cited 17-18 years as the preferred age they intended to disclose. The findings suggest that factors influencing HIV positive status disclosure to children with HIV are multiple, complex, and unique to each family. Family-centred disclosure interventions are needed to address the specific concerns of each family and facilitate safe HIV disclosure to children in this setting. This study offers future research directions on developing protocols for HIV disclosure to children and capacity building approaches for child caregivers.

Keywords: Children, Disclosure, Experience, HIV, Caregivers

DEDICATION

To God be all the Glory. I cannot pay You, Lord Jesus.

This thesis is dedicated to my brother Linus Bozambo Yakanu. God bless you my lovely brother.

I also dedicate this to my mother Justine Norviegbor Nyahe-Yakanu for her spiritual support through prayers and supplications for me on daily basis.

This is also dedicated to all my spiritual fathers, Bishop David Oyedepo, Dr. Kenneth Copeland, Pastor E. A. Adeboye, Dr. Jerry Savelle, and Dr. Bill Winston.

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Finally, I dedicate this research to all children living with HIV and their resilient caregivers.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CLHIV	Children Living With HIV
GAC	Ghana AIDS Commission
GES	Ghana Education Service
GHS	Ghana Health Service
HIV	Human Immunodeficiency Virus
LMIC	Low and Middle Income Countries
MOH	Ministry of Health
NACP	National AIDS Control Programme
NMC	Nursing and Midwifery Council
PLHIV	People Living with HIV
SES	Socioeconomic Status
SSA	Sub-Saharan Africa
TPB	Theory of Planned Behaviour
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children’s Fund
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

This chapter provides the background to the study, the problem statement, the purpose of the study, research objectives, research questions, definition of key terms used in the study and significance of the study. The chapter ends with the organisation of the entire thesis.

1.1 Background of the Study

Disclosure of HIV positive status to children who acquired the infection via perinatal transmission is a global public health concern. Globally, it is estimated that approximately 38 million people were living with Human Immunodeficiency Virus (HIV) infection and Acquired Immunodeficiency Syndrome (AIDS) in 2019. Out of this number, a total of 1.8 million were children who were younger than 15 years old (UNAIDS, 2020b). In 2019, a total of 1.7 million new HIV infections occurred globally and 150,000 were among children below 15 years of age (UNAIDS, 2020b). An estimated 690, 000 people died of AIDS and associated illnesses globally in 2019. An estimated 130,000 HIV-related deaths occurred in children who were younger than 20 years of age in 2018. Approximately 90 percent of infected children are living in sub-Saharan Africa (SSA)(UNICEF, 2018) and accounted for more than two-thirds of the global statistics (UNAIDS, 2018; UNICEF, 2018).

Although there is no cure for HIV, (World Health Organisation (WHO), 2018), antiretroviral (ARV) medications have effectively reduced its severity so that it is now being managed as a chronic disease (Deeks, Lewin, & Havlir, 2013). This shift in the disease process is causing an increase in the survival of children with HIV infection (Deeks, Lewin, & Havlir, 2013). Children who are infected live longer and near to normal lives as their non-infected peers (Banerjee, Pensi, Banerjee, & Grover, 2010; Deeks et al., 2013). However, this improved survival is associated with the challenge of disclosing HIV infection to children infected through their mothers (Meena, Hemal, & Arora 2018; Negese et al., 2012; Ngeno et al., 2019). There is an ethical dilemma as parents and healthcare professionals (HCPs) have to weigh the benefits and risks of disclosure. It is argued that hiding HIV diagnosis from infected children violates their right to health information and HIV-related services available to them (Chilemba & Phiri, 2017; Hudson, Sprigsgs, & Gillam, 2019). Children who are not informed about their HIV positive status usually question their caregivers on reasons for prolonged medicine intake and frequent hospital follow-ups even though they are healthy (Lorenz et al., 2016; Okechukwu et al., 2018). Disclosure becomes necessary if the children start demanding explanations for continuous medicine intake and frequent visits to the hospital (Evangeli & Kagee, 2016; Meena et al., 2018).

Paediatric HIV status disclosure has been defined in several studies (Britto, Mehta, Thomas, & Shet, 2016; Krauss et al., 2013). Disclosure of childhood HIV status entails informing the infected children about their HIV positive status. Paediatric HIV disclosure is done in a gradual and iterative pattern but not as a one-off event. Disclosure could either occur as a partial or total phenomenon. Full disclosure occurs when children are informed that they have HIV, and partial disclosure is when the child is informed that they have another illness but there is no mention of HIV. No disclosure occurs when the children are not told anything about their sickness (Krauss et al., 2013).

Revealing HIV positive diagnosis to infected children is important in their care (Arrivé et al., 2018). However, disclosure is a challenge for children, HCPs, and caregivers (Das, Detels, Javanbakht, & Panda, 2016; Stein et al., 2019). Disclosure of HIV positive status to children involves informing them about a disease that is highly transmissible, highly stigmatized and potentially life-threatening. Due to this, caregivers and HCPs usually argue about the age for the disclosure and how much to tell their children (Klitzman, Marhefka, Mellins, & Wiener, 2008).

Several studies have established that disclosure has numerous benefits for the children, their families and society (Arage, Tessema, & Kassa, 2014; Cluver et al., 2015; Mehta, Ekstrand, Heylen, Sanjeeva, & Shet, 2016). These benefits include a reduction in loss to follow up (Ngeno et al., 2019), prevention of reinfection and reduced viral loads (VL) and decrease in risk of horizontal HIV transmission, improved medication adherence, improved emotional and physical health, and quality of life (Cluver et al., 2015; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013). A study conducted in Kenya (Ngeno et al., 2019) found high mortality in non-disclosed children compared to children who were aware of their status. In South Africa, high adherence was found in children after disclosure, particularly those who were informed about their status before twelve years (Cluver et al., 2015). Similar findings were reported in Ethiopia (Arage et al., 2014).

Despite these benefits, studies and systematic reviews show low disclosure rates in children in Low-and-Middle-Income Countries (LMICs) (Nichols, Steinmetz, & Paintsil, 2017; Pinzón-iregui, Beck-sagué, & Malow, 2013; Vreeman et al., 2013). The WHO published a guideline on HIV disclosure to children in 2011. This guideline suggests early and progressive disclosure to children between the ages of 6 to 12 (WHO, 2011). The guideline recommends that the cognitive and emotional maturity of the individual child should be considered until full disclosure occurs by 12 years of age (WHO, 2011). This early and gradual disclosure helps the children to develop autonomy as they reach adolescence (Chilemba & Phiri, 2017) and for a smooth transfer to adult care by the age of 12.

Yet caregivers delay disclosure until the children become fully mature or accidentally realise their HIV positive status. Delayed disclosure results in self-stigmatization (McHugh et al., 2018), an exhibition of aggressive behaviour such as rebellion, refusing medications, and anger towards their caregivers (Lowenthal et al., 2014). Furthermore, accidental disclosure may occur which can result in emotional distress for the children (Biru, Lunqvist, Molla, Jerene, & Hallström, 2018; Madiba & Mokwena, 2012; Myburgh et al., 2018). Studies have also reported that children experience full disclosure in a single seating due to a lack of disclosure planning by caregivers (Appiah et al., 2019; Bernays, Paparini, Gibb, & Seeley, 2016). A study conducted in 2016 found that caregivers did not routinely prepare and plan for disclosure but only saw the need to disclose if the children start questioning their treatment (Lorenz et al., 2016). Contrarily, the majority (89%) of disclosures in an Indian study were planned (Kodyalamoole, Badiger, Kiran, Dodderi, & Rewari, 2018).

The attitude of the caregivers towards disclosure is another factor that could also influence their decision to disclose to their children. It has been found that biological parents are usually reluctant to disclose to their children who got the infection from them (Gachanger & Burkholder 2016; Hayfron-Benjamin et al, 2018). Disclosure is difficult for biological mothers because they feel the child may blame them for the infection leading to feelings of guilt and shame that they had lived careless lives (Evangeli & Kagee, 2016; Madiba & Mokwena, 2012). There have been several negative behavioural beliefs among caregivers about the consequences of disclosure by early studies conducted. These include perceptions of the immaturity of the children to understand HIV, the inability of the children to keep the diagnosis a secret (Lencha, Ameya, Minda, Lamessa, & Darega, 2018; McHugh et al., 2018; Ubesie et al., 2016), fear of stigma and discrimination, fear of negative emotional, psychological and health consequences (Kalembo, Kendall, Ali, & Chimwaza, 2019; Lencha et al., 2018; Negese et al., 2012) and fear of blame and concerns that the child will be sad and worried if they know their HIV status (Jemmott III et al., 2014).

Concerning perceptions on the appropriate age for disclosure to occur, it has been reported in an Indian study that caregivers feel that 10-12 years is the most appropriate age for HIV disclosure to occur (Meena et al., 2018). Other studies have found that caregivers preferred to disclose HIV positive status to their children at an older age of 14-17 years (Bulali, Kibusi, & Mpondo, 2018; Priya, Nayar, & Purushothaman, 2019). Lack of self-efficacy to disclose and manage the reactions of the child to disclosure has also been found to be influencing the decisions of caregivers to disclose HIV positive status to their children with living HIV (Madiba, 2016; Mweemba et al., 2015). Studies have reported that caregivers require professional aid to disclose (Kalembo et al., 2019; Meena et al., 2018; Mengesha, Dessie, & Roba, 2018). About the intention to disclose, a study done in South Africa found that caregivers with a high level of education had very low intention to disclose HIV-positive status to their children compared to caregivers with low education (Jemmott III et al., 2014). A mixed-method study of 118 caregivers of children living with HIV (CLHIV) and 10 key informants of HCPs in three selected hospitals in the Eastern region of Ghana reported that 89 % of the caregivers expressed intentions to disclose to their children in the future (Gyamfi, Okyere, Enoch, & Appiah-Brempong, 2017).

In Ghana, it is estimated that approximately 26,000 children between the ages of 0-14 years were living with HIV infection in 2019 out of which an estimated 3,000 were new infections (UNAIDS, 2020a). However, only 25.55% of these children are on antiretroviral medications and an estimated 2,441 children between 0-14 years died of HIV-related illnesses in 2019 (Ghana AIDS Commission, 2020). Despite this number, the prevalence of HIV disclosure to children reported in two studies was 21% and 33.3 % respectively (Gyamfi et al., 2017; Kallem, Renner, Ghebremichael, & Paintsil, 2011). This implies that the majority of children living with HIV are still not aware of their status. The present study therefore explored and described the experiences of caregivers on disclosure of childhood HIV positive status to children living with HIV at two selected facilities in the Ho Municipality in the Volta Region of Ghana using the Theory of Planned Behaviour (TPB) as the organizing framework.

1.2 Problem Statement

The standard practice recommends that children living with HIV have their status disclosed to them between 6 and 12 years (WHO, 2011). The disclosure process should be gradual and progressive until full disclosure occurs by 12 years of age. However, extant literature consistently shows that this is usually not the case. Studies have reported that caregivers are either reluctant to disclose or lately disclose to their children (Beima-Sofie et al., 2014; Lorenz et al., 2016; Mumburi, Hamel, Philemon, Kapanda, & Msuya, 2014; Pinzón-iregui et al., 2013). The late disclosure of HIV status to CLHIV is a global phenomenon. In Sub-Saharan Africa, several studies (Biru et al., 2018; Lencha et al., 2018; Vreeman et al., 2015) have reported late HIV status disclosure to CLHIV.

In Ghana, the phenomenon is similar. Although an estimated 26,000 children (between 0-14 years) were living with HIV, 3,000 being new infections in 2019 (Ghana AIDS Commission, 2020), the disclosure rates reported in previous studies were low. A survey among caregivers of 71 children (between 8-14 years) at the Korle Bu Teaching Hospital in Accra revealed that only 21% of children knew their HIV positive status (Kallem et al., 2011). A quantitative study by Hayfron-Benjamin, Obiri-Yeboah, Ayisi-Addo, Siakwa, and Mupepi (2018), in the Central Region, also confirmed a low disclosure rate (23.3%) among children 6-17years. A similar finding was also reported from the Eastern Region in a mixed-methods study where the disclosure rate among children between 4-19 years was 33.3% (Gyamfi et al., 2017). In addition to late disclosure, the process of disclosure also fell short of standard practice. A phenomenological study by Appiah, Kroidl, Hoelscher, Ivanova, and Dapaah (2019), among adolescents who are aware of their HIV status, confirms that HIV positive status disclosure was done as a one-off event and not a progressive process. The study also reported displeasure among the participants regarding the late disclosure (Appiah et al., 2019).

However, there is a dearth of information regarding caregivers' intention, perceptions, attitudes, and self-efficacy to disclose the HIV status of CLHIV to them in the Volta Region of Ghana. The HIV Sentinel Survey (HSS) of 2016 reported an HIV prevalence of 2.7% among pregnant women in the Volta Region. This percentage was higher than the national prevalence (Ghana AIDS Commission, 2017). Besides, as of 2017, the region accounted for an estimated 0.2 % of infections in children of 0-14 years and 0.6 % of adolescents of 15-24 years (Ghana AIDS Commission 2017). This suggests that the prevalence of HIV in children may be increasing. With this backdrop, adequate information on HIV status disclosure to children living with HIV is needed for improved care. However, the literature revealed limited information on the subject in the Volta Region. The scarcity of this vital information to inform care, therefore, necessitates this study aimed at exploring the experiences of caregivers about disclosure of childhood HIV-positive status to CLHIV in the Ho Municipality in the Volta Region.

1.3 Purpose of the study

The purpose of the study was to explore the experiences of caregivers in the disclosure of HIV-positive status to children living with HIV in the Ho Municipality in the Volta Region of Ghana.

1.4 Specific Objectives of the Study

The specific research objectives were to:

1. Describe the attitude of caregivers towards disclosure of HIV positive status to children
2. Assess the beliefs and perceptions (subjective norms) on disclosure of HIV positive status to children by caregivers.
3. Explain the behavioural factors (perceived behavioural control) of caregivers on disclosure of HIV positive status to children.
4. Describe the intention and behaviours of caregivers on disclosure of HIV positive status to children.

1.5 Research Questions

This research answered the following questions:

1. What is the attitude of caregivers towards the disclosure of HIV positive status to infected children?
2. What are the beliefs and perceptions (subjective norm) of caregivers regarding the disclosure of HIV positive status to their children?
3. What are the behavioural factors (perceived behavioural control) that influence the caregivers' decisions to disclose to their children?
4. What are the intention and behaviours of caregivers regarding the disclosure of HIV positive status to children?

1.6 Significance of the Study

Evidence suggests that there is currently little research on paediatric HIV disclosure to CLHIV in the Volta Region of Ghana despite the number of these children in the region. The WHO's guideline on paediatric HIV disclosure indicates that disclosure varies according to the culture and desires of the caregiver (WHO, 2011). The findings of this study will help HCPs in understanding the experiences of caregivers of CLHIV on HIV status disclosure. It was found that HIV disclosure is not part of the routine care provided at the ART clinics in these facilities. These findings will help to inform HCPs to include disclosure preparation and planning for children as part of the routine care provided to caregivers and their CLHIV. Again, the findings of this research will inform policymakers to proactively develop tailored protocols to facilitate HIV status disclosure between caregivers and their CLHIV in the Volta Region and beyond. Disclosure is also a key intervention in improving medication adherence and viral suppression which are key components of the 90 90 90 target (UNAIDS, 2014). These findings have also contributed to the paediatric HIV disclosure literature.

1.7 Definition of Terms

1. **Attitude** - the degree to which a person has a favourable or unfavourable evaluation of a particular behaviour.
2. **Caregiver** - any adult looking after a child living with HIV/AIDS for not less than 6 months. This includes parents, guardians, and older siblings.
3. **Children** - any person who is between the ages of 6 -12.
4. **Children living with HIV**- children who are between 6 -12 years who test positive for HIV and are on antiretroviral medication.
5. **Disclosure** - refers to the process whereby caregivers inform their children about their positive serostatus.
6. **Important referents -** this refers to significant others such as spouses, family members, peers and healthcare professionals.
7. **Intention -** indicates how hard people are willing to try and the effort they want to exert to perform the behaviour.

8. **Perceived behavioural control** - refers to the perception of the person about how easy or difficult performing the behaviour of interest is.
9. **Subjective norm** (Normative beliefs) - refers to the perception of the individual about the social influence to perform or not perform a behaviour.

1.8. Organisation of the Thesis

This thesis is organised into the following chapters. Chapter One presents the study background, problem statement, purpose of the study, study objectives, research questions, and significance of the study, and definition of key terms. Chapter Two dealt with the theoretical framework, review of related literature based on the constructs of the theory used and the research objectives. The Third chapter presented the methodology of the research. Chapter Four presented the findings of the study. Chapter Five entailed the discussion of the key findings, the Sixth chapter tackled the summary of the study, implications, limitations, conclusions, and recommendations.

1.9. Summary

The background of the study, statement of the problem, research questions, and objectives of the study has been presented. The purposes of the study, significance, and definition of key terms used in the study have also been provided in this chapter. Chapter Two will present the literature review on HIV disclosure to CLHIV. It also includes the theoretical review and the search strategy employed for the review of the literature.

CHAPTER TWO

LITERATURE REVIEW

This chapter reviews and discusses relevant literature related to caregivers' experiences about disclosure of HIV positive diagnosis to their children. This chapter begins with a discussion of the theory that guides the study, followed by the literature search strategy, the justification for the choice of theory, and a review of related literature. The chapter ends with a review of the literature and a summary of the chapter.

2.1. Justification and Relevance of the Theoretical Framework

One aspect of a literature review is the review of the theory that guides the study. The use of theory in qualitative research provides the researcher with a lens that shapes what is being studied and directs the questions that are asked in the research (Creswell, 2014). During the search for the appropriate theory to guide this research, the researcher initially identified three theories. The Theory of Reasoned Action (TRA) (Azjen & Fishbein, 1980), Consequence Theory (Serovich, 2001), and the Theory of Planned Behaviour (TPB) (Ajzen, 1991) were all reviewed to assess their appropriateness in answering the research questions. The Consequence Theory (Serovich, 2001), which is an HIV disclosure model proposes that People Living with HIV (PLHIV) are likely to reveal their HIV positive status to important referents and romantic partners when they anticipate that the benefits of revealing their status will be greater than the risks involved. However, this theory was not selected because the researcher is interested in exploring the attitude and behaviour of the caregivers and the factors that they perceive to facilitate or impede their decisions to disclose.

The second theory identified is the TRA which was propounded by (Azjen & Fishbein, 1980). According to the TRA, behaviour is determined by the intention to engage in the specific behaviour, which in turn is influenced by the personal factors called attitude and a social factor referred to as subjective norm. The TRA has been criticised as being deficient in explaining behaviour which individuals do not have sufficient voluntary control over (Ajzen, 1991). This limitation was addressed by the theory of planned behaviour. The TRA was not selected because of this limitation and because its constructs would not help in exploring the control beliefs associated with performing a behaviour.

2.2. Description of the Theory of Planned Behaviour

The Theory of Planned behaviour (TPB) is derived from the Theory of Reasoned Action (TRA) (Ajzen, 1991). The TPB improved on the TRA with the addition of a construct known as perceived behavioural control (PBC). The TPB is designed for predicting different types of behaviours and is not limited to behaviours in which individuals have the motivation to engage in (Ajzen, 2012). According to Ajzen (2012), the TPB is designed to address this limitation identified in the TRA in predicting behaviours in which people do not have voluntary control. The TPB proposes that behaviour is a function of salient information, or beliefs, relevant to the behaviour. Fishbein and Ajzen (2011) explain that performing a particular behaviour is likely to produce both positive and negative outcomes. This may also result in negative or positive reactions from significant others, and it can lead to unanticipated difficulties or facilitating factors. This outcome may influence people’s beliefs and intentions to perform the behaviour in the future. The constructs of the TPB have been explained in detail below.

2.2.1. Intention

Intentions are the immediate determinants that influence the performance of any behaviour of interest (Ajzen & Madden, 1986). The TPB assumes that intention captures all motivational factors which are needed to influence behaviour. Intentions also indicate how hard individuals are willing to perform the behaviour in question and how much effort they want to put in to perform the behaviour (Ajzen, 1991). It has been asserted that the stronger the intentions, the more likely it is that the behaviour will be carried out (Ajzen & Madden

1986). Ajzen (1991) explains further that the intention of an individual to carry out a behaviour depends on personal factors and social influence. The TBP postulates that three antecedents known as attitude, subjective norm (SN), and perceived behavioural control (PBC) influence behavioural intention of people to either execute or not execute behaviour of interest. Therefore, the intention to perform a particular behaviour is formed via the combination of these three antecedents (Ajzen, 2002; Fishbein & Ajzen, 2011). Each of these antecedents of behavioural intention has a belief underlying them. The TPB proposes that behavioural, normative and control beliefs underlie attitude, SN, and PBC constructs, and these beliefs influence intention to perform a behaviour.

2.2.2. Attitude

Ajzen (1991) explains the concept of attitude as the degree to which an individual favourably or unfavourably evaluates a specific behaviour of interest. The beliefs that underlie the attitude of a person towards carrying out behaviour of interest are known as behavioural beliefs. These behavioural beliefs associate the behaviour with a particular outcome (Ajzen & Madden, 1986; Fishbein & Ajzen, 2011). According to Jemmott III et al. (2014), the meaning of the construct behavioural belief is similar to the construct of outcome expectancy described in the Social Cognitive Theory. These outcome expectancies have been described as negative or positive consequences expected after performing a particular behaviour. Hence, behavioural beliefs combine with outcome expectancies to produce a negative or positive attitude towards a specific behaviour (Ajzen, 2012). Individuals who expect a specific behaviour to result in positive outcomes, usually develop a positive attitude and those who expect behaviour to produce negative outcomes exhibit negative attitudes towards that particular behaviour (Fishbein & Ajzen, 2011). Similarly, the consequence theory proposes that people are likely to disclose to important referents when they perceive that disclosure will bring more benefits than harm (Serovich, 2001).

2.2.3. Subjective Norm

Subjective norm (SN) is the second antecedent that influences the intention to engage in behaviour. It refers to the perception of the person about the social pressures that influence them to either engage or not engage in behaviour of interest. The beliefs that underlie the SN of an individual are referred to as normative beliefs (NB). These NB refer to the perception of the person about whether important referents (these include spouses, family members, healthcare professionals and peers) would approve or disapprove of their decision to engage in a particular behaviour (Ajzen, 1991; Madden, Ellen, & Ajzen, 1992). It also involves the motivation of the individual to comply with these referents. If people perceive that most of their significant others would approve of the performance of the behaviour in question and these relatives themselves would perform the said behaviour, then the people would have a great social pressure to perform that specific behaviour.

Furthermore, SN has been explained as the social influence that affects the individual's intention to engage in a particular behaviour. Social influence is the process whereby the belief and behaviour of an individual are influenced by others. This occurs through social norms, the modelling of behaviours and consequences, and social rewards and sanctions (Latkin & Knowlton, 2015). It has been suggested that the NB being held by the caregivers are likely to influence their intentions to perform or not perform disclosure (Evangeli & Kagee, 2016). However, it is suggested that these NB are likely to differ between LMICS and HICs (Pinzón-iregui et al., 2013).

2.2.4. Perceived Behavioural Control (PBC)

This construct is the third antecedent that influences the intention to engage in behaviour. It has both direct and indirect effect on behaviour performance. It can indirectly influence behaviour performance by influencing the intentions of the person to engage in the behaviour. The PBC construct refers to the perception of the individual about how difficult or easy performing a specific behaviour is. It is equivalent in meaning to the concept of perceived self-efficacy described in the Social Cognitive Theory (SCT) (Ajzen, 2012). It has been explained further as all the factors that promote or inhibit the individual's intention to carry out behaviour of interest. It takes into consideration the resources available to the person, the skills required and the opportunities that are needed to perform behaviour of interest (Ajzen, 2012; Cappella, 2008). Ajzen (2002) states that this construct can be assessed by asking questions about the capability to engage in a behaviour or indirectly on beliefs about the capability to deal with specific inhibiting or facilitating factors.

As the previous determinants have their corresponding beliefs, the construct PBC also has control beliefs underlying it. These are related to personal or environmental factors that individuals' perceive can facilitate or inhibit them from performing a particular behaviour. Therefore, there can be a sense of high or low self-efficacy regarding the intention to carry out a specific behaviour. Hence, if a person perceives greater facilitators than barriers, then an individual's PBC is expected to increase (Fishbein & Ajzen, 2011). Environmental factors such as lack of required skills and limitations are capable of inhibiting people from acting on their behavioural intentions. These factors may cause individuals to lack control over performing a particular behaviour. Therefore, intentions can only effectively predict the performance of behaviour if individuals perceive high control over performing that specific behaviour (Fishbein & Ajzen, 2011).

The TPB has been criticised by (Sniehotta, Presseau, & Araújo-Soares, 2014) that it focused mainly on rational reasoning and also lacked predictive validity. They argued that the theory is not explaining sufficient variability in behaviour and some of the propositions are patently false. Contrarily, it has been contended that this issue raised about the TPB needs further exploration and theory development (Armitage, 2015). Conner (2015) also argues that the arguments of (Sniehotta et al., 2014) have limited evidence because the theory is parsimonious and can predict many behaviours in different populations. Other researchers contend that TPB is effective in studying behaviour (Ajzen, 2015; Cappella, 2008). Again, a meta-analyses findings established that the theory strongly predicts intentions and many health-related behaviours (McEachan, Conner, Taylor, & Lawton, 2011; Rich, Brandes, Mullan, & Hagger, 2015).

The TPB was used as the organising framework to guide this study because Jemmott III et al. (2019) asserted that the theory is convenient to apply to qualitative studies and several qualitative studies have used the TPB as their organising framework (Borrero et al., 2015; Jemmott III et al., 2019; Omura, Stone, Maguire, & Levett-Jones, 2018). The theory has also been applied in several HIV-related studies such as predicting intention for voluntary counselling and HIV testing (Abamecha, Godesso, & Girma, 2013; Ayodele, 2017; Kakoko, Åstrøm, Lugoe, & Lie, 2006; Mirkuzie, Sisay, Moland, & Åstrøm, 2011), adherence to ART (Banas, Lyimo, Hospers, van der Ven, & de Bruin, 2017), breastfeeding intention (Kafulafula, Hutchinson, Gennaro, Guttmacher, & Kumitawa, 2013), paediatric and maternal HIV disclosures (Jemmott III et al., 2014; Mo, Wang, Lau, Li, & Wang, 2019), health-seeking behaviour of transgender persons (Prabawanti, Dijkstra, Riono, & Hartana, 2015), and several other studies.

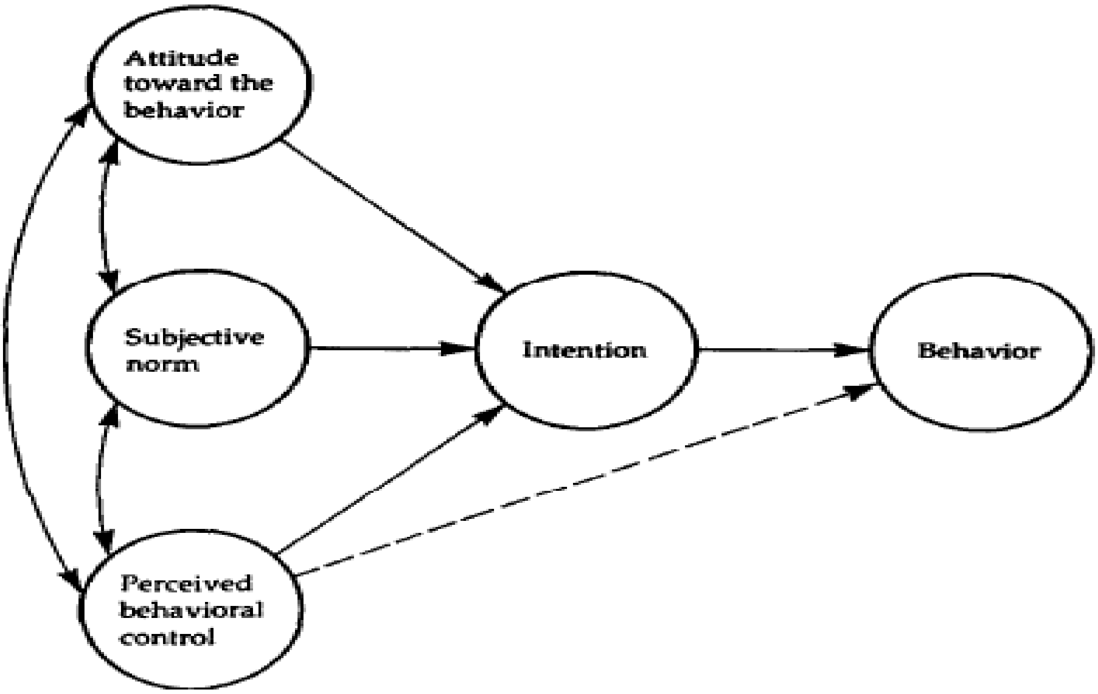

Figure 2.1: Ajzen Icek 1991's Constructs of Theory of Planned Behaviour

Source: Ajzen Icek (1991)

2.3. Literature Search Strategy

To help locate relevant literature for this review, the following databases were used; Google Scholar, ScienceDirect, EBSCOhost, CINAHL, PubMed, MEDLINE, Taylor and Francis, Scopus, and Wiley. Grey literature from government sources such as WHO, UNAIDS, Ghana AIDS Commission was also searched and reviewed. The following search terms and Boolean operators were employed to retrieve articles published in English and authentic journals: HIV/AIDS, HIV disclosure, HIV/AIDS caregivers, paediatric HIV disclosure, HIV/AIDS children, attitude, normative beliefs, intention, behaviour, behavioural beliefs, self-efficacy, barriers and facilitators to HIV disclosure. The references identified in published articles retrieved were also used to access more other relevant articles for the review. The objectives of the study guided the literature review.

2.4. Review of Related Literature on HIV Disclosure

Globally, disclosure of HIV-positive status to infected children is a public health concern and an important component in the management of CLHIV (Arrivé et al., 2018). This concept of disclosure was initially introduced into public health practice in an attempt to prevent unintentional transmission of HIV, especially among sexual partners (Moskowitz, 2015). The Merriam-Webster (2018) online dictionary defines disclosure as the "act or an instance of making known something previously unknown or concealed." In the analysis of the concept of disclosure, Eustace and Ilagan (2010) explain that the concept of HIV positive status disclosure is a complex and multifaceted activity in which individuals voluntarily or involuntarily decide whom to inform their HIV positive status.

According to (Krauss et al., 2013) paediatric HIV disclosure refers to the process whereby caregivers inform their infected children about their seropositive status. Several authors have noted that paediatric HIV disclosure is a complex phenomenon (Kalembo et al., 2019; Mutambo & Hlongwana, 2019). Despite its complexity, several arguments have been made in favour of telling children the truth about their HIV positive status. Disclosure of HIV-positive status to CLHIV has numerous advantages documented in literature (Beima-Sofie et al., 2017; Conserve et al., 2017; Gitahi et al., 2020). These advantages include retention in care, decreased mortality (Ngeno et al., 2019), support from families and enhanced involvement in their management, adherence to treatment (Ammon et al., 2018; Cluver et al., 2015), improved family relationship (Gachanja & Burkholder, 2016), and important for the transition to adult care (Ngeno et al., 2019). Ethical reasons have also emerged regarding disclosure of HIV diagnosis to children with arguments in favour and against disclosure. A review article on ethical reasons for disclosure of information to children by Hudson et al. (2019) asserted that concealing information from minors solely on the grounds of their cognitive immaturity is not rooted in evidence.

2.5. Attitude of Caregivers towards HIV Disclosure

Research findings on caregivers' attitudes towards disclosure ranged from positive to negative with the latter in dominance. Attitude is an important antecedent that influences the intention of caregivers to disclose HIV-positive status to their infected children (Evangeli & Kagee, 2016). In a concept analysis guided by Walker and Avant's (2005) model of the concept, Altmann (2008) noted that attitude is bipolar and has three domains. These components are cognitive, affective, and behaviour and it is a response to a stimulus. This section presents a review of the positive and negative attitudes of caregivers towards disclosure and their behavioural beliefs (anticipated consequences) associated with HIV-positive status disclosure.

Lorenz et al. (2016) conducted a qualitative study in Uganda that explored the experiences of 28 caregivers of CLHIV (0-14 years) about HIV testing and the disclosure of HIV-positive diagnosis to the children. The authors found that caregivers generally possess a negative attitude towards disclosure of HIV-positive status even though all of them admitted that children who know their diagnosis will develop optimal adherence behaviour. Caregivers in the study lied to their children and told them they had different diseases. Other studies have also found that due to unwillingness to disclose, some caregivers persistently lie about reasons for taking medication to their children in an attempt to delay the disclosure (Kiwanuka et al., 2014; Vreeman et al., 2015). A qualitative study of 34 participants (14 caregivers, 14 children, and 6 HCPs) in Peru found that caregivers employed a deceptive strategy as a way of avoiding disclosure to their CLHIV (Baker et al., 2018).

Similar findings were reported in a qualitative study conducted in Zimbabwe (Kidia et al., 2014). The authors reported that caregivers of the children failed to disclose; they either lied to the children or failed in providing full information about the HIV infection notwithstanding the desire of the adolescents to know the truth about their illness. It has been confirmed that caregivers adopt strategies such as ‘lying’, ‘secrecy’ and ‘bargaining’ to compel their children to take medications while delaying disclosure (Wong et al., 2017).

While findings on disclosure by biological and non-biological caregivers are mixed, it is known that the HIV status of the caregiver of the infected child influences their attitude towards disclosure. Studies have found that biological parents are more likely to refuse to disclose to their children (Gachanja & Burkholder, 2016; Hayfron-Benjamin et al., 2018; Medin et al., 2016). Hence, biological parents are more likely to exhibit negative attitudes towards disclosing HIV-positive status to their children. One of such commonly observed negative attitudes is the reluctance to disclose or postponement of disclosure. Reluctance to disclose has been associated with the feeling of guilt about perinatal transmission and disclosure of their role in the child’s infection (Gray, Nieburg, & Dillingham, 2017; Negese et al., 2012; Vreeman et al., 2015).

Other researchers have reported that the reluctance of biological parents is also related to fear of revealing their own HIV positive status to the child (Gachanja & Burkholder, 2016; Mandalazi, Bandawe, & Umar, 2014), and attempt of the caregivers to protect their reputation (Muparamoto & Chiweshe, 2015; Mweemba et al., 2015). Another most cited reason for unwillingness to disclose early is the fear of being blamed by their children for the infection transmission (Mweemba et al., 2015; Sariah et al., 2016). Others include fear that the child would be angry, hate, blame, judge, and reject the caregiver for the perinatal transmission of HIV (Madiba & Mokgatle, 2015; Wagner et al., 2018; Wariri et al., 2020).

These negative attitudes notwithstanding, literature shows other views and beliefs that express a positive inclination to HIV status disclosure to children. Studies conducted in Ethiopia found that majority of the caregivers said that children should be informed about their diagnosis (Abebe & Teferra, 2012; Tadesse, Foster, & Berhan, 2015). Also, a mixed-method study involving 50 caregivers of CLHIV in Zambia found that all the participants possess positive attitudes towards HIV positive status disclosure to their children (Tsuzuki et al., 2018). The study found that all the caregivers viewed disclosure as an important decision in a child's care and said children should be informed about their HIV status. A Nigerian study reported that caregivers felt that disclosure is a beneficial action that should be done (Wariri et al., 2020).

Contrary to the observations of biological parents (Gachanja & Burkholder, 2016; Sariah et al., 2016), some earlier findings reported positive attitude towards disclosure among biological parents. Letteney's (2012) study in the United States of America (USA) among 41 fathers with HIV about disclosure of the father's own HIV positive status to their uninfected children (5-18 years) reported that most fathers felt disclosure was important. Similarly, Mawn (2011) also found from her longitudinal qualitative study using phenomenology that biological mothers were not reluctant to disclose. They did not express guilt and fear of being blamed by their children. Another quantitative study of 83 caregivers of children of ages 6-16 years in Namibia concludes that biological mothers seemed to disclose more than non-biological parents (Kalomo, Liao, Besthorn, Shilunga, & Mbapaha, 2017). Similar findings were reported in a Nigerian study which found that most mothers with HIV disclosed frequently than non-biological parents (Adefalu, Florence, Tunde-Ayinmode, & Adefalu, 2016).

2.5.1. Consequences of Disclosure

Extant literature exists on the negative and positive outcomes of disclosure to CLHIV. They may be real or anticipated. Fishbein and Ajzen (2011) posit that attitude towards a particular behaviour is affected by behavioural beliefs. The reasons for disclosure and non-disclosure of HIV positive status to infected children have been cited in many studies. Fear of negative psychological and emotional reactions from the child are some of the main reasons cited for delayed or non-disclosure of HIV positive status by caregivers in numerous studies and systematic reviews (Britto et al., 2016; Ekstrand, Heylen, Mehta, Sanjeeva, & Shet, 2017; Lencha et al., 2018; Madiba & Mokgatle, 2015; Qiao, Li, & Stanton, 2014).

Caregivers anticipate several emotional and psychological reactions to disclosure. These emotional reactions anticipated ranged from crying, sadness, worrying to suicide (Tiendrebeogo et al., 2013). A qualitative study of 40 caregivers of children (5-15years) in Uganda (Kiwanuka, Mulogo, & Haberer, 2014) reported that concerns about negative psychological consequences, perceived stigma and discrimination, and fear that caregiver and child relationship would be ruined and concerns that child would experience sadness, shame, hatred, despair, hopelessness, social withdrawal, shock, collapse, and suicidal thoughts hindered caregivers from disclosing. Similarly, a mixed-method study of 200 caregivers in Ethiopia reported that 64% of the caregivers delayed disclosure because of concerns of emotional harm when the child learns their HIV status (Lencha et al., 2018).

A systematic review of global literature on issues concerning disclosure of HIV positive status to CLHIV (12 years and below) and reasons for HIV positive disclosure or non-disclosure established that caregivers avoided and delayed disclosure to their infected children due to the following reasons: “anticipation of the child’s negative psychological reaction”, “the child is too young to understand, “the child is unable to keep a secret” (66.7%), “potential social rejection of the child”, and “the parent fears anger/blame from the child”, “parent fears shame/guilt” (Krauss, Letteney, & Okoro, 2016). These findings were confirmed in a recent systematic review of studies done in SSA (Doat, Negarandeh, & Hasanpour, 2019). This review which investigated HIV disclosure to children with HIV found that the concerns about psychological reactions are the reasons for not disclosing HIV positive status to children perinatally infected with HIV.

Several studies conducted among caregivers who disclosed HIV-positive status to their infected children reported actual reactions of the children to disclosure. An Indian study (Vranda, Subbakrishana, Ramakrishna, & Veena, 2017) reported mixed reactions from the children to HIV positive status disclosure. The authors found that some children experienced reactions such as ‘fear’ ‘anger’ ‘depressions and suicidal behaviours’ ‘withdrawn and crying’ as well as positive reactions such as drawing closer to parents, improvement in relations and medication adherence. Vreeman et al. (2019) conducted a randomized controlled trial in Kenya which evaluated a patient-centred intervention for supporting disclosure. The authors reported an increase in symptoms of depression in the group which received the disclosure intervention six months post-disclosure. In contrast, some studies found no significant reactions from children. A study in Thailand used a model to assist caregivers of CLHIV to disclose gradually to their children. They found no significant behavioural or emotional reactions in the children post the disclosure event (Boon-yasidhi et al., 2013). Similar findings were reported in South Africa (Mahloko & Madiba, 2012). A study of 40 CLHIV whose HIV status had been disclosed found that the immediate reactions to disclosure were short term and dissipate 6 months after disclosure (Blasini et al., 2004).

On the positive side, many studies also reported the benefits of disclosure to both the CLHIV and their caregivers. The most cited benefit of disclosure in many studies conducted so far is increased adherence to ART. Many studies have reported an improvement in ART adherence of children post-disclosure of their HIV status (Cluver et al., 2015; Gitahi et al., 2020; Priya et al., 2019). A narrative review of 148 articles on the epidemiology of HIV among adolescents and their ART adherence in sub-Saharan Africa also found that early disclosure to children is associated with optimal adherence (Adejumo, Malee, Ryscavage, Hunter, & Taiwo, 2015). Importantly, early disclosure of HIV-positive status (before 12 years) to children is associated with higher ART adherence as reported in multiple studies and systematic reviews (Ammon et al., 2018; Cluver et al., 2015; Nabukeera-Barungi et al., 2015).

A recent randomized controlled trial (Nichols et al., 2019) was conducted at two large urban teaching hospitals in Ghana. It investigated the prevalence of non-adherence among children who were not disclosed their HIV positive status. They found low adherence among children who are not aware of their HIV positive diagnosis. Non-disclosed children may hide their medication or intentionally missed doses as they rebel against frequent medication (Adejumo et al., 2015; Mafune, Lebese, & Nemathaga, 2017). However, a systematic review of 14 studies conducted in resource-limited settings which investigated the relationship between disclosure and adherence in children found mixed results regarding disclosure and medication adherence. While some studies found positive association whereby disclosure improves ART adherence, other studies reported no significant association between HIV status disclosure with adherence (Nichols et al., 2017).

Besides adherence to ART, several other positive outcomes have been cited in studies. Paediatric HIV disclosure leads to improved psychological health, prevention of onwards HIV transmission to others (Whembolua, Conserve, Thomas, Tshiswaka, & Handler, 2019), and reduction in anxiety, depression, and rebellion behaviour in the infected children (Conserve et al., 2017). Other studies have found that disclosure resulted in improvement in viral loads (VL), increased knowledge on disease condition after participating in a disclosure intervention (Beima-Sofie et al., 2017; Vreeman et al., 2019), decreased mortality (Ngeno et al., 2019) and improved CD4(T-cells) counts (Montalto et al., 2017). Among caregivers, it was found that disclosure to their infected children resulted in relief from keeping a secret and improvement in child-caregiver relationships (Gachanja & Burkholder, 2016; Vranda et al., 2017).

2.6. Perception of Caregivers about HIV Disclosure

Caregivers' knowledge of the disclosure process is a key driver of disclosure to children. Evidence suggests that HIV disclosure to children is a gradual process that evolves over a while rather than a one-time event (Li, de Wit, Qiao, & Sherr, 2015; Marhefka, Turner, & Chenneville, 2016; Woollett, 2016). This gradual approach to paediatric HIV disclosure is important in reducing the adverse reactions of children after learning about their HIV status (Conserve et al., 2017). However, many studies have reported that caregivers usually perceive disclosure as a single event. Multi-country mixed longitudinal qualitative study was conducted in five countries (USA, United Kingdom (UK), Uganda, Ireland, and Zimbabwe) among children and adolescents with HIV (10-24 years) about disclosure and information they are provided at the clinics (Bernays, Paparini, Gibb, & Seeley, 2016). The authors found that children experienced disclosure as a single event without any follow-up after the event. Similar findings were reported in studies conducted in Uganda and Ghana (Appiah et al., 2019; Mutumba et al., 2015). Rochat et al. (2017) suggest that the post-disclosure period is an appropriate time for caregivers to give their children age-appropriate education for them to fully understand HIV. However, it has been found that there is usually a culture of silence post the disclosure event (Bernays et al., 2016; de Moura Bubadué & Cabral, 2019). Conversely, other studies noted that some caregivers agreed that paediatric HIV disclosure should be a gradual process (Finnegan et al., 2019; Gachanja, Burkholder, & Ferraro, 2014).

The literature shows conflicting opinions regarding the ideal person to disclose HIV status to the CLHIV. Some studies conducted among caregivers have found that caregivers felt disclosure is the responsibility of the HCPs, themselves or concerted responsibility

(Madiba & Mokgatle, 2015; Wariri et al., 2020). Other studies found that parents were the preferred individuals to disclose because of the relationship they have with their children (Beima-Sofie et al., 2014; Okechukwu, Kwaghe, & Dike, 2018). A mixed-method study found that caregivers had mixed responses with some agreeing that HCPs should disclose and others felt parents or family members should be the appropriate person to disclose (Suryavanshi et al., 2014). In Ethiopia, it was found that most participants suggested that biological parents should be responsible for disclosure (Abegaz, Walle, & Tilahun, 2019).

2.6.1. Normative Influence and HIV Positive Disclosure to Children (Subjective Norm)

Normative influence is associated with intention to carry out HIV status disclosure (Evangeli & Kagee, 2016). Numerous normative beliefs may influence caregivers' intention to disclose HIV-positive status to HIV-infected children. The following normative factors have been explored under this heading; Disclosure to significant others, cultural and gender norms, marriage and family type.

Disclosure of a child's HIV positive status to significant others has been found to promote disclosure to the child with HIV infection. Studies have documented that children whose HIV positive status has been disclosed to household members were more likely to be informed about their own HIV status than those whose HIV status is known to only the caregivers (Atwiine, Kiwanuka, Musinguzi, Atwine, & Haberer, 2015; Tadesse et al., 2015). A study done in South Africa found that disclosure of a child's diagnosis to an adult in the same household and their school increases the likelihood of informing the infected children about their HIV-positive status (Murnane et al., 2017). A systematic review (Krauss et al., 2016) corroborates these findings that disclosing a child's HIV-positive status to family members promotes disclosure to the infected child.

However, it has been reported that the fear of being stigmatized and discriminated against is the reason for the non-disclosure of a child's HIV status to significant others

(Nyogea et al., 2015). Studies conducted in South India and Uganda found that caregivers have concealed the children's status from close family members such as siblings, spouses and grandparents (Nasuuna et al., 2019; Sarkar, Selvaraj, Krishnamurthy, Balasundaram, & Lakshminarayanan, 2018). Non-disclosure of a child's status to significant others in the same household also promotes non-adherence to ART (Chambers et al., 2015; Nabukeera-Barungi, Kalyesubula, Kekitiinwa, Byakika-Tusiime, & Musoke, 2007). Disclosure to significant others also has benefits such as getting their support to care for the child and reduces caregiver fatigue (Nasuuna et al., 2019; Vreeman et al., 2010). It has been found that caregivers also demonstrate fears about disclosing the child's HIV status at school (Medin et al., 2016).

The family and marriage type or status also influence decision to disclose HIV-positive status to children. Iwelunmor, Sofolahan-Oladeinde, and Airhihenbuwa (2015) assert that the family system plays a crucial role in disclosure decision-making. A systematic and meta-analytic review that investigated factors facilitating HIV disclosure in PLHIV in Nigeria found that 'marital status or type' and 'family type' influence HIV status disclosure. This review confirmed that disclosure was higher among people in monogamous marriage than those in a polygamous marriage and married women were more likely to disclose than unmarried people (Adeoye-Agboola, Evans, Hewson, & Pappas, 2016). Also, other studies conducted on disclosure of parental HIV status to their young children reported that parents who were married were less likely to disclose their HIV diagnosis to their children (Appiah, Adekunle, Oladokun, Dapaah, & Nicholas, 2019; Qiao et al., 2015; Visser & Hlungwani, 2020). In contrast, mothers in current relationships were three times more likely to disclose fully their own HIV positive status to their children in South Africa (Rochat, Arteche, Stein, Mkwanazi, & Bland, 2014).

Another factor that influence disclosure is HIV serodiscordance among couples. A systematic review conducted on the involvement of males in the Prevention of Mother-to-Child Transmission (PMTCT) asserted that serodiscordance which involves a woman may lead to divorce. However, those involving men may result in light consequences (Manjate Cuco et al., 2015). Also, serodiscordant marital relations were identified as a major barrier inhibiting HIV testing in paediatric patients (Wagner et al., 2018). Another systematic review (Tam, Amzel, & Phelps, 2015) on factors influencing disclosure decisions of postpartum and pregnant women and the prevalence of disclosure in this sample in SSA found that having rivals in marriage as well as living with other family members decreased the likelihood of disclosure. The presence of other siblings with HIV in the family was also found to facilitate the disclosure of an infected child's HIV status to them (Ekstrand et al., 2017; Eneh, Ugwu, & Paul, 2019).

Literature shows that bereavement or orphanhood influences caregivers' HIV disclosure intention and decision-making. Studies have found that orphaned children were more likely to be informed about their HIV-positive status than those whose biological parents are alive (Appiah et al., 2019; Gray et al., 2017; Vreeman et al., 2014). Contrarily, other studies have found that caregivers who are uninfected may find it difficult to disclose bereavement to their children (Beima-Sofie et al., 2014). It was reported in some studies that some grandparents found it difficult to disclose HIV-positive status and the death of parents to their children as part of full disclosure (Finnegan et al., 2019; Gachanja et al., 2014).

Cultural norms have been found to influence the disclosure of HIV-positive status to children. It is suggested that HIV disclosure is a kind of health behaviour that is influenced by cultural factors (Conserve et al., 2017; Muhati-Nyakundi, 2019). There are cultural norms about how to communicate bad news such as death and diagnosis of a life-threatening illness to children and others in SSA which may influence caregivers from discussing HIV positive status to CLHIV (Wright et al., 2017). It has been asserted that the death of a primary caregiver who died of HIV/AIDS may affect the disclosure process of children and have a long-standing effect on the CLHIV themselves (Woollett, 2016; Woollett, Black, Cluver, & Brahmbhatt, 2017). A study conducted among oncologists in Australia on non-disclosure requests of family of cancer patients indicated that families from cultures of collectivism and family-centred mostly request for non-disclosure than those from Western cultures such as UK (Chittem, 2015).

Besides, numerous studies have indicated that cultural norms that discourage parents from discussing sexuality with young children may account for caregivers' delay in disclosing HIV positive status to their infected children (Bastien, Kajula, & Muhwezi, 2011; Kajula, Sheon, De Vries, Kaaya, & Aarø, 2014; Orelly, Welch, Machine, Pameh, & Duke, 2018). Other primary studies and systematic review findings have confirmed the findings that cultural values that hinder sexual discussions play a role in delaying paediatric HIV disclosure (Aderomilehin, Hanciles-Amu, & Ozoya, 2016; Kalembo, Kendall, Ali, Chimwaza, & Tallon, 2018).

Another normative factor influencing HIV disclosure is gender norms and roles. There are gender norms that consider women as lower in authority than men to make major decisions such as disclosure of HIV-positive status to an infected child (Manjate Cuco et al., 2015). Some of these gender norms relating to both males and females may influence an individual's communication about HIV in a family (Amzel et al., 2013). According to (Beima-Sofie et al 2014; Krauss et al., 2016) norms that assert that fathers are the ones to make decisions and mothers may only have to look after a child make it difficult for mothers to lead the disclosure process of their children. Also, the presence of a biological father has been found to decrease disclosure to CLHIV (Krauss et al., 2016).

2.7. Factor influencing HIV Positive Status Disclosure (Perceived Behavioural Control)

Several factors may influence HIV-positive status disclosure to CLHIV. Some of these factors are inhibitors of disclosure. Other factors have been identified as facilitators of HIV disclosure. This section reviews the influence of HIV stigma and discriminations, caregivers' self-efficacy, HIV knowledge, child and healthcare provider related factors on HIV disclosure to children living with HIV.

2.7.1. Stigma and discrimination

Fear of stigma and discrimination is another major reason for delaying or non-disclosure of HIV positive status to infected children. Many studies have reported that caregivers fear that their children would not be able to maintain secrecy with their diagnosis and may tell others which will subsequently lead to stigmatization and discrimination (Atwiine et al., 2015; Madiba & Mokgatle, 2017; Vranda et al., 2017). These findings were confirmed that fear of secondary disclosure to others resulting in stigma and discrimination are the reasons caregivers provided for not disclosing HIV status to their children (Britto et al., 2016). Stigma has been described as the major reason for not accessing and adhering to treatment (McAteer et al., 2016; Mwini-Nyaledzigbor, 2014). A longitudinal analysis done in the United States of America among children with perinatal HIV infection found that caregivers' preferred age for disclosure reduced with time. This decrease was associated with a reduction in HIV stigma and fear associated with HIV diagnosis in the setting (Butler et al., 2009).

Several studies and systematic reviews conducted on paediatric HIV disclosure in LMICs have found that the major reasons and barrier to HIV positive status disclosure to CLHIV frequently cited by caregivers is fear of stigma and discrimination (Aderomilehin et al., 2016; Mweemba et al., 2015; Wong et al., 2017). A systematic and a series of meta-analytic reviews of studies on HIV stigma and health among PLHIV found a significant association between stigma and depressive symptoms, adherence, accessing and patronising health and social services (Rueda et al., 2016). Another synthesis of qualitative evidence on stigma and health for PLHIV found that most studies indicated that children had challenges with adherence due to the anticipation of stigma by their caregivers. The caregivers employed strategies to manage anticipated stigma by adopting a "protective silence" in which caregivers try to encourage medication adherence but avoid disclosing HIV status to the infected children (Chambers et al., 2015). Additionally, there are pre-existing negative stereotypes about HIV in many communities. These stereotypes which associate HIV with living promiscuous life prevents caregivers from disclosing or delaying disclosure to their affected children (Biru et al., 2018; Vreeman et al., 2015). In Ghana, studies conducted among caregivers of CLHIV on disclosure found fear of stigma as the main reason caregivers cited for not disclosing to children with HIV (Kallem et al., 2011; Paintsil et al., 2015).

Furthermore, there are specific concerns about the stigmatization of children in the school environment. Some studies found that children and adolescents with HIV experienced discrimination and stigmatisation at school which posed a challenge to their adherence to ART (DeSilva et al., 2018; Nabukeera-Barungi et al., 2015). In Zimbabwe, Busza, Dauya, Bandason, Mujuru, and Ferrand (2014) found that the school environment influenced ART adherence, clinic visits and psychological health of CLHIV. A recent systematic review of studies on challenges young people living with HIV encounter at school in East Africa found that the school environment is a major inhibitor of HIV disclosure and treatment adherence for adolescents (Kimera et al., 2019). This has been attributed to the presence of increased stigma and discriminations in this environment. Contrarily, a Kenyan study found that CLHIV received support from teachers and peers and caregivers felt comfortable revealing child's HIV status to their teachers, though some also experienced stigma and discrimination, and ostracism (Vreeman et al., 2015).

2.7.2. Caregiver Self-Efficacy

Self-efficacy is one of the factors that influence caregivers' disclosure decision-making and intention to carry out disclosure. However, its role in facilitating paediatric HIV disclosure has been under-researched in LMICs (Paintsil et al., 2015). A recent randomized controlled trial (Armistead et al., 2018) was conducted in the USA among 181 caregivers with HIV and their uninfected children. They examined the demographic variations in HIV disclosure self-efficacy. They indicated that disclosure self-efficacy varies based on the educational and socio-cultural background of individuals and how comfortable the individuals feel to discuss HIV with their children in their context. The authors established that the services provided at the current clinics do not teach mothers or provide the skills they need to disclose to children their own HIV status (Armistead et al., 2018).

Several studies have highlighted caregivers' lack of self-efficacy regarding how to carry out disclosure, what to say or when to start the disclosure process as a major factor confronting early HIV positive status disclosure to children (Madiba, 2016; Mweemba et al., 2015; Sutcliffe et al., 2020). Kiwanuka et al. (2014) noted that low self-efficacy among caregivers and feeling incapable to carry out disclosure is the main issues preventing caregivers from carrying out their intention. Similarly, other studies conducted among caregivers have corroborated findings reporting that caregivers do not know 'what' 'when' and 'how' to carry out disclosure of HIV positive status to their children (Hayfron-Benjamin et al., 2018; Ryoo, Hirway, Alexander-Scott, Locke, & Welch, 2017). Also, some studies have reported that caregivers feel incapable to manage the reactions of children to the news of their HIV positive status and responding to questions posed to them during the disclosure event (Das et al., 2016; Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013; Tiendrebeogo et al., 2013).

Another factor contributing to the lack of self-efficacy to disclose among caregivers is the lack of disclosure counselling at ART clinics. Kalembo et al. (2019) found that disclosure to children was not included in the routine care of CLHIV and their caregivers at the clinics but adherence counselling was routinely done. Other researchers noted that disclosure counselling only became important if there are adherence problems and complaints of risky behaviours in adolescents with HIV (Gyamfi et al., 2017; McHenry et al., 2018; Tiendrebeogo et al., 2013).

2.7.3. HIV Knowledge

Health literacy is explained as an individual's ability to read and comprehend health information (Paintsil et al., 2015). Another major barrier identified to be influencing the disclosure intention of caregivers is insufficient HIV and disclosure knowledge. Several studies have indicated that caregivers of CLHIV had inadequate knowledge on HIV and disclosure (Kalembo, Kendall, Ali, Chimwaza, et al., 2018; Meena et al., 2018; Mumburi et al., 2014). It has been found that caregivers with good knowledge about HIV status disclosure were more likely to disclose HIV status than those without any knowledge (Nzota, Matovu, Draper, Kisa, & Kiwanuka, 2015). A 2019 systematic review of studies in SSA confirmed that lack of HIV and disclosure knowledge among caregiver is a barrier to HIV status disclosure to children and many caregivers demonstrated limited HIV-related knowledge (Doat et al., 2019). Similarly, a study (Paintsil et al., 2015) in Ghana concluded that level of education, health literacy, and HIV associated stigma are major challenges confronting paediatric HIV disclosure.

Literature shows that the educational level of the caregivers and the children influences intention to disclose to CLHIV. Both high and low educational level of a caregiver was associated with disclosure (Krauss, Letteney, & Okoro, 2016). Studies have found that caregivers with primary school education were more likely to disclose than those with no education (Abegaz et al., 2019; Madiba & Mokgatle, 2017). Other studies have found that caregivers with higher education were less likely to disclose their HIV positive status to their children than those without any education (Biadgilign, Deribew, Amberbir, Escudero, & Deribe, 2011; Osingada, Okuga, Nabirye, Sewankambo, & Nakanjako, 2016). The education level of the CLHIV was also found to be associated with HIV-positive status disclosure to the children (Adefalu et al., 2016; Bulali et al., 2018; van Elsland et al., 2019).

2.7.4. Child-related Factors

Certain child characteristics have been found to increase the probability of disclosure to children from studies and systematic reviews conducted. One of the factors most cited in studies is the age of the child. Marhefka et al. (2016) stated that the age of a child is a vital factor generally considered for disclosing to CLHIV across different contexts. Numerous studies have confirmed that older children were more likely to be informed about their HIV positive status than young children (Adefalu et al., 2016; Britto et al., 2016; Priya et al., 2019). An Indian study found that HIV disclosure occurred between ages 14-17 years and caregivers who had not yet disclosed also cited the same age as ideal for disclosure (Priya et al., 2019). A similar finding was reported in Tanzania, where the disclosure rate was 64.7 times higher among 14-17 age groups compared to children below these age groups (Bulali et al., 2018).

Furthermore, studies have reported that caregivers' perceptions that their children are immature to understand the implications of living with HIV and maintain secrecy are some of the reasons for non-disclosure of HIV positive status to children (Abegaz et al., 2019; Sutcliffe et al., 2020; Wong et al., 2017). A study in Thailand involving 260 caregivers of children (6-17 years) reported that children older than 12 years were more likely to be disclosed to than younger children. The disclosure was 21% for children between 6-12 years and 84% for those older than 12 years (Sirikum et al., 2014).

Other child-related factors that facilitated disclosure to CLHIV are frequent questions about medication, hospital visits, and decreased adherence to ART (Eneh et al., 2019; John-Stewart et al., 2013). Studies have found that there was a lack of preparation for disclosure to children by caregivers and the need for disclosure arose when a child became inquisitive and refused medication and clinical appointments (Lorenz et al., 2016; Okechukwu et al., 2018). The duration of ART was also found to influence caregivers' intention to disclose. Abegaz et al. (2019) reported that children with ART duration of 6-10 years were more likely to be informed than those with ART duration shorter than this. Also, it was found that children who were diagnosed at an older age and initiated ART at this age were also more likely to be informed about their diagnosis than their counterparts (Madiba & Mokgatle, 2017).

2.7.5. Healthcare Provider related Factors

Given the complexity of paediatric HIV disclosure, numerous studies and systematic reviews suggest that HCPs should support caregivers to disclose to their children early (Boon-yasidhi et al., 2013; Krauss et al., 2016; Mutambo & Hlongwana, 2019; Phuma-Ngaiyaye & Dartey, 2015). This is because parents may have difficulty telling their children the whole truth about their HIV diagnosis (Boon-yasidhi et al., 2013). Evidence from the disclosure of parental life-threatening illnesses such as cancer diagnosis suggests that caregivers do not usually know the amount of information to share with their children and maybe concerned about emotional harm during disclosure, therefore, they need assistance from their HCPs (Dalton et al., 2019). Britto et al. (2016) assert that the complexity of the culture and low educational status of people in LMICs underscores the need for experienced HCPs to support the caregivers in planning disclosure for CLHIV.

A quasi-experimental study conducted in Haiti and the Dominican Republic using a model to assist caregivers to disclose corroborates findings suggesting the need to provide caregivers with psychological, social, and structural support to disclose to their CLHIV (Beck-Sagué et al., 2015). Besides, studies conducted in HICs such as the USA and Peru also found that HCPs prepared caregivers for disclosure and pressured them to carry out the disclosure until the children have been fully disclosed their HIV status (Baker et al., 2018; Mawn, 2011). Similar findings were reported in studies done in Uganda and Tanzania, which found that HCPs regularly educated caregivers on the benefits of disclosure and encouraged them to disclose early (Namukwaya, Paparini, Seeley, & Bernays, 2017; Sariah et al., 2016).

Conversely, other studies have found that some HCPs may possess negative attitudes towards disclosure, and some discouraged caregivers from disclosing HIV status to their children (Atwiine et al., 2015; Mweemba et al., 2015). Also, studies conducted among HCPs found that they had inadequate knowledge of paediatric HIV disclosure (Kalembo, Kendall, Ali, & Chimwaza, 2018; Madiba & Mokgatle, 2015). It was also found in a Nigerian study that some of the HCPs lacked knowledge on when disclosure should begin and participants recommended that disclosure training should be routinely done (Adekunle, Olutekunbi, Animasahun, Afadapa, & Ubuane, 2019).

Several primary studies and systematic reviews have established that the lack of culture-specific guidelines is one of the major barriers to HIV-positive status disclosure to CLHIV by caregivers and HCPs (Biru et al., 2018; Mutambo & Hlongwana, 2019; Pinzón-iregui et al., 2013). A qualitative study of 13 caregivers reported a lack of culturally tailored guidelines, lack of training and caregiver support, and inadequate education of caregivers by HCPs on the disclosure process of their children as the main factors delaying disclosure to children (Vranda et al., 2017). Similarly, an online survey conducted to assess paediatric

HIV care at selected sites in LMICs confirmed that only one-third of the sites had guidelines on paediatric HIV disclosure. It was found that though the sites reported offering disclosure counselling, this was mainly done by counsellors rather than trained medical staff, with inadequate use of guidelines for disclosure (Arrivé et al., 2018).

2.8. Intentions of Caregivers to Disclose HIV Positive Status to Children

HIV disclosure is largely influenced by the individual's intention to disclose. Literature shows that intention to carry out disclosure depends on the individual's context and can change over time (Ajzen, 2011). It has been suggested that intention to carry out disclosure to children results in disclosure planning which is moderated by available inhibitors or facilitators (Evangeli & Kagee, 2016). A quantitative study of 546 women with HIV which investigated factors associated with intention to disclose HIV status to their children in China found that less than half (40.3%) of the women had a positive attitude towards disclosure of HIV positive status to their school-age children. They also found that all the constructs of the TPB were significantly related to intention to disclose and attitude was the most predictive variable of intention to disclose parental HIV positive status to children (Mo et al., 2019). Jemmott III et al. (2014)) conducted a quantitative study among 100 caregivers of children (9-13 years) guided by the TPB. They found that the normative beliefs and self-efficacy belief constructs in the TPB are strongly associated with caregivers' intention to disclose HIV positive to their children in South Africa.

Other studies indicated that intention to carry out disclosure is associated with actual disclosure to children early. A 12-month longitudinal study among a cohort of 123 caregivers who had not disclosed HIV-positive status to their children in Zimbabwe found that age influenced caregivers' intention to disclose. The authors reported that caregivers of mature children were more likely to have an intention to disclose than those with young children (Finnegan et al., 2019). The study found that caregivers who had an intention to disclose were more likely to act on their intention to disclose and took steps to prepare for disclosure even if actual disclosure to children did not occur. Some studies have found that caregivers intended to disclose to their children who are older than ten years (Madiba & Mokgatle, 2017). It was reported in a Zambian study that 59.0% of caregivers stated 10 to 12 years as the preferred age for disclosure (Tsuzuki et al., 2018).

A quantitative study of 233 caregivers of school-age children 5-18years in India found that 80% of caregivers who did not disclose planned to do it in the future. They cited 16 years as the intended age to disclose to their children (Ekstrand et al., 2017). Also, a study carried out among caregivers of children aged 6-15 years in Ethiopia reported that caregivers who have not yet disclosed, have plans to disclose in the future and recommends 10-14 years as the intended age to disclose (Abegaz et al., 2019). It has been reported that persuasion by HCPs influences the intention of caregivers to disclose to their infected children early even if they do not want to (Mahloko & Madiba, 2012). An interventional study in South Africa that supported mothers with HIV to disclose to their uninfected children found that those who had no intention to inform their children about their HIV status disclosed either partially or fully when they participated in an intervention (Rochat, Mkwanazi, & Bland, 2013).

2.9. Summary of Literature Review

HIV is now being managed as a chronic disease because highly effective antiretroviral drugs have improved the survival rates of children perinatally infected with HIV. This increased survival is associated with the challenge of disclosure to children who got infected perinatally. This chapter presented a review of related literature on the disclosure of HIV-positive status to infected children by their caregivers. Findings from the literature review indicate that multiple and complex factors influence caregivers disclosure intention and decisions to disclose. These factors include the child’s age, caregivers’ willingness, perceived stigma and discrimination, healthcare-related factors, normative beliefs, caregiver self-efficacy, HIV and disclosure knowledge, and sociocultural factors.

The literature shows several benefits of disclosure to children and anticipated and real consequences of paediatric HIV disclosure. There is mixed finding regarding the influence of disclosure on ART adherence. Also, there are conflicting results about the influence of the duration of ART and actual disclosure to children. However, the influence of caregivers' attitude and beliefs on intention to disclose has been found. Even though some quantitative studies reviewed were guided by theories, most qualitative studies did not report using a behaviour change theory to guide their study. This study was relevant because it explored individual, interpersonal and sociocultural factors that may influence caregivers' disclosure intention to their children. Chapter Three will describe the research methodology and the ethical clearance procedures.

CHAPTER THREE

METHODOLOGY

This chapter presents the study setting and provides an overview of the research design, and how the whole research will be carried out. The research design, population, sampling, data collection procedure, and data analysis have been discussed and justifications of the methods are given where necessary. The chapter also provides a discussion of the measures to be taken to enhance methodological rigour. Ethical considerations for the study have also been discussed at the end of the chapter.

3.1. Research design

Research design refers to the overall plan that the researcher will use to answer the research questions. The research design spells out the basic strategies that the researcher will employ to answer the research questions of the study (Polit & Beck, 2014). This study employed a qualitative exploratory-descriptive design to explore the experiences of caregivers of CLHIV on disclosure of childhood HIV-positive status to their children in the Ho municipality of the Volta Region. According to Creswell (2014), a qualitative approach is useful for exploring and understanding the meanings people attach to social or human problems. Qualitative research attempts to describe and explain the world from the perspective of those who are experiencing it (Merriam & Tisdell, 2015).

The qualitative exploratory design was appropriate for this study because it helped in collecting in-depth information about caregivers' experiences with disclosure, perceptions and beliefs, perceived control beliefs, and how these factors influence their decision to disclose to their children. The qualitative design was also appropriate for the study because little is known about paediatric HIV disclosure in the Ho Municipality, Volta Region. To the best of the researcher's knowledge, no study exists currently in the Volta Region on paediatric HIV disclosure and caregivers' experiences with the phenomenon.

Grove and Gray (2019) maintain that this design is used to address problems that particularly require the perspectives of the patients or their families to be correctly addressed. Sandelowski (2000) concords that qualitative descriptive research is a useful method when a direct description of the phenomenon being investigated is required, and it is useful when a researcher is interested in knowing the ‘who’, ‘what’, and ‘where’ of events.

3.2. Study Setting

This study was conducted in the Ho Municipality in the Volta Region of Ghana. The setting was selected because little is known about paediatric HIV disclosure in the region. The Volta Region is one of the administrative regions of Ghana. The Northern Region bounds it to the north, the Gulf of Guinea to the south, Volta Lake to the west, and the Republic of Togo to the east (Ghana Health Service, 2018). The region occupies a surface area of 20,570 square kilometres. The total population of the Volta Region is 2,118,252 (Ghana Statistical Service, 2014).

The Ho municipality is one of the five (5) municipalities in the Volta Region. It was established by a legislative instrument (L.I) 2074 of 2012. Ho is the capital of the municipality and also doubles as the regional capital and economic hub of the Volta Region. The Ho municipality is situated between latitudes 6^0 20”N and 6^0 55”N and longitudes 0^0 12’E and 0^0 53’E. Adaklu and Agortime-Ziope Districts bound the Ho municipality to the South, Ho West District to the North and West, and the Republic of Togo to the East. The municipality occupies a total land surface area of 2,361 square kilometres which represent 11.5 % of the total land area of the Volta Region (Ghana Statistical Service, 2014). According to the 2010 population and housing census report, the population of Ho municipality is 177,281. This represents 8.4 % of the Volta Region’s total population. The females constitute 52.7% and the males represent 47.3%. About 62% of the population resides in urban localities. The sex ratio of the municipality is (number of males per 100 females) of 89.7. The Christian religion is predominant in the municipality and constitutes 91.9% of the population. The Islamic religion accounts for 3.2 %, traditional religion constitutes 2.2% with others being less than 1%.

Agriculture and other agricultural related activities are the main work of the people in the Ho municipality. The agricultural sector employs almost 70% of the labour force in the municipality. Almost every household is involved in farming and farming related activities. Farming is done on a small scale basis in the municipality. The rest of the people are engaged in various occupations both in the public and private sectors. The public sector employs about 9% of the people, while the private sector employs the remaining 91% (Ghana Statistical Service, 2014).

The Ho Municipal hospital (HMH) and the Ho Teaching Hospital (HTH) are the major public health facilities in the municipality and the Volta Region. Currently, the HTH operates at a bed capacity of 306 with a wide range of services. The HTH served as a regional referral Hospital for the Volta Region of Ghana until it was recently upgraded to a teaching hospital in 2019. The HTH and the HMH were used as outlets for recruiting participants for the study. The participants of the study were recruited from the antiretroviral clinics of both hospitals. The HTH was selected for this study because it serves as a referral centre for all hospitals within the Volta Region and so it has a large number of children living with HIV coming from different districts. The second-largest health facility in the municipality is the HMH. It is also the oldest government hospital in the municipality that serves the people of Ho and its surrounding towns and villages.

3.3. Target Population

The target population for this study included the caregivers of CLHIV who are accessing antiretroviral treatment at the Teaching and Municipal hospital in the Ho municipality of the Volta Region of Ghana. A population refers to the entire aggregation of cases in which a researcher is interested and the target population is the entire population in which a researcher is interested (Polit & Beck, 2014). Robinson (2014) defines a population as the total number of people from whom the sample for the study is drawn.

3.4. Inclusion and Exclusion Criteria

3.4.1. Inclusion Criteria

1. This study included both adult male and female caregivers of children living with HIV between the ages of 6 -12 years who were accessing ART at the two major public health facilities in the Ho Municipality in the Volta Region of Ghana.
2. The participants comprised both biological and non-biological caregivers of CLHIV.
3. Caregivers who were willing to participate in the study and consented to an audio recording of the interview were included in the study.
4. The study included both caregivers who disclosed and those who did not disclose to their children.

3.4.2. Exclusion Criteria

1. The study excluded caregivers of children who were above twelve (12) years and below six (6) years of age.
2. Caregivers of children who fall within the ages of 6-12 years but had any form of cognitive impairment as reported by the caregivers and the nurses at the clinic were excluded from this study
3. Caregivers of children with other infectious illnesses were excluded from the study.

3.5. Sample Size and Sampling Method

Sampling is the process of selecting a portion of the population to represent the entire population (Polit & Beck, 2014). The sample size included 13 caregivers of children living with HIV between the ages of six to twelve (6-12) who were accessing ART at two facilities in the Ho municipality of the Volta Region. The sample size used was guided by data saturation (Polit & Beck, 2014). Data saturation was achieved on the thirteenth participant as no new information was emerging. It is argued that the adequacy of the sample size in qualitative research is determined by the depth of data and not based on frequencies (O'reilly & Parker, 2013). Onwuegbuzie and Leech (2007) suggest that the sample size in qualitative studies should not be too large so that it would be easy to obtain in-depth information from the participants. Also, the sample size used in a similar study could be used in a current study if the studies are similar (Guetterman, 2015).

The participants were selected using a purposive sampling technique. The nurses at both clinics assisted the researcher to recruit primary caregivers who met the inclusion criteria of the study. The participants who had experience caring for CLHIV on ARV medication and could provide detailed information on the phenomenon of interest were selected for the study. Purposive sampling is often used when researchers want a sample of experts who possess rich information on a phenomenon being studied (Etikan, Musa, & Alkassim, 2016; Polit & Beck, 2014; Robinson, 2014). It is based on the belief that researchers' knowledge of the population can be used to select study participants and enables the selection of individuals with adequate knowledge about the phenomenon being studied. The technique involves the intentional selection of participants who possess certain qualities that the researcher is interested in and includes them in the study (Etikan et al., 2016).

3.6. Data Collection Tool

A semi-structured interview guide (Appendix B) was used to collect the data. The semi-structured interview guide allowed for the generation of spontaneous responses and in-depth exploration of caregivers' experiences on disclosure of childhood HIV positive status to their CLHIV (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). The questions in the interview guide were based on the constructs of the TPB such as attitude, subjective norm, perceived behavioural control, intention, and behaviour. The interview guide also included major questions and probes to elicit relevant information on behavioural, normative, and control beliefs which are beliefs that underlie attitude, subjective norm, and perceived behavioural control constructs of the theoretical framework. The interview guide was developed in the English language and later translated into the Ewe language by an expert who is fluent in Ewe (Appendix F).

The interview guide comprised six sections. Section A had items which included the demographic characteristic of the participants and their children. Section B asked questions about the perceptions of caregivers about the HIV disclosure process for children. Section C asked questions about the attitudes of caregivers towards disclosure and behavioural beliefs. The behavioural belief section contained questions on good and bad things caregivers think would happen when they disclose HIV positive status to their children. Section D asked questions about the normative beliefs on what they think important referents would think or say about their decision to disclose to the children, and their willingness to comply with these referents. Section E asked questions on the self-efficacy of caregivers to carry out disclosure and what they think would make it easy or difficult for them to disclose HIV positive status to their CLHIV. The last section F asked questions about the intentions of caregivers to disclose to their children. Also, field notes were taken during the interview to enrich the data collected from participants. An audio recorder was used to record the interviews. It is asserted that in qualitative research, the researcher is also the primary instrument for collecting and analysing data (Clark & Vealé, 2018).

3.7. Pilot testing of the Data Collection Instrument

The researcher was mentored on interviewing before the fieldwork using the interview guide developed for the study. The researcher also attended a workshop on qualitative research methods for two days. After obtaining ethical clearance, permission was sought from the ART clinic of another hospital where pilot testing of the interview guide was conducted. Three primary caregivers of CLHIV who were accessing ART services at the facility were used for the pilot testing (Kallio et al., 2016). Pilot testing of the interview guide is one of the phases of interview guide development. The aim was to assess the coverage and relevance of the contents of the interview guide. It also helped to identify questions that need reformulation and to test the implementation of the interview guide (Kallio et al., 2016).

The participants used for the pilot testing were recruited with the assistance of nurses at the ART clinic. The pilot testing enabled the researcher to assess the clarity of the questions in the interview guide and improved her interviewing skills (McGrath, Palmgren, & Liljedahl, 2019). These interviews were audiotaped with the permission of the participants, transcribed verbatim and analysed. The transcripts and the interview guides were shown to the supervisors of the researcher for comments and corrections (Chenail, 2011). The findings from the pilot testing helped to inform the revision of the questions and update the probes before the actual data collection began. New probes emerged during the pilot testing; they were added to the interview guide and explored during the main data collection. However, the transcripts of the pilot testing were excluded from the actual study findings.

3.8. Data Collection Procedure

Ethical approval for the study was obtained from the Ethics Review Committee of the Ghana Health Service (ERC-GHS050/11/19) (Appendix C) before the commencement of the data collection. After the ethical approval was granted, a permission letter was sent to the directors of both facilities. Approval letters were then obtained from the research and development department of the HTH, and the medical director of HMH. These letters were sent to the heads of the ART clinics of the facilities. After a formal introduction, the ART clinic nurses were briefed the nature of the research, its purpose and significance, the inclusion and exclusion criteria for recruitment of participants were also explained to them and their support was sought for recruiting participants for the study.

Eligible participants were identified and recruited with the assistance of nurses at the ART clinics. The nature of the research on participant's information sheet was explained to all eligible caregivers in their preferred language. The benefits and risks as well as their right to withdraw from the study at any time if they no longer feel comfortable were emphasised to them. Caregivers who were willing to participate in the study and met the inclusion criteria were sent to a private room at the ART clinics. This is because all caregivers said they felt comfortable being interviewed at the clinic. Caregivers who consented to audio recordings were made to sign the consent form. Data was collected through face to face individual semi-structured in-depth interview of the participants in a private room at the ART clinics after the informed consent was granted. The majority (11) of the participants spoke Ewe and two (2) participants spoke English. The interview was recorded on a digital audio recorder with permission from the participants which was also discussed before the consent form was signed. According to Munhall (2012), interviews are likely to yield fruitful outcomes when it is conducted in an environment where participants are comfortable, safe and relaxed, and where there is no interference. Measures were put in place to prevent inadvertent HIV status disclosure to children who accompanied their caregivers to the clinic. These children watched television at the nurses' station while their caregivers were interviewed in one of the offices at the clinic.

The duration of the interviews ranged between 35 minutes and 1 hour 40 minutes. Field notes were taken on the participants' gestures, non-verbal cues and the environment to enhance the richness of the data collected (Sutton & Austin, 2015). The service of a Clinical Psychologist (Appendix G) was made available at no cost to participants. However, no participant used this service. Effective interviewing skills such as the use of probes, active listening, reflection and summarising responses were used by the researcher. The non-verbal cues were observed and documented in the field note. This non-verbal communication served as an additional means of getting pieces of information (Onwuegbuzie, Leech, & Collins, 2010). Participants were thanked after the interview. Their telephone numbers were also taken, and they were made aware that the researcher may call them for clarifications.

3.9. Data Analysis

Analysing qualitative data involves the analysis of texts, visuals, or audio data; it covers a spectrum from confirmation to exploration (Mihas, 2019). Data were analysed using the steps of thematic content analysis described by (Braun & Clarke, 2006). The analysis occurred simultaneously with the collection of data and the recruitment of participants (Merriam & Grenier, 2019). The rigorous and trustworthy steps for conducting thematic analysis in qualitative research (Braun & Clarke, 2006) have been applied in the data analysis. Thematic analysis is a robust process for identification and interpreting patterns in the data (Braun, Clarke, & Weate, 2016).

To ensure familiarisation with the data, the audiotapes of the interview were transcribed verbatim. After the transcription, the Ewe transcripts were translated into English. Even though the researcher is very fluent in Ewe (the local language), the service of a qualified translator was also employed to enhance the trustworthiness of the translation process and prevent the loss of the actual meaning of the information. The transcripts were then actively read several times and the audios were played repeatedly to familiarise with the information collected (Crowe, Inder, & Porter, 2015; Javadi & Zarea, 2016). This approach was used to extract meanings and concepts from the data and interesting quotes were noted during reading the transcripts. Also, re-reading the transcripts enhanced the researcher's immersion in the data before coding the transcripts (Merriam & Grenier, 2019; Moser & Korstjens, 2018). Vaismoradi, Turunen, and Bondas (2013) stated that the approach provides essential skills for the researcher to conduct other types of analysis.

After the initial familiarisation and immersion in the data, the researcher began manually coding the transcripts. The researcher identified interesting statements in the data and manually assigned codes which were either words or phrases to these statements. Coding is the process of reviewing the data line by line to identify key issues that are assigned a label such as a word or a phrase to those statements (Neale, 2016). A codebook (Saldaña, 2015) was kept which comprised the codes, their description, and examples of statements that represented that code. The initial codes were shown to the supervisors for their review and comments. After manual coding of a few transcripts which were accepted by the supervisors, the entire transcripts were uploaded onto a qualitative data analysis software (Atlas ti version 8). The Atlas ti was then used to code all the transcripts and also helped to label, organise, and categorise the codes (Moser & Korstjens, 2018).

Furthermore, after the coding, there was sorting and categorisation of the codes where similar codes were grouped and given a phrase to represent them with the help of supervisors. Sub-themes were then developed from these categories. Review and refining of the sub-themes were done. This enabled the researcher to review interrelated sub-themes and refine them. The main constructs of the theory which guided the study were used as the major themes. The final report of the study was presented using the thematic areas from the theory of planned behaviour and the sub-themes that were derived from the data codes.

Nowell, Norris, White, and Moules (2017) argued that the approach can be used across different epistemologies and research questions.

3.10. Data Management

The following measures were taken to protect the data collected and the identities of the participants. The interviews were conducted in a private room at the clinic to ensure confidentiality. The electronic data comprising the interview transcript were saved on the researcher's personal computer and protected with a password that was only accessible to the researcher and her supervisors. De-identification of the transcripts was done. Pseudonyms were used to replace the real names of the study participants (Moen & Middelthon, 2015). The audiotapes were transferred onto an external hard drive and securely kept at the researcher's office. A copy of the audiotapes was saved on a password-protected personal computer of the researcher. The consent forms, demographic datasheets, and field notes which included identifying information of the participants were separated from the audiotapes and stored securely. Qualitative data analysis software (Atlas ti version 8) was used to manage the data. All the data collected will be kept for a minimum of 5 years after which it will be destroyed. The transcribed interviews were saved with pseudonyms in a folder on the researcher's personal computer and protected with a password.

3.11. Methodological Rigour (Trustworthiness)

The criteria for ensuring rigour (trustworthiness) in qualitative research described by the framework of Lincoln and Guba (1985) were applied in this study. These four criteria; credibility, dependability, confirmability, and transferability were applied to enhance the trustworthiness or quality of the findings of this study.

3.11.1. Credibility

Credibility involves two aspects: first, carrying out the study in a way that enhances the believability of the findings; and second, taking steps to demonstrate credibility to external readers (Polit & Beck, 2014). Merriam and Tisdell (2015) posit that the credibility of a qualitative study is determined by the experiences, intellectual rigour, and training of the researcher. To enhance the credibility of the findings, the following criteria were applied: The researcher ensured a prolonged engagement during the interview as interviews lasted between 35 minutes and 1 hour, 40 minutes. The researcher visited the ART clinics of the selected facilities several times to be familiar with the setting and the participants.

Field notes were taken during interviews to enhance the richness of the data collected. Prolonged engagement is also essential for building trust and rapport with informants, which in turn makes it more likely that useful, accurate, and rich information will be obtained (Polit & Beck, 2014). Besides, debriefing sessions between the researcher and her supervisors were held frequently. The nurses at the ART clinics were allowed to review the study findings. Reflective notes were also taken before, during, and after each interview of the participant. The interviews conducted in Ewe were translated into English by the researcher and an expert who is very fluent in the Ewe language. Member checking was done by restating the comments and responses made by the participants to ensure the accuracy of what they meant. Follow up interviews were done to confirm and clarify some statements from participants. Also, a thick description was achieved by giving a detailed description of the study setting in the report. Direct and verbatim quotes from participants were used in the reports.

3.11.2. Dependability

These criteria assess whether the study findings will be the same when it is repeated in a similar setting or using the same participants (Krefting, 1991). To enhance the dependability of the study, the researcher gave a detailed description of the methods which were used to collect and analyse the data and how the data were interpreted (Polit & Beck, 2014). All the processes used in analysing data were clearly stated. The supervisors of the researcher had access to all the data collected and transcripts and ensured that genuine interpretations of the findings were done. They also ensured that the codes generated from the data and how the themes were developed are genuine (Krefting, 1991). The limitations of the study have been acknowledged under the limitations section. The coding of the transcripts was done repeatedly both manually and using Atlas ti version 8 software. The re-coding of the transcripts was done by the supervisors to ensure the accuracy of the codes.

3.11.3. Confirmability

Confirmability refers to objectivity, that is, the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning. This criterion is met when the findings of the study reflect the participants' voice and the conditions but not the researcher's (Polit & Beck, 2014). To enhance the confirmability of the findings, the researcher kept an audit trail. An audit trail refers to a detailed description of the data collection procedure, how the categories were derived, and how the decisions were made throughout the enquiry (Merriam & Tisdell, 2015). All the data analysis procedures have been well documented. All the transcripts were uploaded onto the software Atlas ti version 8. Also, the codes that are categorised into themes and sub-themes were shown to the supervisors to ensure that the sub-themes were generated from the data. Reflective notes were also taken during the coding of the transcripts. Even though the researcher is very fluent in the Ewe language, the service of language experts was engaged in data transcription to enhance the quality of the transcripts and the translation process.

3.11.4. Transferability

Transferability refers to the extent to which qualitative findings can be transferred to (or have applicability in) other settings. The criteria are used to assess the applicability of the findings of a qualitative study to other contexts (Krefting, 1991). Transferability was ensured by a detailed description of the study setting and context. The research methods, participants, data collection procedures, the target population, and the criteria for inclusion and exclusion from the study were clearly described in the final report to make the transferability of the study easy for any individual.

3.12. Ethical Considerations

Ethical approval for the study was obtained from the Ethics Review Committee of the Ghana Health Service (ERC-GHS050/11/19) (Appendix C). Permission and certificate of authorisation to conduct research (HTH/RPPME/19/1) (Appendix D) were obtained from the Ho teaching hospital. Approval for the study (Appendix E) was further obtained from the director of the Ho municipal hospital. These letters were sent to the heads of the ART clinics of both facilities and a formal introduction was done. The nurses at the ART clinics were briefed the nature of the research and the criteria for the recruitment of participants. The participants were made aware that participation is voluntary and that they had the right to withdraw from the study at any stage. The principles of privacy, anonymity, confidentiality of information, no harm to respondents, and autonomy were strictly adhered to during data collection, storage, and analysis, and reporting of the study findings. The purpose of the study, the benefits and anticipated risks involved in participating in the study were made known to participants. Written informed consent (Appendix A) was obtained from the participants who were eligible for the study before the interview began. The consent was obtained in the presence of a witness after the information on the participant's information sheet was explained.

Consent was sought from participants to record the interviews. To prevent accidental disclosure to children, the interview was conducted in a private room at the ART clinics away from the children. The participants were assured that withdrawal from the study will not affect the care they are provided at the ART clinics. To ensure confidentiality, no personal identifiers such as name, address and house number, or telephone numbers were included in the transcripts and the final thesis. The participants were informed that later publications of this study will also ensure anonymity and pseudonyms will be used. The recorded audiotapes were transferred from the original audio recorder onto an external hard drive which was kept under lock. To prevent harm to participants, no sensitive question was asked during the interview. The service of a Clinical Psychologist (Appendix G) was made available at no cost to the participants. However, no participant made use of this service.

3.13. Summary

This chapter provided the methodology of the study. The sample size and sampling technique were stated. The data collection tool, procedure for data collection, and recruitment of participants were described. The ethical procedures were also described. The next chapter (4) will present the findings of the study with verbatim statements from participants.

CHAPTER FOUR

FINDINGS

This chapter presents the findings of an exploratory descriptive study of the experiences of caregivers about childhood HIV positive diagnosis disclosure to affected children in the Ho Municipality of the Volta Region of Ghana. The chapter begins with a description of the demographic characteristics of participants of the study, the profile of participants, a table of the themes, and sub-themes. The findings of the study have been presented thematically based on the objectives of the study which were developed from the constructs of the model that underpinned the study.

4.1 Demographic Characteristics of Participants

A total of thirteen (13) participants were interviewed for the study. Majority (10) of the participants are females and three (3) are males. Twelve (12) participants are Ewe, which is the largest tribe and dominant language spoken in the Volta Region of Ghana, and one (1) is a Kotokoli. The ages of participants in this study ranged between 34 to 66 years. With their marital status, seven (7) participants reported being in a marital relationship; two (2) were separated; three (3) were widows, and one (1) is single. In this study, participants' educational levels varied. Five (5) participants were reported to have Middle School Leaving Certificate (MSLC); three (3) participants had primary education; two (2) completed Junior High School; one (1) completed Senior high school; one (1) tertiary; and the remaining one(1) participant had no formal education.

Regarding the occupation of participants: one (1) is a baker; one (1) is unemployed; one (1) self-employed; two (2) retired; five (5) are traders; two (2) are farmers, and one (1) is a teacher. All participants reported being associated with a religion. Majority (12) reported being Christians and one is a Moslem. Six (6) participants were biological parents comprising two (2) fathers and four (4) mothers. Two (2) were grandmothers, one (1) step-grandmother and one aunt, uncle, and a biological sister. Their monthly income ranges from one hundred (100) Cedis a month to four hundred (400) Cedis per month. Seven (7) caregivers reported they are HIV negative and five were positive. One (1) participant's HIV status is not known.

The ages of the children were between 6 to 12 years. The duration of ART for the children ranged from 1.6 months to 9 years. Their educational level ranged from nursery to primary five (5). The time of diagnosis of HIV ranges from three (3) months to nine (9) years. Six (6) of the children are males and the remaining seven (7) are females. Out of the thirteen (13) caregivers, only one (1) caregiver had disclosed to her child. The demographic characteristics of the participants have been presented in a table (Appendix H).

4.2. Organisation of Themes and Sub-themes

The four major themes of the study were derived from the objectives of the study which were based on the constructs of the theory that underpinned the study. The sub-themes were directly developed from the data and are twelve (12) in number. These have been presented in Table 4.1.

Table 4.1: Themes and Sub-themes

THEME	SUB-THEMES
1. Attitude of caregivers towards disclosure	a. Negative attitude b. Positive attitude of caregivers and mixed attitude c. Anticipated disclosure consequences
2. Beliefs and perceptions (subjective norms) of caregivers	a. Knowledge of the disclosure process b. Normative influence of Caregivers (Family influence, Healthcare providers' influence, Peer influence)
3. Factors facilitating and inhibiting HIV disclosure	a. Personal level barriers b. Interpersonal level barriers c. Facilitators to disclosure
4. Intention and behaviours of caregivers	a. Caregiver's intention to disclose b. Disclosure practices among caregivers c. Medication regimen d. Coping Mechanisms

4.3. Attitude of Caregivers towards Disclosure

This first theme answered the research question- What is the attitude of caregivers towards the disclosure of HIV positive status to infected children? Three sub-themes were identified under this theme: 1. Negative attitude towards disclosure (unwillingness to disclose and avoidance of disclosure) 2. Positive and mixed attitude of caregivers 3. Anticipated disclosure consequences (negative and positive behavioural beliefs). The theme describes the attitude of the caregivers towards disclosing HIV positive status to their children who are living with HIV. The attitude of an individual towards a specific behaviour can be evaluated on a dimension ranging from negative, positive, and neutral. It was realised that the participants hold varied attitudes towards disclosure of HIV positive status to CLHIV. The data showed that majority of the participants possessed a negative attitude towards disclosure while very few also expressed positive attitude. Mixed feeling was also expressed towards disclosure to children by a participant.

4.3.1. Negative Attitude of Caregivers towards Disclosure

This describes the unwillingness and displeasure expressed by caregivers towards disclosure. The data revealed that majority of the caregivers hold negative attitudes towards disclosure to children infected with HIV. This negative attitude was reflected in the use of deception, avoidance of disclosure, and using age as an excuse to delay the HIV positive status disclosure to their children. Some caregivers who have not disclosed explained that they feel their children should never be informed about their status. Some caregivers felt that the children will learn their status by attending ART clinics through the health education provided at the clinic:

> *"I would not tell her anything. I only told her the convulsion she suffered earlier was the reason she was put on medication because I do not want her to know. But any other person may tell her, but for me, I will never say it…If somebody would tell her, then I will not be present but she would come and ask me. But even that, I would tell her I do not know anything about it with the sense that her heart would be at ease. I would only tell her it was due to the sickness she suffered when she was very young that is why she was put on the medication so that she might not think too much" (Kwadzo, 63-year- old father of 11- year-old girl).*

Deception and avoidance were used to escape disclosing HIV-positive status to infected children. Some children were accidentally told their HIV positive status at home and the clinic. However, the caregivers persistently lied that they did not have HIV. Some participants narrated how they have deferred disclosure of HIV positive status to their children as seen in these participants' accounts:

> *"I have never said it and I will never say it. Whenever she makes me angry, I just tell her she is worrying me but a time is coming, when I will tell her all her background story. From the entire period, she has passed through till this stage" (Afeafa, 63-year-old grandmother of a 10-year-old girl).*
>
> *One day, one of his siblings insulted him that he is HIV positive. Though he was eating, he immediately left the food; he cried and came to ask me if what the sister said is true…He cried the whole day and was severely traumatized and could not eat. I cried too but I told him it is a lie. He woke me up at dawn about three times and asked me again but I insisted that it was not true (Ablator, 45-year-old step-grandmother of a 10-year old boy).*

Other participants considered maturity (age) as a basis for the negative attitude towards disclosure. The following participants expressed their displeasure and unwillingness to disclose to young children in their accounts:

> *"I think that it is not appropriate for us to tell them now. If they are of a certain age, we can tell them…if you tell this young child about this issue at this time, he does not know the difference between this disease (HIV) and other diseases. He may feel that it is just any ordinary disease he is living with" (Ameyo, 45-years-old, mother of a 12-year-old boy).*

> *"If the child grows to a certain age, you can call her one early morning and tell her but right now, I think it is not fine to tell this young child. She cannot conceal it from others" (Mawumenyo, 45-year-old mother of a 7-year-old girl).*

Additionally, the findings indicated that caregivers avoided disclosure to their children even though some demonstrated readiness for HIV status disclosure. A caregiver narrated how she avoided disclosure to her granddaughter in this statement:

> *"She is demanding to know her mother. Once in a while, she would ask me where her mother is. She is also anxious to know the medication she takes so I told her the time is coming so when the time comes, I will tell her the whole issue. Last year in December, when I went to the clinic, one nurse told me that she (the child) came. The nurse said they went to their school to give health education, and my daughter came to them that they should test her to see whether she had HIV. That means she wanted to know if she was living with any of the diseases which the nurses taught them in school so that she will know how to conduct herself. She went herself so I feel that, as she grows up (laughs), she would get to know through the education they are re giving her" (Afeafa 63-year-old grandmother of a 10-year-old girl).*

As reported above, most caregivers were unwilling to disclose HIV positive status to their CLHIV. There were opportunities for caregivers to initiate discussions on disclosure with their children, however, caregivers felt the children were not yet mature to be told their HIV positive status.

4.3.2. Positive Attitude of Caregivers towards Disclosure

Positive attitude refers to a favourable evaluation of disclosure to children by caregivers. These are caregivers who demonstrated willingness to disclose and felt HIV status disclosure should be done to their children between the ages of 6-12. Positive attitude was demonstrated by a few participants towards the disclosure of HIV diagnosis to their children. Some participants mentioned that disclosing HIV positive status to children early is good and appropriate. However, a caregiver who expressed a positive attitude also discussed that the children should be warned during the disclosure process to keep their status a secret by HCPs.

A 46-year-old male caregiver opined that:

> *"I do not think disclosing is bad. The reason is that if they know that at their age or an earlier stage, it will help them and help others too because if he knows that he has it and that is why he has been going to the hospital and taking his medicine, he will be very happy to take the medicine always. If not, he will go back to the previous life where he will sit down quietly, so it is very fine we tell them." (Baba 46-year-old uncle of 6- year-old boy).*

Some caregivers who initially expressed negative attitudes subsequently discussed that HIV positive status could be disclosed to the children but with a warning to keep it secret.

> "*It is appropriate they inform her but she should be advised on how to talk about it in the presence of outsiders" (Esinu 39-year-old mother of 11-year-old girl).*

Another participant who has disclosed to her 10-year old boy expressed a positive attitude towards disclosure to school-aged children as follows:

> *"No matter how long the child stays, by all means, you have to brace yourself to tell them. This is because, if you want to tell the child when he or she is older, he or she may ask you why you did not tell him earlier when he was diagnosed with this disease. This would cause the child to think about it because he is now grown. Now he is in Primary Four and I disclosed to him, he would no longer think so much about it like that as he grows up" (Sefakor 40-year-old mother of a 10-year-old boy).*

Similarly, a male participant who expressed a positive attitude towards early progressive disclosure explained further that:

> *"…I know definitely I have to tell him… I know if I do not tell him and he discovers it on his own from the hospital, maybe he will tell me or assume I do not like or love him because I knewew what was going on but I did not tell him. I know he will not be happy with me (Baba 46-year-old uncle of a 6-year-old boy).*

In contrast, it was observed that one caregiver exhibited a mixed attitude towards disclosure. A grandmother of a 6-year-old boy expressed her ambivalence as follows:

> *"I said earlier that, left to me, it will not be necessary for him to know but if it is about this sickness which does not quickly go away and requires medicines to suppress it, he should, by all means, know since my prayers cannot help to cure this sickness. Since he will have to continue with the medicines, he should by all means know that this is the reason he is on medication. If it does not come from me or you (nurses), what if he hears it in the community?...that is why I said that if it necessary that by all means, he must know, we will not prevent him but on my part, it is not necessary to tell him" (Mawutor 66-year-old grandmother of a 6-year-old boy).*

As presented above, it was observed that most caregivers of this study possessed negative attitudes towards disclosing HIV status to their children.

4.3.3 Anticipated Disclosure Consequences

The sub-theme describes the negative and positive consequences that are expected by the caregivers after disclosure of HIV status to their children. The data showed that most participants anticipated several negative consequences of disclosure. It was realised from the narratives that even though some children were anxious to know why they have been on medication for so long, the anticipation of negative outcomes inhibited caregivers from disclosing. The expected consequences range from the risk of the children accidentally exposing their status to others, which subsequently would result in being stigmatized and discriminated against in the community, family, and school. Others were apprehensive about adverse psychological and emotional reactions such as "sadness", "thinking or worrying", "social isolation", "shame", "premature death", and "suicide." The following participants narrated their beliefs about the consequences of disclosure.

> "*Calling the child to tell him about this issue is not a problem for me but the adverse outcomes are what I am talking about. For telling him, I can go home right now, call him at dawn and tell him, but the outcome of this action is what I am worried about"(Ablator, 45-year-old step-grandmother of a 10-year-old boy).*

Furthermore, it was realised that the caregivers believed that disclosure to young children between 6-12 years will result in serious psychological harm to the children compared to late disclosure:

> *"Ah if you tell her now, this child will be worried about that and she will be afraid. That is why I do not want to tell her now. If she grows up to about 18 years or 17 years, I can tell her. Now she does not know anything. If she hears it now, she will feel like she will be dying. She will be afraid. But if she reaches that age and you inform her that she is taking the medicine to live long, then she knows that the medicine will make her live longer but if you tell her at this age, she will be thinking that maybe she is going to die prematurely and she would not be happy" (Mawumenyo 45-year-old mother of a 7-year-old girl).*

Some participants opined that the children will feel unhappy whenever they recall that they are HIV positive:

> *"She would no longer feel happy compared to the way she feels happy now. Even if she is happy, and she recalls her diagnosis, she may stop playing and start feeling sad" (Tsoenamawu 39-year-old aunt of a 12-year-old girl)*

Surprisingly, some caregivers expressed concerns about economic consequences. Some participants worried that if people in the community became aware of a child's HIV status, it would result in economic loss for them. These participants shared their views:

> *"I do not want anyone to know that he is on medication because we sell foodstuff, so if anyone comes to the shop and sees that medicine and supposing they are also on it, they may tell other people that this person who sells foodstuff and uses knife in her business is HIV positive. So if you don't take care, your business will collapse, so I put it inside and when he comes, I give water to him to swallow it. I always consider myself as the patient and I do not see him as the one who is sick" (Ablator, 45-year-old step-grandmother of a 10-year-old boy).*

Another participant who sells foodstuff has this to say:

> *"… If you are selling foodstuff and people hear that you are living with this disease, they will discriminate against you. They would not want to buy it. They would never want to buy from you because they think that they will be infected if they buy food from you" (Tsoenamawu, 39-year-old aunt of a 12-year-old girl).*

Madam Ablator further commented on the risk of economic loss resulting from adverse reactions to her adopted child in this account:

> *"If disclosure can be done without harming the child, I will accept it- that is, if only it is done in that way so that the child is not harmed and the money I have spent on him is not wasted. This is because I have suffered so much. Talking about money, I have spent a lot of money on him. My money, all the efforts and sleepless nights cannot be in vain" (Ablator, 45-year-old step-grandmother of a 10-year-old boy).*

Positive outcomes were discussed by some caregivers when they were asked if they anticipate disclosure will bring any benefit to their children. These participants mentioned some benefits they anticipate as a result of disclosure such as; medication adherence, prevention of infection to others, and becoming responsible as well as prolonged life.

> *"The benefits it would bring is that she would know how to conduct herself; she would not live anyhow because she knows the type of person she is. She will know how to conduct herself so it is beneficial that when they grow up, we tell them. If we don't tell them, they may die early. Dying early means she will not take the medication; she will leave the medication and the sickness would worsen and she will die but when we tell her that this is why you are taking the medicine so continue from where you are, then she can know"(Afeafa, 63-year-old grandmother of a 10-year-old girl)*

Similarly, some mentioned benefits such as adherence to medication:

> *"If you tell him he is living with HIV and that it is because of this disease he is taking the medicine, then he also knows that it is because of this disease that he is taking the medicine so when the time is due for him to take the medicine, he will not hesitate; he would come to take his medicine" (Ameyo, 45-year-old mother of a 12-year-old boy)*

Some participants commented that disclosure will make the child take measures to prevent infecting others:

> *"The benefit of it is the risk involved when playing with his brothers or sisters, considering how they have been playing with sharp objects like milk tin, tomato tin and all those things they use to play when they are outside. When you educate him by telling him that if something cuts you and it cuts somebody else at the same time, your blood can get into contact with the person's blood and he could be infected so do not let somebody have the same sickness you have. These are some of the advantages if we tell them" (Baba, 46-year-old uncle of a 6-year-old boy)*

A grandmother narrated the need to disclose to her granddaughter whom she felt may start a sexual relationship as follows:

> *"I have to tell the older one because where she is now, she may start a sexual relationship at any time. So l have to tell her that with the disease she is suffering from, she doesn't have to enter into any sexual relationship. If she does, the man could also contract the disease. She will know how to conduct herself, so I can explain it to her but the younger one won't understand anything if I tell her now" (Amewosina, 65-year-old grandmother of a 12-year-old girl).*

The only caregiver who disclosed HIV status to her son shared her post-disclosure experience in the following statements:

> *"At first when they did the test and confirmed that it was this disease, I was thinking about how I was going to handle this child for him to take the medicine, and should he ask me about the medicine he is taking, how would I answer him? The whole time he was put on medicine, I was always thinking about it to the extent that I could not sleep well. I thought about it because, for some children, when they have a sickness and you do not tell them, they may go mad. Some children also pick up weapons against their parents. I was thinking about these issues so when he came to ask me and I revealed his condition to him he stopped misbehaving like he used to…Formerly when I asked him something, he would insult me that I should get away from him but now, when he asked and I disclosed to him, he does not do anything like that again and he no longer insults me."(Sefakor 40-year-old mother of a 10-year-old boy).*

4.4 Beliefs and Perceptions of Caregivers

This theme addressed the research question- What are the beliefs and perceptions (subjective norm) of caregivers regarding the disclosure of HIV positive status to their children? The sub-themes developed under this theme are 1. Knowledge of the disclosure process 2. Normative Influence of caregivers (Family influence, Healthcare provider's influence, and Peer influence). This theme describes the beliefs and perceptions of caregivers towards the disclosure of HIV-positive status to children. The theme also discusses the normative influence of whether important referents will approve or disapprove of a participant's decision to disclose HIV positive status to their children. This also entails whether these important referents themselves would perform or support disclosure to the affected children. The important referents described here include the family, healthcare professionals, and peer influence.

4.4.1 Knowledge of the Disclosure Process

This sub-theme describes the knowledge of caregivers about the HIV status disclosure process for children. It also describes the perception of caregivers about HIV disclosure to children. Most participants asserted that their children were too young to understand HIV positive diagnosis. Some felt their children have not even heard of HIV. The following participants expressed their perceptions of their children's ability to understand HIV in these statements:

> *"I feel he is a child and he does not even know what the disease is so I feel that even if I tell him, he does not know what HIV is so he would not understand anything that this is the disease called HIV" (Ameyo 45-year-old mother of a 12-year-old boy)*
>
> *"When you tell this child, he will not understand. He has not even heard of it so, if he is told now, he will not understand but when he grows up a little and he is told or he hears from somewhere that there is a sickness known as such, then maybe he will understand" (Mawutor 66-year-old grandmother of a 6-year-old boy)*

Contrarily, a caregiver who had disclosed remarked that:

> *"I have realised that, if you tell the child this time, it is better than if he grows up before you tell him. Because currently, he is not yet grown out of childhood so if you tell him now, he would not think so much about it. When you tell them at an older age, some children may even go and commit suicide but if you disclose it to him at a younger age, he will stop thinking about it as he grows" (Sefakor 40-year-old mother of a 10-old boy)*

HIV disclosure to affected children is a process that must be done gradually from 6 years or based on psychological maturation. The caregivers were asked about their views on beginning the process gradually until full disclosure occurs later. It was observed that most caregivers expressed poor knowledge about the disclosure process. Majority described HIV disclosure as a single event where the child would be informed about their status at once and not as a progressive process. The following statements from participants described their perceptions of the disclosure process:

> *"I do not know how to say it gradually; if I want to say it, I would mention at once that this is the disease she is living with. That is why I am saying that she should be fully mature before I tell her" (Mawumenyo 45-year-old mother of a 7-year-old girl).*

Another participant expressed an inability to disclose gradually until full disclosure occurs:

> *"I do not know what else should be said apart from mentioning the name of the disease to him" (Mawutor, 66-year-old grandmother of 6-year-old).*

Similarly, some explained that disclosure should be done in a single event if the child is about to leave to another place as follows:

> *"I will endure till the time she is going to senior high school. When she is about to leave for another place, then that day I will bring her here (clinic) with me. They will guide her on how to live" (Afeafa 63-year-old grandmother of a 10-year-old girl).*

Conversely, some explained that the disclosure process should be done gradually at the clinic or home. The following are their statements:

> "*…he is maturing gradually so what I have decided is that, I will start educating him about this sickness. I will start telling him that he should not do this or that in public. I think he won't ask me any question now but if he asks me to, I will answer him… If I start early maybe he will also be happy with it" (Baba, 46-year-old uncle of a 6-year-old boy).*

As reported above, the findings indicated that most caregivers felt that their children were too young to understand HIV diagnosis.

4.4.1.1. Who Should Disclose?

Concerning the person deemed appropriate to disclose, caregivers expressed divergent opinions. Some caregivers indicated that it is the responsibility of the HCPs to undertake disclosure. Conversely, some indicated that both caregivers and HCPs could disclose. Others reported that the children would not believe their diagnosis if they (caregivers) disclose their status to them as they have lived with them for long:

> *"If I tell them, I do not know if it would be clear to them. However, if health workers tell them, they will add counselling so they will understand it better. The children no longer trust what we parents tell them, especially those of us who are not educated so they no longer accept our advice, so if those with the knowledge explain it to them, it would be easy for them to understand"(Amewosina, 65-year-old grandmother of a 12-year-old girl).*

Some of the caregivers indicated that the children will be afraid to disclose their HIV status to others if it is HCPs who disclosed it to them:

> *"For us their parents, when we tell them, they will hear but they can go and tell their peers. But children fear nurses so if there is a group that can help disclose it to them, it will be better" (Kofi, 48-year-old father of 7-year-old girl).*

However, a caregiver opined that both healthcare professionals and the parents could disclose HIV positive status to the children:

> *"In my view, you the parent can tell the child but if you look at the child and realise that if the parents tell him, he would not understand, you can bring him to the hospital for the doctors to tell him" (Ameyo, 45-year-old mother of a 12-year-old boy).*

The data showed that most caregivers preferred that disclosure should be done by HCPs.

4.4.2 Normative Influence of Caregivers (Perceived Social Pressure)

This sub-theme is related to the perceptions of the caregivers on whether important referents (family members, healthcare professionals, and peers) would approve or disapprove of their decision to disclose HIV status to their children. Caregivers explained what they think these important referents such as family members and HCPs would say or think about their decision to disclose. Caregivers mentioned that significant others such as spouses, grandparents, uncles, and aunts who are aware of the child's HIV status will disapprove of their decision to disclose to young children. The influence of important referents (family, healthcare professionals and peers) has been discussed under this subtheme.

4.4.2.1. Family Influence

Regarding disclosure of the child's HIV status to family members, almost all caregivers have disclosed the child's status to someone. Those who are aware of the child's diagnosis include older siblings, uncles, aunts, grandparents, and pastors. Most caregivers discussed that those significant others who are aware of the child's status would disapprove of their decision to disclose to the children:

> *"I made the father as well as my daughter aware …I know these two persons are aware so when the time is due for us to make her aware, these two persons would agree. But all of us have agreed not to tell her anything yet" (Afeafa, 63-year-old grandmother of a 10-year-old girl).*

Conversely, some have not disclosed to close family members such as grandparents and uncles, and siblings:

> *"Her grandmother and her maternal uncles wanted to know but I have not revealed it to them that it is this sickness (HIV). Her grandmother is insisting on knowing the sickness she is suffering that has consequently brought about regular medication and I said I was not the doctor who put her on it… so I did not know what sickness it was…They are desperate to know the kind of disease the child is living with. Even my mother who gave birth to me is not aware. If I let her (grandmother) know she will publicise it. She will no longer take care of her as expected" (Kwadzo, 63-year-old father of a 10-year-old girl).*

Another participant commented about concealing HIV status from family members:

> *"If none of them (family members) is living with this disease, then how did you contract it? In fact, if your relatives are aware of your HIV status that you are living with this disease, then you will become a 'carpet' for them. You do not find it easy with outsiders, how much more the insiders?" (Esinu 39-year-old mother of 11-year-old girl).*

Concerning caregivers' perception of whether significant others who are aware of the child's HIV positive status would approve or disapprove of caregivers' decision to disclose to the children, the participants expressed varied opinions. Majority indicated that family members would disapprove of disclosure to children between 6-12 years of age. Some also mentioned that family members might approve if the decision comes from HCPs. Some participants expressed their views as follows:

> *"On the part of my sisters, they cannot disclose it to the children now. They can never tell these young children. My elder sister wants to take special care of the children and all of us so she cannot tell them that this is the kind of disease that they are living with. She can never tell these little children. She cannot tell them because telling the children means betraying your children" (Kofi 48-year-old father of 7-year-old girl)*

Another participant explained that significant others would disapprove of disclosure to her 12-year-old son below:

> *"They would never accept that I should tell the child at this age because they know that the child is still very young and does not know anything" (Ameyo,45-year-old mother of 12-year-old)*

Some caregivers with serodiscordant spouses discussed that HIV-negative fathers would disapprove disclosure to the child due to differences in their serostatus.

> *"I think the father will not agree. He would ask me which doctor diagnosed her. Because he, who gave birth to the child does not have this (HIV)" (Mawumenyo 45-year-old mother of 7-year-old)*

One participant narrated how a biological father disapproved of disclosure to his 10-year son as follows:

> *"There was a time last year when a sister made me aware that it was about time we told the child that he had the virus. So, I said that, if that was the case, then I had to discuss it with my father. I discussed it with him but he was not in support of it. He told me to hold on for sometime because he felt it was too early" (Fafali 34-year-old sister of 11-year-old boy).*

As described above, the narratives indicated that most caregivers believed that family members would not approve of their decision to disclose HIV positive status to their CLHIV.

4.4.2.2. Healthcare Professionals' Influence

Some participants revealed that they perceive negative influence from Healthcare providers towards paediatric HIV disclosure. This negative influence was in the form of warning caregivers to conceal the child's HIV status from others. Most caregivers revealed that HCPs warned them to conceal their child's status from others to prevent stigmatization. Some caregivers discussed that some HCPs disapproved of their decision to disclose when they sought their opinions about it. Participants also explained that they have been counselled to not talk about children's HIV status because it is a 'shameful disease':

> *"when the doctor (name) made me aware that the baby had contracted the disease (HIV), he warned me to keep it a secret and that it should be between the two of us. Even my husband is not aware up till today because I have been warned against it so my husband has not been informed. The warning was that I should not talk about it because the child would surely grow up and get to know about it…they said when she grows up, I should bring her here (clinic). They would talk to her themselves, that this is what is happening to her so it is not a good thing for me to say this and that so once I have been advised to keep it between myself and the nurses, I have kept it ever since I heard it. No other person has heard it till today" (Afeafa 63-year-old grandmother of a 10-year-old girl)*

Another participant narrated how they have been warned by HCPs:

> *"When we came that day for the test, they warned us that if the news spreads, they would arrest him (child's uncle)"* (Tsoenamawu, 39-year-old aunt of 12-year-old)

Other participants also narrated how they were advised to conceal their children's HIV positive status as follow:

> *"First, we went to the hospital where the thing (HIV) was detected and we were referred to this place – the doctors told us not to tell anybody or when we are caring for them, we should not make anyone suspect that this is the kind of sickness he is suffering from…that is why I am saying that perhaps if he is older and he is told with the warning that he should not say it, perhaps he will understand"* (*Mawutor, 66-year-old grandmother of a 6-year-old boy).*

Some caregivers described how they were advised by HCPs to postpone disclosure to their children in their statements as follows:

> *"I was talking to the doctor on phone about him (name). I asked her (Doctor) what her thoughts about the boy were because he is now 10 years old so I wanted to find out from her what she thought about telling the boy his HIV status. She said 'mama I'm begging you just take your time' and then she asked me if the boy is doing anything. I said no but he is asking me about the medication, so she asked me what I told him initially about the medication. I explained that I told him it was for breast milk replacement. She said I should continue to tell him that because the boy is too intelligent. She told me that if it will be convenient, I should wait till he is 15years of age. So I asked her,' mama are you sure ?' she said,' oh by then, he would have known what is good and bad so if you tell him, he will comport himself and take care of himself '"(Ablator 45-year-old step-grandmother of a 10-year-old boy).*

Another caregiver shared her view as follow:

> *" ..She said she wants to know the kind of sickness she has that requires a daily intake of medicine…But when I went to inform them (nurses) at the clinic about it, they said I should let her know that she is a sickler and that if she takes it, she can be in good health. They (Nurses) said it is not appropriate for me to tell her now. When I told her this, she said we give her different reasons every day and nobody is telling her the truth…She told me that they were taught that people living with HIV are put on medicines so is it HIV? She wants to know if the medicines are for HIV and if that is why I am finding it difficult to tell her (sighs) because we are always going for medicine and whenever she asks me, I tell her different stories (sighs)" (Esinu 39-year-old mother of 11-year-old girl).*

Another caregiver revealed how she has been counselled not to disclose to her granddaughter by a healthcare provider in this statement:

> *"I have to do what I have been told by the nurses. What the nurses told me was that the disease is a shameful sickness…The nurse who treated her made me aware that I should not tell anybody; it must be between us until the child is fully grown. They said the time to disclose is coming so that is what I have been holding on to. I know that when the time is due, the nurses would ask me to bring her and they would disclose it to her. I will not be the one to tell her" (Afeafa 63-year-old grandmother of a 10-year-old girl).*

Despite some HCPs' warnings against disclosure, some disclosed to the children at the ART clinic without prior preparation of the children or caregivers. A caregiver shared her experience at the clinic:

> *"I brought him to the clinic one day and one of the workers here who is close to him during a conversation said that, "this medicine is for HIV/AIDS so take it well so that you will not die". When we got home he asked me "mama did you hear what the sister said?" And I asked him what? He told me that, the worker (name) said the medicines were for HIV/AIDS. I told him he probably heard wrong. He (child) told me that if the medicines are really for HIV then he will never, ever take them again" (Ablator 45-year-old step-grandmother of a 10-year-old boy)*

To explore caregivers' willingness to comply with HCP's suggestion to disclose, the participants were asked if they would comply with a disclosure suggestion from their HCPs who are involved in the care of their children. Most caregivers revealed that they would accept it when HCPs suggest that they should disclose to their children between 6-12 years.

4.4.2.3. Peer Influence

Peers refer to individuals who possess the same qualities as the person in question. Peers play a role in engagement in health behaviour. In this study, peers refer to other caregivers who care for a child living with HIV and attend the clinic with the study participants. The participants explained that there was no peer support and influence. Majority said they do not know about other caregivers. Some explained that they do not meet other caregivers because of the nature of the ART clinic. Some explained that they do not know whether other caregivers have disclosed to their children or not.

> *"Regarding how I have concealed this issue from my child, I do not know if other parents are also hiding it from their children. It may be that I have kept this secret from my child because of my special challenges but maybe, other caregivers have told their children. As for me, my child has still not heard it because of my special issue" (Ablator 45-year-old step-grandmother of a 10-year-old boy)*

Some explained that they meet only adults at the ART clinic but not children:

> *"In the past, I used to meet some children and their parents but we did not converse about such things. But now, they have grouped us so I meet only adults. I no longer meet caregivers of children" (Amewosina 65-year-old grandmother of a 12-year-old girl)*

However, a caregiver shared how the conversation of another caregiver influenced her not to bring her child to the clinic again:

> *"The last time we came to the clinic, one woman said that she would not bring her child to the clinic because the health education they give at the clinic could give her child a clue about his HIV status…she explained that her child is intelligent and may get to know his status through health education given at the clinic. I brought my child to the clinic last week but because of what the woman said last week, that's why I also decided not to bring her today. So, I did not bring her because, she is growing up and if they are giving education about the disease, she will get to know. So I did not bring her today, I decided to come alone" (Tsoenamawu 39-year-old aunt of a 12-year-old girl).*

Regarding complying with peers' suggestions to disclose, some of the participants gave varied opinions. Some said they can agree and others said they would not agree.

4.5. Factors Facilitating and Inhibiting HIV Disclosure

This is the third theme and it addressed the research question- What are the behavioural factors (perceived behavioural control) that influence the caregivers' decisions to disclose to their children? Three subthemes have been identified under this theme: 1. Personal level barriers 2. Interpersonal level barriers 3. Facilitators to disclosure. The theme describes all the factors that participants explained would facilitate or inhibit their ability to disclose to their children. The caregivers discussed several factors they felt are inhibiting them from disclosing HIV-positive status to their children. They also outlined factors they believed would make it easy for them to disclose HIV-positive status to their children. It was realised that some of the barriers identified were directly related to the caregivers, others were focused on the healthcare professionals and some were related to the community.

4.5.1. Personal Level Barriers

These are barriers that are directly related to the caregiver and their children. Several inhibitors of disclosure were identified from the data which were directly related to the caregivers of the children. Some of the barriers identified among caregivers are bereavement, inadequate HIV disclosure knowledge, difficulty telling source of infection, empathy, lack of self-efficacy regarding how to disclose, answer questions, and manage any reaction post-disclosure, and differences in HIV status within the family. These individual factors are discussed below.

4.5.1.1. Bereavement

Disclosure of HIV-positive status to perinatally infected children requires that the source of the child's infection (mother-to-child transmission) be disclosed as part of full disclosure. Some caregivers explained that their children are orphans and have not been informed of the death of their biological parents and the actual relationship with the current caregiver. Hence some participants described their fears about disclosing bereavement and HIV status to their children as follow:

> *"He is not aware that I am not his biological mother. He does not know that I am not the one who gave birth to him. He has never been told anything about it. So my problem is not about telling him that he is living with HIV but telling him about the origin of his infection. But it will be very difficult for me to disclose to this child that he is an orphan because the child does not know up till now that he is an orphan. All he knows is I am the one who gave birth to him" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

A grandmother who worried about disclosing to the child that she is suffering from the sickness that killed her mother says:

> *"She is not aware that her real mother is not alive up till now. I have become her mother since she was seven months old so what the child went through was very difficult. This sickness killed her mother so I would like to wait a little longer before making her aware that this was what killed her mother and that is why she is in the current situation and taking medicine" (Afeafa 63-year-old grandmother of a 10-year-old girl).*

Similarly, a father spoke about undisclosed bereavement to his children. He explained that the children are unaware of the death of their mother:

> *"Even, they are not aware of their mother's death. They do not know their mother is dead. They always ask me to take them to their mother… they came back from school the last time to tell me that somebody told them that their mother is dead so I told them not to mind the person so they are not aware that their mother is dead. That is why I am saying that they should mature a little" (Kofi 48-year-old father of a 7-year-old girl).*

As discussed above, both the biological and non-biological caregivers were worried about disclosing to their children the death of their parents.

4.5.1.2. Telling Source of Infection

Disclosure of HIV-positive diagnosis to young children requires that caregivers disclose how the children got infected. Biological mothers worried that their children would ask about how they got infected when they are disclosed. Some participants were apprehensive about revealing the source of infection to the children as MTCT since it is a component of full disclosure in their statements below:

> *"for me this disease I do not know anything about it, it even surprises me because if she asks me I do not know what to say. But what I realised is that it resulted from fixing of artificial nails but not from living promiscuous life" (Mawumenyo 45-year-old mother of a 7-year-old girl).*

Some non-biological caregivers also expressed concern about disclosing to children that they have a biological mother from whom they got the infection as follows:

> *"For me, telling the boy about this disease and people getting to know that he is HIV positive is not a concern to me. If he gets to know about his HIV-positive status, it is not a problem for me, but my main problem is where it originated from. That is my problem. He would ask "my mother this is the disease I have been diagnosed with, they said it can be acquired from these sources but you are not taking this medicine". Then that means I have to reveal certain secrets. So for this boy to hear that he has this disease is not what is shaking me" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

Again, the only participant who disclosed to a 10-year-old boy failed to disclose the source of the child's infection as perinatal transmission:

> *"He told me that they have been taught at school that toilet facility spreads diseases so did he get the disease through that? When I told him the issue but I did not even tell him he got it from either the toilet or any other source. I only disclosed the disease to him" (Sefakor 40-year-old mother of a 10-year-old boy).*

Furthermore, Ablator who has not disclosed 'adoption' to the child, further explained her difficulty to reveal to her child that he got infected from his biological mother in the statement below:

> *"I would have to tell him in such a way that he would not get to know that he acquired the disease from his biological mother. My child, you did some tests the last time. Have you seen the results? This is what they have seen, where did you get it? What were you doing before this disease got into your blood? Did you take any food from anyone to eat? God will give me the knowledge to do it so that he will not know that it is anybody's fault but it is through his own fault he got it so that he will not take his mind off me that I am not his biological mother" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

The data showed that both biological and non-biological caregivers find it difficult to disclose how the child got infected. Some caregivers who 'adopted' the children and have not disclosed this secret to the children expressed difficulty telling their children that they are not their biological parents. However, some biological mothers who are widowed explained that the children could be informed that they got the infection from their deceased fathers.

4.5.1.3. Caregivers' Self-Efficacy

A major challenge described by participants of this study is the lack of skills and courage to initiate disclosure to children. Many caregivers discussed that they have been thinking about how and when to disclose to their children. Some expressed the lack of courage to answer children's questions, and manage any reaction of the children during and after disclosure. The following statements typically describe caregivers' perceived self-efficacy to carry out disclosure to affected children.

> *"I have been thinking about how to explain it to her understanding. This gives me worrying thoughts...Hmmm, at times, when she asks me questions about it at home, I only tell her to exercise patience" (Esinu 39-year-old mother of 11-year-old girl).*

Another participant revealed that she does not know how to break the news of HIV positive status to the child:

> *"I have been thinking about how to break the news to this child. Up till now, I do not know how I am going to go about it" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

Some participants also explained they lack the courage to answer the child's questions during disclosure:

> *"She will ask questions about where she contracted the disease. She will ask me "Mama, where did I get this disease from", by all means. She would ask me this question. Where? How did she manage to get it? This one, in fact, without fail, she will ask me this question"* (Esinu 39-year-old mother of 11-year-old girl)

Some participants narrated that they lack personal confidence to manage the reactions of the child after disclosure:

> *"I do not have personal confidence. The issue about capability is that I do not know how the child would react if I tell her. I do not know what would happen to her. As I said, that day, the nurse who treated her, made me aware that I should not tell anybody; it must not be heard by anyone, except them and me until the child is fully grown. The time to disclose it to them is coming so that is what I have been holding on to. For me, I do not have the courage"* (Afeafa 63-year-old grandmother of a 10-year-old girl).

As reported above, the caregivers revealed that they have lacked the self-efficacy to disclose to their children. Most of them lacked knowledge of when and how to disclose HIV-positive status to their children.

4.5.1.4. Empathy

Several caregivers expressed empathy towards the HIV diagnosis of their children by themselves. Most of them discussed that they will feel sad to disclose HIV-positive diagnosis to their children. Some explained that this feeling is inhibiting their ability to initiate HIV disclosure discussions with their children. Some caregivers narrated their feelings as follows:

> *"I do not know how I would manage to tell them because this whole issue saddens me. I do not know how old they should be before I tell them…The issue has been worrying me. Because this is an issue about children, I do not know how to say it; it has been saddening me. That is why I have not told them anything. I cannot say that I have called them to tell them anything about their sickness that it started from here or there"* (Amewosina 65-year-old grandmother of a 12-year-old girl)

Also, an aunt of a 12-year-old girl narrated how empathy is inhibiting her decision to disclose HIV diagnosis to the child herself:

> *"It will sadden me to tell her that she is living with this disease, that's why I said if she should know, then the two of us would come here (clinic) for them to tell her, and counsel her…When I look at her sometimes, I shed tears. I weep, knowing that she will grow up and come to know that this is the disease she is living with. It saddens me so much so I cannot tell her" (Tsoenamawu 39-year-old aunt of a 12-year-old girl)*

Another participant expressed empathy towards disclosure in this account:

> *"It really disturbs me because the child is not mature and has not reached any stage, yet he is living with this disease. I cannot say it does not disturb me. At times, I think about it that if it had happened to just me, I will not even think about the disease; I will not think about it that I am living with any disease because I know my ways; he does not know anything yet. Sometimes, I could say it is the result of my own actions that I contracted the disease but he is innocent" (Ameyo 45-year-old mother of a 12-year-old boy).*

As described above, some of the caregivers expressed empathy towards the children's HIV status. Most of them revealed that they would feel sad to disclose HIV positive status to their CLHIV.

4.5.1.5. HIV Knowledge

The caregivers' HIV knowledge is very important in the management of children infected with HIV. Majority of participants demonstrated inadequate knowledge on the mode of transmission of HIV/AIDS itself, as well as misconceptions about antiretroviral medications. Some caregivers explained that HIV can be transmitted through eating together, eating leftover food from an infected person, sharing drinking cups, and bathing articles such as a sponge:

> *"They said if you are eating with somebody, or the person has a cut and you are eating with the person, you can be infected or if you use the same sponge, you can be infected"(Mawumenyo 45-year-old mother of a 7-year-old girl).*

Some caregivers believed that HIV will be cured with antiretroviral medications. Participants revealed that if the child will be cured, then there will be no need to disclose:

> *"In your investigations and what you (nurses) teach us, would it be that the sickness cannot be completely cured but it would continue till such a time that it has to be disclosed to the person? If the sickness can be cured, it will not be necessary to disclose it to the child. If the sickness can be cured, then there is no need to tell him that this is what is wrong with him. If it will not be completely cured but it is a case of forever, it will disturb my mind. Which kind of sickness does one suffer from forever and ever? (Mawutor 66-year-old grandmother of a 6-year-old boy).*

Similarly, another woman shared her view in this statement:

> "*…can no medication cure this sickness which the children have contracted? So would they be on these medicines till their adulthood? It is only that aspect that worries me about the whole thing. Is there any help that can be offered to them because they began treatment from childhood? Is there anything to be done for them to stop the medicines later? So would it be with them till their adulthood and forever? That aspect is the only thing I want to ask that what kind of assistance could be given them because they were not even grown before they contracted this disease" (Amewosina 65-year-old grandmother of a 12-year-old girl).*

The data showed that caregivers had misconceptions about the mode of HIV transmission and some felt that the children would be cured of HIV later as they grow.

4.5.1.6. Family Differences

Another peculiar factor caregivers reported to be inhibiting disclosure to their children is the difference in HIV status within the family. Some caregivers mentioned that they have been thinking about how to safely disclose to their children with different HIV statuses. Some caregivers revealed the issue of serodiscordance in their spouses. Some worried about how to safely disclose to children of different mothers in a polygamous family:

> *"The child's father is not aware of her HIV status. I told him and he said I should forget about that issue because it is not HIV because he regularly visits the hospital but he does not have it (HIV) so how did the child get it? I told him I have also been diagnosed with it and he said, 'ah does the doctor want to scare me to death?' He told me to disregard it. So that is the end of it and we do not talk about it again" (Mawumenyo 45-year-old mother of a 7-year-old girl)*

Also, some participants expressed concern about disclosing to children with different mothers in a polygamous family:

> *"Whenever I wake up, I think about how to do it, how should I tell the children because the children belong to different mothers. If I tell one mother's children that this is their siblings' condition, will they agree to get closer to those children with the disease? Or would it bring separation between them? These are things I think about. How would I do it to make it safe?" (Kofi 48-year-old father of 7-year-old girl)*

Additionally, some biological parents were concerned about how to disclose to infected children while uninfected siblings are not aware of HIV in the family:

> *"I wanted to tell my older son the last time but after pondering over it for a while, I said, this is the person who says I am not sexually promiscuous, I do not have any man, I do not even have time for such things – then now if I tell him, will he not question himself and ask me how I got this thing (HIV)? When we came for the test and he tested negative, he was excused from us before my daughter and I were counselled. So truly, I was telling myself the last time, if I tell him, will he not stigmatize me? He may stigmatize me so I did not make him aware. He is 15 years now so I have been thinking, he is the eldest child, I need to inform him but will he not become afraid me? Truly, that is the reason I do not want to tell the younger one now, though she has the disease." (Esinu 39-old-old mother of 11-year-old girl).*

From the narratives, it is obvious that the HIV status of spouses, siblings, and other family members is influencing the intention of caregivers to disclose HIV-positive status to their CLHIV. Also, non-disclosure of the parents' HIV status to older siblings and spouses is influencing the decision to disclose to the infected children.

4.5.2. Interpersonal Level Barriers

Interpersonal level barriers refer to barriers that are beyond the caregivers. Caregivers described many barriers which were related to the community they live in and their family. Some of the barriers discussed were related to healthcare institutions and healthcare providers. The barriers reported by caregivers were perceived stigma and discrimination and actual stigmatization in the community, verbal abuse, gossips, and school-related concerns. At the institutional level, participants discussed the nature of the HIV clinic and the health education they are provided at the clinic. Other barriers found are the lack of guidelines at the clinics.

4.5.2.1. Fear of Stigma and Discrimination

Stigma and discrimination are the major barriers caregivers described as inhibiting their HIV disclosure intention. Caregivers described that they anticipated stigmatization and discrimination due to secondary disclosure of the child's status in the family, school, and community. Some participants revealed some children experienced actual stigma and discrimination due to exposure of their HIV status in the community and school. Caregivers who are HIV negative were worried that exposure of a child's HIV status would lead people to presume that the whole family is infected:

> *"If that word (HIV) proceeds out of my mouth to my child, they can be playing and she will tell others that she has HIV. If the community members hear that, it would worry her. They may start making mockery of her and everything about her would decline. That is why I am saying it. As it is in the school, so will it be in the family and the whole of the community. Right now if they hear that a very young child has that, where did she get the disease from? Either from the father or the mother. Now that she is living with us, they will ridicule us that the whole household is living with the disease" (Afeafa 63-year-old grandmother of a 10-year-old girl)*

> *"I said he is young and can tell his peers that his mother said he has HIV. As I am here now, I have the disease. You see, the last time I became sick, my mother said it was HIV! As for him, he does not know that this disease is the most stigmatized disease on the earth now. The moment you mention that disease yourself, you will be stigmatized. Your peers will be scared to approach you but he is not aware of it. To him, it is just an ordinary word" (Ameyo 45-year-old mother of a 12-year-old boy)*

Some caregivers were concerned about associative stigmatization:

> *I am even becoming tired of coming to the hospital because if some persons see people here (clinic), they know that it is such people who always sit there so once I regularly sit there if a known person passes by and sees me, the person may assume I have come for treatment so it is disturbing me that I have been coming with this child and to sit here. People would be passing by and watching, not even thinking that it might be because of the child (Mawutor 66-year-old grandmother of a 6-year-old boy).*

Furthermore, some participants reported their children experienced actual stigmatization and discrimination in their community due to secondary disclosure of their HIV status to others by family members and friends. A biological father shared his experience and personal observation of discrimination of his children at their school:

> *"I am bothered about the children because my children said whenever they go to school, they are excluded and isolated by their peers because their peers said their mothers told them that they (my kids) have an evil disease and that they might infect other children with it…This caused me to tell the children that they do not have any disease because they are children and they would not understand whether it is a bad or good thing. I witnessed an instance where one of the teachers prevented my children from entering the classroom and stopped them at the door. While their classmates were singing and playing in the classroom, my children were crawling at the door…" (Kofi 48-year-old father of 7-year-old girl).*

As reported in the participants' comments, fear of stigma and discrimination was one of the major reasons for not disclosing HIV-positive status to CLHIV. Caregivers were concerned that secondary disclosure of HIV status to others may result in stigmatization and discrimination.

4.5.2.2. Verbal abuse

Besides stigma and discrimination, some participants reported verbal abuse by neighbours who suspect the children of taking ARVs. Some participants said verbal abuse of the children is making it difficult for them to disclose to their children:

> *"Even last time, somebody insulted them that they are living with AIDS and that is why they have been put on medication. So if we ourselves raise this issue for everybody to hear, they will know they have the disease then they will start mocking them" (Amewosina 65-year-old grandmother of a 12-year-old girl)*

Another participant narrated how her brother was verbally abused by a family member as follows:

> *"…he told me that my sister insulted him that the medication he has been taking, he will continue to take it till he goes to the grave. That means he will take the medicine till he dies so he came to ask me what kind of medicine it was that he had to take until death as said by a cousin. I told him that, he should not mind her because it is not true. I told him that there is no medicine you can take till you die and that she was lying so if he recovers, he will not take the medicine again" (Fafali 34-year-old sister of an 11-year-old boy).*

Verbal abuse was experienced by some caregivers and their children by neighbours who became suspicious of the child's HIV status.

4.5.2.3. School-related Factors

Apprehension about the effect of disclosure on the child's education was described by many caregivers. Some caregivers worried that disclosure would make the child's school performance decline. Others felt children would be discriminated against at school when they accidentally reveal their HIV status to their peers. Some explained that accidental exposure of a child's HIV status at school will result in social isolation which can result in dropping out of school:

> *"She is very brilliant…I think if we tell her early, she may develop low self-esteem and her performance may decrease in school. In our environment, schooling is low on our part – the children do not like going to school. They like to be at home roaming about so if I tell her that this is the kind of person you are, entering the classroom would be difficult for her. She would think that I have disclosed her HIV status to her peers, classmates or her teacher so when she reaches there (Classroom) when the teacher is talking to her she may not pay attention again" (Afeafa 63-year-old grandmother of a 10-year-old girl).*

Another woman expressed fear about accidental exposure of the child's HIV status at school which could result in stigmatization and subsequently, dropping out of school. She shared her experience about how her child was asked to stay at home until ringworm on the scalp healed below:

> *"When the child developed some rashes once, she was sacked from the school until it was fully gone. That is what some teachers normally do to the children in the classroom because even if a small ringworm spot is found on the head of a child, they would tell the child not to come to school again. If the child develops some rashes, they would tell them not to come to school until it is completely gone. How much more this disease? That is why I think that they can tell her not to come to the school or teachers may cause other pupils not to play with her. So the best thing is the child should be mature so that when you tell her, she would know how to conduct herself among her peers" (Mawumenyo 45-year-old mother of a 7-year-old girl).*

Another participant expressed fear about disclosure affecting the education of the children as follows:

> *"I just want to thank you for this thing (research) you are doing. It means that you are thinking about the welfare of the children. However, in all these things, though you have started well, it may affect the education of the children at the end because there are people -even the teacher who is teaching the child can discriminate against the child living with this disease in the school if they do not fear God. So, the child will not feel free, he will be sad and will not be happy among his peers in school. If this happens, the child will not be able to study" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

The caregivers were concerned about the school environment. The major concern about the school environment is fear of being stigmatized and discriminated against by peers or even schoolteachers which may result in social isolation.

4.5.2.4. Child's HIV Knowledge

Some of the participants said that their children have a negative perception of HIV. The negative perception of the children is inhibiting them from disclosing their HIV status to them.

> *"The way this child talks about HIV when they are playing, I feel she perceives that HIV is a bad disease. If I tell her right now that she is living with this disease, she would not be happy again…for instance, if someone coughs, she tells the person to cover the mouth because the person would infect her with this disease. So, I think she sees this disease (HIV) as bad that is why she says the person should cover the mouth because she may infect her with the disease" (Tsoenamawu 39-year-old aunt of a 12-year-old girl).*

Likewise, another participant shared her view on the child's perception of HIV:

> *"I want him to mature a little because if he hears that name (HIV), as for this boy, anytime he hears the name of this disease, (sighs) I do not know what happens to him, he will ask you questions…before I tell him suddenly that he has this disease, it will bring a problem. The way this child reacts to the news of this disease (sighs), if he gets to know that he is living with this disease, he will faint (sighs)" (Ablator 45-year-old step-grandmother of a 10-year-old boy)*

Another woman also narrated that her child brings HIV-related issues home so she fears telling her about her HIV diagnosis:

> *"…The last time I called her, we were conversing about these issues then she said to me, "Mama, they said people living with HIV suffer from certain things," I thought to myself that, this is the person who brings up such issues that they are taught in school at home so how would it be if I disclose her own HIV status to her now?" (Esinu 39-year-old mother of an 11-year-old girl).*

As indicated above, there were concerns about the perceptions of some children about HIV/AIDS. Some caregivers expressed that their children perceived HIV as a deadly disease. Due to this perception, caregivers said they are unwilling to disclose to their children that they are living with HIV.

4.5.2.5. Health Education

Participants described the nature of health education provided at ART clinics. Some participants revealed that the health education provided at the ART clinic is more focused on adults. Some participants explained that they receive general education on HIV but not children.

> *"They do not teach us about the children. They only give a general education about HIV but not the children; they do not tell us that you have to tell your child in this way or it is from here to there" (Ablator 45-year-old step-grandmother of a 10-year-old boy)*

Another participant explained the nature of health education provided at the ART clinic:

> *"The way they have been educating here at the clinic, it's just something that they will not go deep, they tell us these are the symptoms or this sickness, everybody can contract it but they do not mention that this is how it is done (disclosure)" (Baba 46-year-old uncle of a 6-year-old boy)*

It was realised that adults and children attend the clinic on the same day. There is currently no special paediatric HIV clinic day for the children living with HIV and their Caregivers. Paediatric HIV clients come to the clinic on the same day as adults. This makes the education given at the clinic to be more focused on adults than children.

4.5.3. Facilitators to Disclosure

The facilitators to disclosure are things that participants perceived would facilitate their ability to disclose. Many participants mentioned that support from nurses and doctors would facilitate disclosure to their children. Some mentioned that they need counselling on how and when to disclose HIV status to their children. Some said guidelines on steps of disclosure would increase their confidence to undertake disclosure to their children. Some discussed that disclosure should be taught at the clinic to make things easy for caregivers. Also, many participants explained that the child's maturity and questions would facilitate disclosure to them.

4.5.3.1. Influence of Age

Concerning the age of the children, most participants indicated that the children are too young to be told that they are living with an illness considered to be life-threatening. Many participants explained that they would be willing to disclose to older children:

> *"I have already said that she is not yet grown for us to tell her such issues. Her concentration on studies may decline and her social life may be disturbed so we have allowed her to mingle with us freely" (Afeafa 63-year-old grandmother of a 10-year-old girl)*
>
> *"If she is not mature, I will never tell her. You see, the child is brilliant so she likes asking questions. If you tell her something, she has a good retentive memory and also ability to retain issues in her mind so I am very careful when answering her questions" (Mawumenyo 45-year-old mother of a 7-year-old girl).*

The children's ages were the main reason for not disclosing their HIV-positive status to them. Majority of the caregivers revealed that their children were too young to be told about their HIV-positive status.

4.5.3.2. Child's Questions

Some caregivers revealed that they do not feel pressured to disclose to their children because their children do not ask about why they take medicines and visit the hospital regularly.

> *"…These children do not ask me any question to understand issues; whatever I tell them is final. They did not even come to ask me anything that grandma, what happened…because we have been coming here and they educate them on HIV, so I think the older one knows so they did not come to ask me anything" (Amewosina 65-year-old grandmother of a 12-year-old girl).*
>
> *"… Whenever we come to the hospital and they (nurses) give education about the disease, the child does not ask me anything about it, even when we go home that "Mama, why did they teach about this disease when we went to the hospital today?" He has never asked me" (Ameyo 45-year-old mother of a 12-year-old boy)*

Contrarily, some caregivers explained that children ask questions about their medication and follow-up visits.

> *"She has been asking me about why she takes medication daily so when the date is due for us to come to the hospital, she would say "Oh, mama what is the reason for these frequent visits to the hospital?" (Esinu 39-year-old mother of 11-year-old girl)*
>
> *"Whenever she asks me any question, I think through carefully before answering her questions ...the child's mind is mature so she likes asking questions. Whenever you tell her something, she has a good retentive memory and is able to retain issues in mind so I am very careful with her" (Mawumenyo 45-year-old mother of a 7-year-old girl).*

The findings revealed that some children were asking questions but their caregivers were reluctant to disclose. The findings indicated that some children did not ask their caregivers questions about their health status and reasons for daily medications.

4.5.3.3. Disclosure Guidelines

Disclosure guidelines are important tools that facilitate disclosure to children by caregivers and HCPs. Some participants explained in their narration that the development of guidelines on disclosure would increase their ability to disclose HIV status to their children.

> *"...I am going to use my personal idea to tell him. That is what I have planned to do but if there is a guideline that this is what you have to do to educate your child about his HIV status, I will also be very happy with that" (Baba 46-year-old uncle of a 6-year-old boy)*

Other participants revealed that guidelines on disclosure would increase their understanding and confidence to disclose.

> *"If there are guidelines, it will help us to gain more understanding on it than just me telling him" (Fafali 34-year-old sister of 11-year-old-boy)*

Another caregiver commented that guidelines on disclosure would increase her confidence to disclose in her statement:

> *"If there is a book (guideline) that will teach me how to tell the child, it will even increase my confidence to tell him" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

The need for a guideline that specifies the steps to take to disclose HIV-positive status to the infected children was described in the narratives of the caregivers. Some caregivers revealed that disclosure guidelines will increase their capability to disclose to their children with HIV.

4.5.3.4. Disclosure Teaching

Teaching caregivers of CLHIV on disclosure is important to equip them with the knowledge and skills necessary to initiate and execute disclosure to their children. In this study, several participants mentioned the need for disclosure counselling on how and when to disclose HIV status to their children. Some participants discussed lack of disclosure teaching at the ART clinic in their statements below:

> *"It is good that they teach us these things or they should call us, sit us down (those of us who have been taking care of our nephews, nieces or our children) and have time to educate us that go through this way, pass through this channel because telling them is not easy. If they educate us about it that will help us too" (Baba 46-year-old uncle of a 6-year-old boy)*

Another participant described the health education at the clinic in her statement below:

> *"They only tell us to take care of their children's diet and that they should take the medicine on time; that is the only thing they tell us. They do not teach us that we should go and disclose it to them that they are living with this sickness. They do not tell us about that" (Amewosina 65-year-old grandmother of a 12-year-old girl)*

This participant also explained the lack of disclosure discussion at the ART clinic:

> *"We have never been taught how to tell the children, but when we come to the hospital, they tell us how to care for the children and the kind of food we should give them" (Mawutor 66-year-old grandmother of a 6-year-old boy).*

The caregivers' narratives indicated that there was no education on paediatric HIV disclosure at both clinics. The caregivers expressed the need for education to be done on how to go about HIV-positive status disclosure.

4.5.3.5. Supported Disclosure

Several participants expressed the need for support from nurses to be able to disclose. Some revealed that nurses should invite their children and disclose to them:

> *"The experts (nurses) of this disease have to invite them, inform them about it, and explain everything to them so they can understand" (Amewosina 65-year-old grandmother of a 12-year-old girl).*

Likewise, some participants felt the children would believe their diagnosis if it is disclosed by HCPs. Another participant expressed the need for doctors and nurses to help her disclose in this account:

> *"If I tell him, I do not know how he will believe it because he knows that I am not a nurse or a doctor but if these people present it to him, he will understand it more than the way I will present it to him"(Fafali 34-year-old sister of an 11-year-old boy)*

Another participant expressed the need for Healthcare professionals' support to be able to disclose as follows:

> *"I think that what the health workers would say would encourage the children more, than what I would say. Because when I first heard it, I wept and I was saddened so much; I wept a lot but as time went on, with the education they were giving us, I came to forget all those things so I cannot tell them myself" (Kofi 48-year-old father of 7-year-old girl).*

The findings reported above suggest that most caregivers want to be supported by the HCPs to be able to disclose HIV-positive status to their children.

4.6. Intentions and Behaviours of Caregivers

The fourth theme addressed the research question-What are the intention and behaviours of caregivers regarding the disclosure of HIV-positive status to children? Sub-themes discussed under this theme are; caregivers' disclosure intentions, disclosure practices of caregivers, medication regimen, and coping mechanisms. The theme explains the intention and disclosure behaviour of caregivers. Most caregivers said they have the intention to disclose to their children when they are fully mature.

4.6.1. Caregivers Intention to Disclose

The caregivers reported varied ages which they think disclosure should occur. Most caregivers mentioned that 17-18 years would be appropriate for them to disclose. Others intend to disclose by the time the child is about to go to senior high school. Some male caregivers gave 8 and 10 years as appropriate to commence HIV discussions with the children until full disclosure occurs. The following participants described their intended age for disclosing to their children:

> *"I think that he should be at least 18 years and above. By that age, he can understand what HIV is when it is explained to him or he can know and talk well about it. Now, he is still young, he does not know what it is" (Ameyo 45-year-old mother of a 12-year-old boy)*
>
> *if she is about 18 years and could come by herself to the clinic then, she is mature enough, then she will get to know, but if she cannot come by herself at that age, then she would not know, she can only get to know at the age she will be able to come for the medication by herself (Tsoenamawu 39-year-old aunt of a 12-year-old girl).*

A biological father commented on the intended age for disclosure in the statement below:

> *"I don't make up my mind to tell them but if they grow up for instance from 10 years, I will disclose it to them, then they would know how to conduct themselves" (Kofi 48-year-old father of 7-year-old girl).*

Concerning planning disclosure to their children, some participants revealed that they have been thinking about how and when to disclose to the children:

> *"About my plans, I would say for some time, I have been pondering over it, yet it is not only these children who are living with the disease but the rest of my children" (Kofi 48-year-old father of 7-year-old girl).*

A mother of a 12-year old boy revealed that:

> *"The plan I am making is that, when I realise that he is a little mature and can also conceal his personal secrets when he is told, then I will tell him his HIV status" (Ameyo 45-year-old mother of a 12-year-old boy)*

Another mother expressed her desire to disclose HIV positive of her daughter as follows:

> *"I wanted to tell her but it is an issue of children. If you do not know how to say it… so I have just been encouraging her to continue taking the medicine and that if she continues taking the medicine, one day everything will come to an end and she would not be sick" (Esinu 39-year-old mother of 11-year-old girl).*

As reported above, most caregivers intend to disclose at an older age. However, male caregivers intended to disclose at a younger age. Most caregivers whose children were older than 10 years intended to disclose at a higher age.

4.6.2. Disclosure Practices among Caregivers

It was realised that even though caregivers have not disclosed, they gave their CLHIV strict instructions about lifestyle modification to prevent infection to other household members. Many participants revealed instructing their children not to engage in certain behaviours at home though they have not disclosed HIV status to the children. Some reported warning children not to eat, share food, or drinking cups with their siblings. Others warned children against playing with sharp objects:

> *"…but the warning I have given her is that she must not eat and give the leftover food to anybody so whenever I tell her not to do something, she would say okay" (Afeafa 63-year-old grandmother of a 10-year-old girl)*

Other participants informed their children against contaminating surfaces with blood to prevent infection to others:

> *"I told him because of the medicines he is taking, if he attempts to have sex with a girl, he will die and the other child too will die. He said 'eh mama what is it?' so I told him though he is not mature, I am only warning him because of the medications he is taking. I told him the medicines will cause both of them to faint which will result in them being caught… I also told him that when he sustains any cut, he should not wash the blood in any utensil, but he should inform me so that I can dress the wound for him myself because blood is not good and pouring blood on the ground is a sin. His blood should not touch anything and nobody's blood should mix with another person's blood because blood is dangerous. So this is how I have been handling him" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

Some have also advised their children with HIV not to eat with their uninfected siblings, share drinking cups with uninfected siblings, or use sharp objects like needles when playing:

> *"Because her siblings are not aware. What I do is that I do not allow her to eat with her other siblings so her elder brother expressed his anger as to why I do not allow their sister to eat with them. Her brother said he did not understand because whenever their sister eats with them, she eats well to her satisfaction but she seems not to enjoy the food whenever she eats alone and I said no, it is from me" (Mawumenyo 45-year-old mother of a 7-year-old girl)*

Most caregivers who have not disclosed to their children put in measures to prevent infection transmission to others.

4.6.3. Medication Regimen

Most caregivers used deception as a strategy to compel the children to adhere to their medication as actual HIV-positive status disclosure is being delayed. Participants gave a variety of reasons to their children to persuade them to take medicine and visit the hospital regularly. Some mentioned that they told their children their medications were for breastmilk replacement, treatments for skin rashes, worms in the stomach, tuberculosis, and vitamins that will make them healthy and intelligent. Others explained that they lied to their children about the duration of the medication regimen to encourage them to adhere to the treatment. The following statements from some participants capture the use of deception by caregivers:

> *"I told him that when I gave birth to him, I developed sores on both breasts so I stopped breastfeeding him and went for this medicine from the hospital. So he is taking this medicine to enable him to get the nutrients that are present in breast milk which he lacks in his body because he was not breastfed" (Ablator 45-year-old step-grandmother of a 10-year-old boy)*
>
> *"I told her that the medication is for rashes that appear on her skin. Sometimes I tell her she has some worms in her stomach, so she must take the medicines as scheduled so that these worms would not multiply" (Afeafa 65-year-old grandmother of a 10-year-old girl)*

Some participants have not mentioned any condition to their children but only encouraged them to continue taking medication:

> *"Whenever they ask me about it (Medicine), I only tell them that they have only been put on medicine. So they do not know the disease they are suffering from and if you call them and ask them the disease they are suffering from, they cannot say it" (Amewosina 65-year-old grandmother of a 12-year-old girl).*

Some participants explained that their children were aware of a recent sickness that led to the initiation of ART. These children are told their medicine was for that illness:

> *"I told him he once fell sick and we went to the hospital. He was asked to continue taking the medicine that cured the sickness. He should not stop taking it" (Ameyo 45-year-old mother of a 12-year-old boy).*

The caregivers lied to their children and gave them different reasons for frequent medication intake.

4.6.3.1. Non-adherence to Medication

Many caregivers reported that their children refused to take their medicines. The caregivers explained that they had to persuade and give incentives to encourage their children to continue taking medicine. Madam Ablator shared her experience:

> *"Recently, my son refused to take the medicines again. He said "Mama even if it means I would die, let me die. The breast milk (referring to ARVs) is enough". I told him he will stop taking it (medication) when he is 12 years. As soon as he is 12 years, he will not take the medicines again because by 12 years, the required vitamins will be adequate. It was very difficult for me; I had to persuade him to continue taking it. I also bought some gifts for him which made him happy and he started taking it again" (Ablator 45-year-old step-grandmother of a 10-year-old boy).*

Others commented that they have to supervise their children to make sure they swallow their medicines because they deliberately throw them away:

> *"So now I have to be very alert when she is about to take the medication. I have to stand on her to convince her because she said she is fed up with the medication; she even throws it away pretending she had swallowed it. Sometimes I find the medication when I am sweeping the room. If I confront her, she would say it dropped from her hands when she wanted to take it. I know she is just telling lies because she is fed up with the medication" (Esinu 39-year-old mother of 11-year-old girl)*

Others explained that their children do not take medication when they travel:

> *"For the medication, currently if you do not force her, she would not take it. If you do not supervise the intake of the medicine, she would not take it. So whenever I am not at home, I think about it because currently, if you do not remind her to take it, she does not take it. I am bothered now because if I am not around to remind her to take her medications, she does not take it" (Tsoenamawu 39-year-old aunt of a 12-year-old girl)*

Furthermore, it was observed that some caregivers have misconceptions about the treatment regimen. Some caregivers believed that the children would be cured because they contracted the disease early in life:

> *"The time we started coming here (ART Clinic) is long overdue for the child to recover from this thing (HIV). The sickness should have been over by now because he has been on medication since infancy, that is, at the age of two years so I think by this time the sickness should be over" (Mawutor 66-year-old grandmother of a 6-year-old boy)*

> *"…I will tell him that a time will come that the virus will leave his system or? Just that I cannot tell the exact time that it will leave his system…it means that if he is taking it continuously, it will make the virus leave his body that is why we made him start at a tender age. Do you know when he started taking the medicine? He started at age 5 so you can see that we want to remove the virus from his body that is why we allowed him to start taking medicine from infancy so that when he gets to some stage he will not take it again" (Fafali 34-year-old sister of an 11-year-old boy).*

Another participant wanted to know if anything could be done for the children to stop taking the ARVs:

> *"I want to know if the sickness which the children have contracted can be cured by any medicine. So would they be on this medication till their adulthood? Is there any help since they began taking medication from childhood? Is there anything to be done for them to stop? Or would they have the disease till their adulthood or forever? They were not even mature before contracting this disease" (Amewosina 65-year-old grandmother of a 12-year-old girl)*

4.6.3.2. Secrecy

The data showed that there was a lot of secrecy associated with the child's diagnosis as well as being on ART. Some participants revealed that they concealed the child's medication to prevent unintentional disclosure of a child's status to others. Caregivers mentioned warning children against disclosure of medication intake to people in the family or friends. Some said they warned children to take medications indoors so others do not see them.

> *"He knows very well because I have made him aware that when he takes the medicine out and somebody sees it, it would no longer work for him when he takes it. So he knows very well and so whenever he is going to take the medicine and his friends are following him, he would tell them to wait at the door entrance for him to go and take the medicine. So, his friends do not enter the room with him and he alone goes inside the room to take it" (Ameyo 45-year-old mother of a 12-year-old boy)*

Similarly, other participants explained that:

> *"I have been giving her the medicines at 6.00 o'clock so when she is at any other place by 6 pm and she informs her peers that it is 6.00 o'clock so she is going to take medicine, when she comes to me, I scold her for telling her friends. The reason is that, if she says it repeatedly among others that she is going to take medicine, somebody would start asking about the medicine she is taking. So that is why I scold her" (Tsoenamawu 39-year-old aunt of a 12-year-old girl).*

Some participants mentioned that they conceal medication from their children:

> *"I do not administer the medication to her in the presence of other siblings. I give it to her when she and I are alone in the room but not outside" (Mawumenyo 45-year-old mother of a 7-year-old girl).*

As described above, most of the caregivers reported that they concealed ARV medications to prevent inadvertent disclosure of the child's HIV status to others.

4.6.4. Coping Mechanisms

The caregivers discussed the role of God, the scriptures, and prayer in the prevention of negative consequences of disclosure. Some explained the ideal time for disclosure to be done safely would be revealed by God. Others mentioned that God will make disclosure easy for them through prayers. These statements from participants explain their belief in God to prevent adverse reactions to disclosure.

> *"It is not my might but the power of God. I do not have that courage but the ideal time that God thinks He will intervene in the child's issue so that when he hears the news it will not bring any adverse outcomes to me, God himself will intervene. I have faith in God. But for now, it will be very difficult (sighs). It will be very difficult (sighs)" (Ablator 45-year-old step-grandmother of a 10-year-old boy)*

Similarly, others discussed using the scriptures to encourage the children during the disclosure:

> *"…we will go into the bible, we will discuss the Bible and the scripture before introducing her to this issue too…we can talk about things like Jesus' ministry of healing the sick, the woman with the issue of blood who touched the hem of Jesus' garment and those things. We can read that part on the day I want to tell her. We will talk about these healing scriptures until we get to the stage where I will let her know that this is the disease that we are living with so we should be praying that God should be gracious to us so this medicine is what is keeping us … so if we do it like that, the Holy Spirit would intervene so that if I tell her, she would neither shake nor be afraid" (Mawumenyo 45-year-old mother of a 7-year-old girl)*

Another participant narrated that:

> *"Though it will disturb her but with God, we will use the words of Jesus to encourage her so that she will not be disturbed" (Afeafa 63-year-old grandmother of a 10-year-old girl)*

Several participants expressed belief in divine healing either through taking ART, scriptures, and the power of God. Some reported that they are hopeful that children would be healed even before they reach their intended disclosure age:

> *"God can do anything. If God is really God, by the time the child reaches that age (intended age for disclosure), God will use His consuming fire to destroy this disease in her body. We can go for another test and it will reveal that she is completely cured" (Mawumenyo 45-year-old mother of a 7-year-old girl)*

Another participant expressed her belief in divine healing for the grandson through prayer:

> *"Whenever I lay on my bed, I pray to God to take away this disease out of the child but we went to the laboratory for another test again today so we do not know what will happen" (Mawutor 66-year-old grandmother of a 6-year-old boy)*

Likewise, some revealed that they would be healed as they continue to take their ART:

> *"I have been praying and by God's grace, we are being supplied with the medicines. What I usually say is that one day, a test would be repeated on us and it will show that we no longer have this disease, then we will give God thanks" (Esinu 39-year-old mother of 11-year-old girl)*

4.7 Summary

The purpose of this study was to explore the experiences of caregivers about the disclosure of HIV-positive status to children in the Ho Municipality. Four major themes were developed with their respective sub-themes which answered the research questions of the study. Under the first theme, it was found that most caregivers possessed a negative attitude towards disclosure to CLHIV. Caregivers were delaying disclosure despite some of the children exhibiting cognitive maturity. The findings also indicated that caregivers were concerned about negative psychological reactions in the children and the ability of their children to maintain confidentiality after disclosure. Under the second theme of beliefs and perceptions of caregivers, it was found that caregivers lacked knowledge about the paediatric HIV disclosure process and considered it as a single event. It was found that caregivers were influenced negatively by HCPs as some of these important referents actively discouraged them from disclosing to their children. Most caregivers also revealed that significant others would not approve of their decision to disclose to their children in the ages of 6-12 years.

Under the third theme, it was found that several barriers are inhibiting disclosure. Major barriers identified are; fear of stigma and discrimination, family type, serodiscordance and non-disclosure of child’s status to significant others, bereavement, lack of HIV knowledge and self-efficacy, and concerns about telling the source of child’s HIV infection. Despite these barriers, most caregivers cited 17-18 years as their intended age of disclosure. While the disclosure is being delayed, caregivers employed deception to compel their children to adhere to their medications. Finally, caregivers revealed that they believed God can prevent negative disclosure consequences and preferred to pray about the disclosure event. The Fifth chapter will provide a detailed discussion of the findings of this qualitative exploratory descriptive study.

CHAPTER FIVE

DISCUSSION OF FINDINGS

This chapter presents a discussion of the findings of a qualitative exploratory descriptive study. The findings of this study were compared to relevant literature on paediatric HIV disclosure. The findings have been discussed according to the major themes that were developed. Hence, this discussion is organised under these headings: 1. Attitude of caregivers towards disclosure 2. Beliefs and perceptions of caregivers 3. Factors facilitating and inhibiting disclosure 4. Intention and behaviour of Caregivers.

5.1. Attitude of Caregivers towards Disclosure

Disclosure of HIV-positive status is a health-related behaviour. Disclosure is influenced by the attitude of the individual. Hence, an individual's attitude is an important determinant of intention to perform any behaviour (Ajzen, 1991). The study revealed that caregivers possessed a negative attitude towards HIV-positive status disclosure to children. It was found that caregivers were unwilling to disclose HIV-positive status to their children. The findings indicated that most caregivers deliberately avoided instances that could lead to unintentional disclosure of HIV status to their children infected with HIV. This finding is consistent with previous studies (Das, Detels, Javanbakht, & Panda, 2016; Mweemba et al., 2015; Namukwaya et al., 2017). A previous study conducted in Uganda also found a negative attitude and reluctance of caregivers to disclose to their children (Lorenz et al., 2016). Conversely, the findings of the current study were inconsistent with a study done in rural Zambia which found a positive attitude towards disclosure among all participants (Tsuzuki et al., 2018). This inconsistency in the findings may be partly attributable to the availability of national guidelines on HIV disclosure in Zambia since 2011. The availability of disclosure guidelines in the setting might have played a role in changing the disclosure attitudes of the caregivers.

Studies have found an association between the attitude of caregivers and their intention to carry out disclosure of either their status or the children's HIV status to them (Evangeli & Kagee, 2016; Mo et al., 2019). Positive attitude towards disclosure is strongly related to intention to disclose. Previous studies on maternal HIV disclosure to HIV-infected children reported that people with more positive attitudes towards disclosure were more likely to carry out disclosure compared to those with unfavourable attitudes (Mo et al., 2019; Qiao et al., 2015). Attitude was the highest predictor among other variables investigated by (Mo et al., 2019). The findings of the study suggest that interventions to promote HIV status disclosure to children should be directed towards improving the attitude of caregivers towards disclosure to HIV-infected children.

This negative attitude of caregivers identified in the current study can also be explained by caregivers' perceptions of immaturity of the children. Also, the caregivers' desire to protect young children from distressing news of HIV diagnosis can influence their decision as reported in systematic reviews (Chilemba & Phiri, 2017). Previous studies noted that children who are diagnosed with HIV at an older age were more likely to be disclosed to (Madiba & Mokgatle, 2017). However, the current study found that caregivers of children who were around 9 years before diagnosis were not experiencing any problem with medication adherence. Hence, these caregivers revealed that they do not feel pressured to disclose HIV status to their children. These caregivers usually attribute the continuous medication intake to the recent illness that led to the HIV diagnosis of the children. The current study found that some caregivers expressed a positive attitude but revealed that the children must be instructed to keep it secret. Some caregivers also demonstrated ambivalence about paediatric HIV disclosure.

Paediatric HIV disclosure is a very complex phenomenon and a challenging task. Disclosure may result in either positive or negative consequences for the discloser (Chaudoir

& Fisher, 2010). Hence, it has been highlighted in the consequence theory that disclosers with a stigmatised condition usually weigh these outcomes before performing disclosure (Serovich, 2001). Similarly, the TPB (Ajzen, 1991) stated that behavioural beliefs underlie attitude towards performing a specific behaviour such as disclosure. These beliefs are related to the expected consequences of performing the behaviour. The findings of the present study revealed that many caregivers were apprehensive of negative psychological and emotional reactions that might occur in the children after the disclosure event. Many caregivers were worried about the ability of their young children to handle such difficult news of an HIV-positive diagnosis. This apprehension may be related to the existing socio-cultural factors in the Volta Region and Ghana as a whole. There is a misperception of HIV in this context as a deadly disease with high levels of stigma. The caregivers' apprehension about consequences of disclosure has been supported by systematic reviews and primary studies conducted among caregivers on HIV disclosure to children as the major reasons for non-disclosure or delaying disclosure to CLHIV (Doat et al., 2019; Ekstrand et al., 2017; Krauss et al., 2016). Delaying disclosure initiation increases the difficulty of actual disclosure to children (WHO, 2011).

Notably, the current study findings revealed that some of the children demonstrated readiness with cognitive and emotional maturity to either receive full or partial disclosure of their HIV status. For instance, a caregiver revealed that her 10-year old granddaughter went for an HIV test to see if she was living with HIV. Others revealed that their children were suspecting their HIV status and specifically asked them if they were HIV positive. Despite these, caregivers delayed the disclosure due to the child's chronological age and fear of negative psychological reactions. This finding is consistent with a model on disclosure which noted that a child's age affects the caregiver's disclosure attitude (Evangeli & Kagee, 2016). Several studies have also found that age is a significant predictor of disclosure (Atwiine et al., 2015; Vreeman et al., 2015). However, since children's maturation and cognitive development differ, there is the need to tailor disclosure to suit the individual child as recommended (WHO, 2011).

Evidence suggests that late disclosure might result in more severe psychological reactions. Previous researchers documented that caregiver concerns for psychological reactions post-disclosure are not supported by evidence. Systematic reviews conducted on parental and paediatric HIV disclosure established that disclosure rather improved psychological outcomes (Conserve et al., 2017; Whembolua, Conserve, Thomas, & Handler, 2017). It has been further indicated that a timely and well-planned disclosure event produces positive outcomes (Li et al., 2015). Others noted that any post-disclosure reactions in the children do not last and the benefits of disclosure outweigh the risks (Blasini et al., 2004; Boon-yasidhi et al., 2013; Vreeman et al., 2019).

Corroborating with other studies, the current study indicated that caregivers were also concerned about the ability of the children to ensure confidentiality of their diagnosis (Madiba & Mokgatle, 2017; Orelly et al., 2018; Vranda et al., 2017). Importantly, the findings of this current study revealed that some caregivers anticipated economic consequences resulting from accidental exposure of the child's status to others in the community. Also, a foster mother was concerned that all the money she spent on the child's healthcare would be wasted if disclosure resulted in harm to the child. A similar finding was found in a study done in the UK. The authors reported that participants feared economic consequences if people in their community became aware of their status (Glendinning et al., 2019). However, the authors did not explain the actual economic consequences their participants anticipated. The caregivers of the current study who sell foodstuff revealed that accidental disclosure by the child to others may prevent people from buying their foodstuff. Also, other researchers have found that the caregivers' SES is associated with disclosure (van Elsland et al., 2019). It has been reported that the effect of HIV on the economic activities of PLHIV is the main driver for the non-disclosure of HIV status (Mwini-Nyaledzigbor, 2014).

Despite the apprehension about negative psychological reactions in the children, some caregivers admitted that disclosure may result in some positive outcomes for the children. Caregivers mentioned anticipated benefits such as improvement in the children's willingness to take their medicine and prevent transmission of HIV to household members and sexual partners. This finding has been supported by other studies as well as systematic reviews (Ammon et al., 2018; Jemmott III et al., 2014). Furthermore, as reported in previous studies (Gachanja & Burkholder, 2016), the only participant who disclosed to her biological son revealed that there is an improvement in medication adherence and the child's behaviour towards the mother. She confirmed that the child did not disclose to anyone after knowing his own HIV positive status. This caregiver also revealed that she observed an improvement in the child's school performance after disclosing HIV status to him. This finding confirms what previous studies reported that disclosure improves adherence, emotional, and physical health.

5.2. Beliefs and Perceptions of Caregivers

Paediatric HIV disclosure is a process that evolves gradually as the child matures (Allison & Siberry, 2015). It is tailored to suit the cognitive and emotional development of the individual child. The study findings indicated that almost all caregivers lacked knowledge of the disclosure process for children. Most caregivers considered disclosure as a discreet event where their children would be informed at once about their HIV status in a single interaction by either themselves, family members, HCPs, or in concert with these people. The caregivers revealed that when their children mature enough, they will bring them to the clinic one day for HCPs to carry out the HIV status disclosure. This finding aligns with previous research, which reported that caregivers perceived disclosure as a single event (Mutumba et al., 2015; Tsuzuki et al., 2018). Also, this has been highlighted in a recent study conducted in Ghana among adolescents. The authors reported that disclosure was done in a single interaction without any prior preparation and follow-up (Appiah et al., 2019).

The perception of disclosure as a discreet event is the main reason for the delay by caregivers in initiating the disclosure process to the children infected with HIV in this setting. This perception is likely to result in sudden disclosure which may lead to deleterious outcomes. In contrast, the current study is inconsistent with the findings of previous studies conducted in Nigeria and Zimbabwe and a systematic review, which reported that caregivers perceived disclosure as a gradual process (Britto et al., 2016; Finnegan et al., 2019; Wariri et al., 2020). The differences in the findings may be attributable to the presence of Specialists such as consultant paediatricians in HIV care and other paediatric specialists in the Nigerian study. Likely, the presence of Specialist HCPs and a specialised clinic for CLHIV may have resulted in the provision of age-appropriate care to the children with HIV in this setting.

The current study settings do not have any specialised clinic days for children living with HIV, and HCPs who care for children are largely general nurses, doctors, and counsellors. Lack of specialist nurses at the ART clinics may lead to a lack of age-appropriate care for children and adult-focused care (McHenry et al., 2018). The WHO recommends a gradual disclosure to children of school-going age. This should range from a continuum of partial disclosure until children are provided with full information on their HIV status while considering the emotional and cognitive maturation of the individual child. This finding underscores the need to commence disclosure teaching at the clinics to improve caregivers’ knowledge of the process of HIV status disclosure to children.

Consistent with previous studies, the findings of the current study indicated that most caregivers preferred that disclosure should be done by healthcare professionals at the clinic as reported by the following studies (Madiba & Mokgatle, 2015; Vranda et al., 2017). Many caregivers said they require the support of the HCPs to be able to disclose. In contrast to this, other studies reported that caregivers were deemed as appropriate individuals to disclose to their children due to their relationship with the child (Beima-Sofie et al., 2014; Okechukwu et al., 2018). However, studies conducted among HCPs have also reported that the participants said that disclosure should be done by the caregivers alone while others felt the responsibility should be shared between caregivers and HCPs. The current study revealed that caregivers preferred the HCPs to initiate disclosure to their children. Many said that disclosure suggestion must come from their primary HCPs at the clinic before they will comply with it. The findings suggest that HCPs should be actively involved in the disclosure preparation for caregivers and their children in this context.

In addition, the findings of the study revealed that caregivers perceived negative normative influence about disclosing to children (6-12 years) from important referents such as HCPs and family members. As noted, normative beliefs underlie people’s subjective norm to engage in performing behaviour such as disclosure of HIV status to their children. These normative influences or beliefs are related to what these significant others or important referents would say or think about caregivers’ decisions to disclose (Fishbein & Ajzen, 2011). This is very important in exploring disclosure in this context because decision-making regarding a sick child in a Ghanaian context and for that matter in the Volta Region depends on other family members. The issue is even more important in the case of children infected with HIV who may have lost one or both parents to the disease. The caregivers described what they think their significant others who are aware of the child’s HIV status would say or think about their intention to disclose. Some caregivers discussed that they had to consult other family members such as the child's grandparents, aunts, and uncles before disclosing to the children. The finding suggests the need for HCPs to employ a family-centred approach in the disclosure planning for children and their caregivers. Previous research has established that positive influence from significant others is strongly associated with intention to carry out disclosure (Mo et al., 2019).

Again, the findings indicated that some HCPs discouraged disclosure and warned caregivers to conceal the child's HIV status from others. This finding was pervasive in the narratives of most caregivers. Most caregivers revealed that they concealed the child's status from close family members such as spouses and grandparents due to this advice from HCPs to maintain secrecy. Concealing a child's status from others such as spouses may affect the intention to disclose to the children. Previous studies reported that disclosure of a child's HIV status to others in the same household promotes disclosure of the child's own HIV status to them (Atwiine et al., 2015; Murnane et al., 2017). Also, the current study found that some HCPs discouraged caregivers to defer disclosure to children who were asking questions and refusing medications for a long time. This finding is consistent with systematic review findings and previous studies (Atwiine et al., 2015; Krauss et al., 2016). This finding is similar to what was found in a Zambian study that some HCPs themselves may possess negative attitudes towards HIV status disclosure (Mweemba et al., 2015).

Conversely, the current study contradicts some studies in Peru and Uganda which reported that caregivers were compelled to disclose based on the influence of their HCPs who supported them to disclose (Baker et al., 2018; Namukwaya et al., 2017). The negative influence from HCPs may be partly attributable to factors such as lack of training, lack of knowledge on disclosure, and paediatric HIV care as reported by past researchers (Adekunle et al., 2019; Kalembo, Kendall, Ali, & Chimwaza, 2018). Other likely factors that may contribute to HCP's negative attitude towards early progressive disclosure may be due to lack of clear institutional protocols on disclosure to children, lack of specialists such as paediatric nurses and paediatricians at these clinics which make the clinics to be more adult-focused.

Furthermore, the findings of the study indicated that most caregivers stated that their family members who are aware of the child's HIV status would not approve of their decision to disclose to the children at this age. This finding is contrary to a study in South Africa which found that caregivers have strong normative support for disclosure to children and those who are in steady relationships said their partners will approve HIV status disclosure to their children (Jemmott III et al., 2014). A Kenyan study suggests that a caregiver's decision to disclose to children is shaped by environmental factors such as caregiver, child, family, neighbours, friends, schools, churches, and the media. The negative beliefs exhibited by these important referents influence caregivers' decision to carry out disclosure to the child infected with HIV (Vreeman et al., 2015).

The findings also suggest a lack of peer support/influence at the ART clinics. Many caregivers revealed that they did not know about other caregivers of children living with HIV and whether they disclosed to their children. Some also revealed that the nature of the ART clinic is such that they hardly meet adults. This finding emphasised the need to form peer support groups for both the children and their caregivers. This may help in alleviating the psychological burden in the CLHIV and encourage sharing of views with peers. Support groups may also help in sharing experiences about caring for children infected with HIV and help facilitate disclosure. Many caregivers revealed that they will comply with other caregivers if they suggest disclosure to their children because they are all in the same situation.

5.3. Factors facilitating and Inhibiting Disclosure (Perceived Behavioural Control)

The findings revealed that there are multiple factors influencing caregivers from disclosing HIV-positive status to their children with HIV. The most formidable barrier identified to be inhibiting disclosure in this study is the fear of stigma and discrimination. All caregivers discussed that the HIV status of their children may be accidentally exposed by the children themselves due to their immaturity to maintain secrecy. The caregivers were concerned that exposure of the child's status to others will certainly lead to ostracism and discrimination at home, school, or the community.

Stigma related to HIV is destructive and acts as a huge barrier to HIV testing, disclosure, and adherence to treatment by PLHIV (Mwini-Nyaledzigbor, 2014). Stigma may cause close relatives to react negatively to HIV-positive diagnosis disclosure by their loved ones (Katz et al., 2013). Stigmatizing attitudes and discriminatory acts of people cause severe damage to the individuals living with the stigmatized condition (Florom-Smith & De Santis, 2012). Stigma is pervasive in every community in Ghana and this has been supported by previous HIV studies in Ghana (Gyamfi et al., 2017; Kallem et al., 2011).

Additionally, there are several sociocultural beliefs about the mode of HIV transmission, and different interpretations have been given to the sexual route of HIV infection by individuals, groups, and society (Mwini-Nyaledzigbor, 2014). Negative stereotypes exist about persons infected with HIV in many communities in Ghana. These stereotypes view persons infected with HIV as sexually promiscuous as reported in previous studies (Biru et al., 2018; Vreeman et al., 2015). For instance, an early study conducted in Ghana found that HIV was seen as a disease of a 'spoiled wife' which results from having extramarital sex in some communities (Mwini-Nyaledzigbor & Wright, 2011). These factors can negatively influence caregivers' disclosure decisions.

The finding of the current study that fear of stigma and discrimination is the major barrier to early disclosure corroborates previous studies and systematic reviews, which reported that stigma is the major reason for non-disclosure of HIV status to children (Aderomilehin et al., 2016; Madiba & Mokgatle, 2017; Mweemba et al., 2015). Some of the caregivers revealed that their children experienced actual discrimination and ostracism due to exposure or suspicion of their HIV status in the community. It can be asserted that these negative sociocultural beliefs about HIV and the persistence of HIV stigma in communities in Ghana might have influenced caregivers' decisions and intentions to conceal their children's HIV-positive status until an older age. Caregivers revealed that older children of ages 17-18 years would be able to understand the implications of HIV diagnosis and maintain secrecy of their HIV status.

It has been found in an early randomised controlled trial conducted in the USA that age of disclosure has declined significantly. The authors associated the decrease in preferred age of disclosure with a reduction in social stigma and fears surrounding HIV diagnosis (Butler et al., 2009). It has been asserted that the postponement of disclosure to children by their caregivers is due to a misplaced desire to protect their young children from knowing that they have a stigmatized illness (Bernays, Jarrett, Kranzer, & Ferrand, 2014). Furthermore, the findings indicated that HIV-negative caregivers expressed fear of associative stigmatization if the HIV status of the children in their care became exposed. Associative stigma is a type of stigma which is extended to relations of the person living with a stigmatized condition such as informal caregivers (Mwini-Nyaledzigbor, 2014). The caregivers revealed that they concealed the child's HIV status because if people became aware, they would surmise that their entire household was also living with HIV. The findings underscore the need to develop and incorporate interventions to destigmatize HIV in our communities. Also, there is a need to develop interventions that take into consideration these sociocultural barriers inhibiting when to disclose to CLHIV to facilitate early HIV status disclosure to the children by their caregivers.

Besides, the findings also revealed that caregivers have specific concerns related to the school environment. The caregivers were concerned about the school environment and the attitude of some teachers and pupils towards children living with HIV. The caregivers revealed that disclosure may affect the children's concentration on their studies resulting in dropping out of school or decreased school performance. Some caregivers shared their experiences about their children being ostracized at school by their teachers and peers. For example, a caregiver narrated how his daughters experienced discrimination from their peers. The caregiver revealed that other children told his children that they were cautioned by their parents not to play with them because they have an 'evil disease'. The findings corroborate previous studies and systematic reviews, which reported that the school environment acted as a barrier to caregivers' disclosure decisions (Busza et al., 2014; DeSilva et al., 2018; Kimera et al., 2019; Nabukeera-Barungi et al., 2015).

Surprisingly, the caregivers interviewed revealed that they have not disclosed to any schoolteacher due to the concerns discussed above. This finding is similar to what a previous study reported that caregivers feared to disclose their children's HIV status at school (Medin et al., 2016) Contrarily, a Kenyan study found that the school environment served as an effective support system for CLHIV (Vreeman et al., 2015). This finding emphasised the importance of training for schoolteachers as stakeholders in the care of CLHIV. There is also an urgent need to scale up interventions to de-stigmatize HIV/AIDS in schools. Some caregivers revealed their children bring negative comments about HIV from school, which is the main reason they are hesitating to disclose their status to them.

Also, lack of self-efficacy to disclose and lack of HIV and disclosure knowledge were cited by many caregivers as other barriers preventing disclosure. Many caregivers revealed they do not know how or when to disclose to their children. Majority of caregivers revealed that they will feel sad to tell their children that they have HIV. These findings are similar to previous studies and systematic reviews, which reported that caregivers' lack of skill, knowledge on HIV, and disclosure are other major issues inhibiting HIV disclosure to children (DeSilva et al., 2018; Doat et al., 2019; Kalembo, Kendall, Ali, & Chimwaza, 2018; Paintsil et al., 2015). Similarly, a Tanzanian study reported a strong association between caregivers' HIV disclosure knowledge and actual disclosure to children with HIV (Nzota et al., 2015). It was observed that there were so many misconceptions regarding the mode of transmission of HIV and ART among the caregivers. Some caregivers believed that ART would cure HIV so disclosure may not be necessary. The findings emphasize the need to improve health education at ART clinics to equip caregivers with the required knowledge and skills to promote disclosure to children infected with HIV.

Other barriers found to be inhibiting disclosure to children in the current study are bereavement of one or both parents, telling source of infection, and family differences. Some caregivers were concerned about disclosing bereavement to the children. It was found that some of the children have not been told about the death of their biological parents. Informing children with perinatal HIV infection about their HIV-positive status requires an explanation of how the children got infected. This implies that children need to be informed about the source of their infection as MTCT. Some caregivers who did not disclose to their children about their deceased parents said they would find it difficult to disclose to their children that they are suffering from the same sickness that killed their parents. This finding is consistent with the literature (Beima-Sofie et al., 2014; Finnegan et al., 2019; Gachanja et al., 2014). Contrarily, other studies have found that the death of one or both parents facilitated disclosure of HIV status to the children (Gray et al., 2017; Vreeman et al., 2014). The differences in the findings can be explained by the sociocultural variations in the settings. For instance, some cultural values require that young children should be protected from distraught news such as the death of parents or diagnosis of a life-threatening illness (Tiendrebeogo et al., 2013; Wright et al., 2017).

Furthermore, the findings revealed that some caregivers have difficulty disclosing to the children, how they acquired the HIV infection as a component of full disclosure. This hesitation to disclose to children that they acquired HIV perinatally may leave children wondering about how they got infected. Caregivers' hesitation could be attributed to the sexual nature of HIV transmission and the general misconception among Ghanaians that HIV is a divine punishment for sexual immorality committed (Mwini-Nyaledzigbor, 2014). These misconceptions may make it difficult for disclosure especially for women in polygamous families where there is serodiscordance. The only caregiver who disclosed in this study said she did not explain how the child got infected to him even though the child asked about how he got infected.

The finding that biological mothers expressed reluctance to disclose to young children the source of their infection as MTCT is consistent with previous studies, which reported that biological parents were more likely to refuse to disclose due to feelings of guilt about HIV transmission (Hayfron-Benjamin et al., 2018; Medin et al., 2016; Sariah et al., 2016). The reason for this reluctance can also be explained by the sexual nature of HIV infection as noted previously. Literature indicates that cultural beliefs that frown upon discussions of sex with young children may act as barriers to communicating to children about their own HIV status (Aderomilehin et al., 2016; Kajula et al., 2014). Some caregivers expressed concerns that their children would ask questions about how they got infected. A foster mother also shared a similar concern about revealing the source of infection as part of HIV status disclosure to her son. The caregiver who has not disclosed 'adoption' to the child revealed that she would find it difficult to disclose to the child that he had a deceased biological mother from whom he acquired HIV infection. The findings suggest that the factors inhibiting disclosure to CLHIV in the area are diverse, multiple, and complex, therefore disclosure interventions should be tailored to focus on the needs of each family and their peculiar concerns.

The study findings indicated that the issue of serodiscordance among couples and siblings is also influencing HIV disclosure to children infected with HIV by caregivers. Some caregivers expressed difficulty in disclosing HIV status to an infected child in a polygamous family. For example, a father worried that disclosure may bring separation between his children in a polygamous family involving HIV-negative children and the younger infected siblings. A mother also expressed concern that her husband would oppose HIV disclosure to the infected child because he is HIV-negative. These findings are consistent with systematic review findings, which found that disclosure is more likely to occur in monogamous families compared to polygamous families (Adeoye-Agboola et al., 2016; Bott & Obermeyer, 2013). Some parents whose older children were not living with HIV also revealed that they were concerned about disclosing to the infected child while older but uninfected siblings have not been disclosed their parents' HIV status. This finding corroborates previous research, which found that the presence of other HIV-infected siblings in the family promotes HIV status disclosure (Ekstrand et al., 2017; Eneh et al., 2019).

From these findings, it can be explained that disclosure of a child's HIV status depends on disclosure of the caregiver's own HIV status to significant others such as spouses and older siblings in the family. Hence, disclosure may pose a great challenge to mothers who might have not disclosed their HIV-positive status to their spouses.

Serodiscordant marriages were identified as a major barrier to HIV testing in paediatric patients (Wagner et al., 2018). The findings of the current study underscore the importance of a family-centred approach when developing disclosure interventions and disclosure planning for children and their caregivers. As noted previously, the factors influencing disclosure of HIV-positive status to CLHIV in the setting are complex, multiple, and unique to each family. All these factors have to be explored and carefully dealt with, for disclosure to be beneficial to all parties involved.

The findings of the study revealed some factors that caregivers felt will make it easy or facilitate disclosure to their children. Many caregivers revealed that they needed to be educated on paediatric HIV disclosure at the clinic. Many caregivers revealed that they have not received any counselling on disclosure to children as HCPs do not teach them about HIV disclosure at ART clinics. Others mentioned that the health education provided at the clinics was more focused on adults living with HIV. This finding is consistent with a Malawian, Indian, and USA study, which found that disclosure counselling was not part of routine care of children, and caregivers expressed the need to be taught how to disclose (Armistead et al., 2018; Kalembo et al., 2019; Vranda et al., 2017). Lack of disclosure counselling at the ART clinics might be the reason for the very low disclosure among the caregivers interviewed. The lack of disclosure-related teaching may also be the reason for the delay in disclosure. This is because many caregivers revealed that they do not know anything about how to disclose to children. Many caregivers revealed that they were prompted by the current study to think about disclosing to their children. Some also asked the researcher about her view about when HIV disclosure should occur.

Many caregivers said they required the support of HCPs to be able to disclose to their children. Some revealed the need for guidelines on the steps to take to disclose to their children. This finding is similar to the findings reported in studies conducted in India, South

Africa, and Botswana (Madiba, 2016; Priya et al., 2019). Dalton et al. (2019) asserted that caregivers require the assistance of HCPs in deciding the amount of information about a life-threatening illness that could be shared with their children. Also, it has been found by previous studies that the support of HCPs facilitated disclosure to children even among caregivers who were reluctant to disclose (Baker et al., 2018; Namukwaya et al., 2017). Finally, the study findings revealed that caregivers demonstrated readiness to build disclosure skills and expressed the need for disclosure teaching at the clinic. Consistent with previous studies, the caregivers of this current study revealed that the older age of their children would facilitate disclosure to them (Bulali et al., 2018; Murnane et al., 2017).

5.4 Intention of Caregivers to Disclose

The findings of the study indicated that all the caregivers had no intention to disclose to their children of ages 6-12 years. However, the caregivers expressed an intention to disclose to children when they perceived that they are mature. Most cited 17-18 years as the age they intended to disclose, except a caregiver who revealed he would start the process as early as eight years. These findings are similar to a study conducted in India, which reported that caregivers intended to disclose at age 16 (Ekstrand et al., 2017). Also, these findings support quantitative studies conducted in India and Tanzania, which found that disclosure was higher in children 14-17 years (Bulali et al., 2018; Priya et al., 2019). Surprisingly, a caregiver said he would never disclose to his child and would allow the girl to figure it out as she grows and becomes lean by either testing or other people telling her in the community.

The age caregivers intended to disclose in this study is later than the WHO-recommended age for initiation of disclosure. Disclosing HIV status to children at an older age may make it difficult for children to adjust to their diagnosis. There is a need for CLHIV to know and understand the meaning of living with HIV and how to develop self-management skills. For children who have been infected with HIV early in life through

MTCT, early disclosure is vital in the development of these skills and autonomy. The intention of caregivers to postpone disclosure until young adulthood will limit the time the children have to acquire knowledge on their disease (Crowley, van der Merwe, & Skinner, 2019). It is important for parents of children infected with HIV to be informed about the evolving capacity of children to understand their HIV diagnosis (Mburu et al., 2014). Hence, there is a need for parents to be taught to identify signs of cognitive maturity in their children and how to initiate the disclosure process early.

Contrarily, the findings of the current study were inconsistent with studies conducted in South Africa and India which reported 10 -12 years as the caregivers' preferred age to disclose to their children (Madiba & Mokgatle, 2017; Tsuzuki et al., 2018). Disclosing a child's HIV status early is more beneficial and associated with numerous benefits as reported in a systematic review (Whembolua et al., 2017). The findings suggest that caregivers are not willing to disclose to their children within the ages recommended in the WHO guideline. Moreover, this finding might be explained by the unavailability of guidelines on disclosure to children in this context. As previously noted, this could be partly explained by a lack of knowledge of the disclosure process. Also, the attitude of some of the HCPs in discouraging caregivers might have accounted for this postponement in disclosure intention. The findings underscore the need for the inclusion of disclosure counselling in the routine care provided to children at these ART clinics.

Also, the findings of the study revealed several practices of caregivers as the actual disclosure to children is delayed. It was found that the caregivers instructed their non-disclosed children on modification of lifestyle. The children were instructed not to share food, drinking cups, bathing articles, or play with sharp objects such as needles or used cans. Others were prevented from eating with their uninfected siblings. Some also warned their children not to allow others to touch them if they sustained any cuts while playing. This was done to prevent unintentional transmission of infection to uninfected siblings and friends while actual disclosure is delayed. This finding is similar to findings reported in an Indian study where caregivers warned their non-disclosed children from engaging in certain behaviours to prevent unintentional transmission of HIV to peers at home, school, or community (Sarkar et al., 2018).

Adherence is very crucial to the survival of children perinatally infected with HIV. The findings of the study revealed that most children of the caregivers interviewed have problems with adherence. According to the caregivers, their children refused medication and kept asking them about the diseases they have that warrant daily medication intake and regular hospital visits. Some caregivers revealed that their children sometimes threw the medication away with the excuse that they do not know the disease they have that requires daily medication. This finding agrees with previous studies, which reported that early disclosure is associated with optimal medication adherence among children infected with HIV (Adejumo et al., 2015; Gitahi et al., 2020; Nabukeera-Barungi et al., 2015). On the other hand, the current study’s findings contradict the findings reported by previous studies that non-adherence prompted caregivers to disclose to their children (Gyamfi et al., 2017).

Furthermore, many studies found a strong association between early disclosure and medication adherence. Some researchers found that adherence is higher when disclosure occurred before twelve years compared to late disclosure (Ammon et al., 2018; Cluver et al., 2015). This suggests the need for HCPs to start planning disclosure to these children to promote adherence. Poor ART adherence has negative outcomes such as poor health, increased VL with viral resistance, and the possibility of transmitting the infection to others (Adejumo et al., 2015; Cluver et al., 2015). This finding emphasises the need to urgently step-up efforts to facilitate disclosure to these children. A narrative review of studies conducted in SSA found that children sometimes intentionally missed doses in reaction to non-disclosure by their caregivers. It was also found that children whose status has been kept secret from others have a greater likelihood of being non-adherent compared to their counterparts (Adejumo et al., 2015).

Also, the findings revealed that caregivers provided deceptive information to persuade their children to adhere to their ARVs. It was observed that caregivers gave varied reasons to their non-disclosed children as conditions that require daily intake of medication while the disclosure is delayed or avoided. The reasons provided for medication included breastmilk replacement, vitamin supplements for good health, intelligence, and treatments for skin rashes. Consistent with other studies, caregivers of the current study persistently lied to persuade their children to adhere to their medications (Baker et al., 2018; Wong et al., 2017).

Surprisingly, the findings indicated that some caregivers persistently denied the HIV-positive status of their children who became suspicious of their diagnosis and those who received accidental disclosure of their HIV status from others. For instance, some caregivers revealed that their children directly asked them if they were finding it difficult to disclose to them that they were HIV positive. According to some caregivers, their children received accidental disclosure of their status at home, school, and in the community and some were verbally abused about living with HIV. However, the caregivers revealed that they told their children to ignore those claims because they did not have HIV. This finding is similar to previous studies, which reported that caregivers usually employed deception in an attempt to postpone actual disclosure (Shallo & Tassew, 2020; Wong et al., 2017). Although it appears understandable that caregivers wanted to protect their young children, the extent of deception employed by some of the caregivers may result in harmful consequences when actual disclosure occurs to the children later.

The WHO recommends partial disclosure to young children until they are mature to be given full information on their disease. Employing deceptive strategies to encourage adherence is not advisable. It is worthy of note that gradual disclosure has to be distinguished from deception (DeSilva et al., 2018). The use of deception may result in a lack of trust and the destruction of the child-caregiver relationship. Children develop the capacity to trust early as they grow up through the relationship they have with their parents (Marfatia, 2014). Delaying disclosure and using deception to postpone disclosure to later adolescence may disrupt the development of trust and ruin the caregiver-child relationship when the truth is discovered later. An open and honest caregiver-child relationship from early childhood builds trust. A previous study has found that some adolescents lose trust in their parents because of how long they postponed disclosure and their post-disclosure experience with their parents (Crowley et al., 2019).

Some caregivers deceived their non-adherent children that they would stop taking ARVs when they reach a certain age. This finding was reported in a previous study conducted in China (Wong et al., 2017). For instance, one of them explained that her suspicious daughter rebelled about the different reasons given about taking medication daily. Previous studies have documented that adherence is likely to decrease during adolescence (Adejumo et al., 2015; Closson et al., 2019). As these children are approaching adolescence, there is an urgent need to scale up measures to disclose safely to these children to enable them to develop optimal adherence habits. It is interesting to note that caregivers also used incentives in the form of favourite foods, soft drinks, and other materials to motivate their rebellious children to continue taking medications while they postpone actual disclosure. Some caregivers revealed that they will continue employing deceptive strategies and the use of incentives until they feel the children are old enough to be told.

The findings also revealed that caregivers engaged in diverse behaviours to maintain the secrecy of the child's HIV status. The findings indicated that caregivers instructed their children to not disclose to people that they are on medication. Others encouraged them to take medication indoors because they felt that people might observe the repeated intake of medication and surmise that the children are HIV positive, which will result in stigmatization. Caregivers also mentioned that HCPs should caution their children not to disclose to others that they are on medication. This finding has been supported by previous studies that PLHIV and caregivers hide their medication or change the bottles of the medications to prevent others from guessing their HIV status (Chambers et al., 2015; Dzansi, Tornu, & Chipps, 2020; Nyogea et al., 2015).

However, this practice of concealing medication is likely to result in non-adherence to medication. Some caregivers revealed that their children find it difficult to take medicine when the caregiver travels. Disclosure of a child's status to at least an adult member of the household may help in supporting the children to adhere to the regimen even if their primary caregivers are not around. The practice of non-disclosure to significant others who can assist in caring for the child may affect adherence. Studies conducted in Kenya and Nigeria found that caregivers who disclosed the child's HIV status to others gained support when primary caregivers were not available (Ugwu & Eneh, 2014; Vreeman et al., 2010). These findings suggest the need to encourage caregivers to disclose a child's HIV status to at least a trusted adult member of the family who can assist in caring for the children in the caregivers' absence. Also, studies have found that non-disclosure of a child's status to others and fear of taking ART in front of others is the main reason for non-adherence (Chambers et al., 2015; Nyogea et al., 2015; Ugwu & Eneh, 2014).

An important finding of the current study is that most caregivers regarded religion as important in disclosing HIV-positive status to their children. Most caregivers discussed belief in God's ability to prevent negative consequences of disclosure to their children. The caregivers engaged in religious behaviours such as praying, fasting, and reading scriptures to positively cope with their own or their children's diagnosis. Many caregivers revealed that they would pray about the correct timing of disclosure and read the Bible during disclosure to encourage their children. Another thing worthy of note is the belief in divine healing by caregivers. Caregivers mentioned that they regularly pray to God for healing as they take their ARVs and believe that God will surely intervene in their situation.

The influence of religion in facilitating HIV disclosure has been documented in previous studies and a systematic review conducted in the Democratic Republic of Congo (DRC) (Whembolua et al., 2017). Qiao et al. (2015) found in a study in China that parents who believe in religion were more likely to disclose their HIV status to their children than their counterparts who did not. Similarly, it has been found in a Ugandan study that parents of the Pentecostal faith were more likely to disclose to their children than others and confirms that religion plays a role in HIV disclosure (Osingada, Okuga, Nabirye, Sewankambo, & Nakanjako, 2017). The current study revealed that caregivers would prefer to pray about disclosure and engage in certain religious practices before disclosing to their children.

Furthermore, the role of religion in improving the health of PLHIV has been well documented in HIV studies. It is therefore vital that HCPs perform a pre-disclosure assessment of caregivers and families about these practices and their preferences and incorporate it in disclosure planning for children living with HIV. Also, the findings suggest that religiosity and religious practices are vital factors that influence caregivers' disclosure decision-making and should be incorporated in disclosure planning, disclosure interventions, and paediatric HIV programmes.

5.5 Application of Model to the Study

The theory of planned behaviour (Ajzen, 1991) was the framework that guided the study. The constructs of the theory guided the development of the interview guide used for the data collection. The theory was very relevant for this research because it helped to explore all the factors that may influence the caregivers' decision-making and intention to engage in behaviour such as disclosing HIV-positive diagnosis to their children with HIV. As a behaviour change model, the theory helped to explore individual factors, interpersonal level factors, and the sociocultural factors that may be influencing caregivers' disclosure intention. The TPB constructs and their underlying beliefs enabled an in-depth exploration of all the factors that are influencing the disclosure of HIV-positive status to CLHIV in this context.

The findings of the study were consistent with the TPB and offer important implications for all HCPs involved in paediatric HIV care. The findings also have implications for stakeholders such as the Ghana AIDS Commission (GAC) National AIDS Control Programme (NACP), the Ghana Health Service (GHS), the Ministry of Health (MOH), and the Ghana Education Service (GES). Also, the findings from this theory-based study suggest that paediatric HIV disclosure interventions should also target other important referents such as community members, schoolteachers, and significant others of the caregivers and their children. For instance, it was found that most caregivers hold negative attitudes towards HIV disclosure to children in this setting. As noted earlier, since attitude influences intention to engage in a behaviour, these findings suggest that there should be interventions that target attitudinal change for caregivers. It is only when caregivers' attitudes change that we can be sure of their willingness to disclose to their children. Besides, most caregivers believed that HIV status disclosure would result in more negative consequences. There is a need for education to be done to promote the positive outcomes and long-term benefits of paediatric HIV disclosure. As discussed in the TPB, people's belief that the performance of a particular behaviour will result in more negative consequences will influence their attitude towards carrying out that behaviour. Hence, HCPs should counsel and assure caregivers of continuous post-disclosure support. Caregivers who disclosed should be encouraged to share their experiences with others who are yet to disclose.

Exploration of the second construct revealed that caregivers perceived negative normative influence from their significant others and HCPs. Most caregivers discussed that their significant others would not approve of their decision to disclose. Some caregivers of children whose parents are deceased discussed that they must seek the views of other family members before deciding to disclose. Exploration of this interpersonal factor in the Ghanaian context is very important for the development of disclosure interventions for the setting. This is because, in the African culture, individuals act more as collectivists than as individualists (Triandis, McCusker, & Hui, 1990). Therefore, caregivers would be more willing to carry out disclosure if they perceive that more of their significant others think it is the right thing to do. These findings also suggest the need for peer support groups that can help to encourage and positively influence caregivers to carry out HIV disclosure to their children.

The third construct known as perceived behavioural control is the perception of caregivers about how easy or difficult caregivers think disclosure is. The findings revealed several barriers to HIV disclosure to infected children in this setting. These barriers were categorised as personal and interpersonal level barriers. It is suggested that disclosure interventions should focus on reducing both personal and interpersonal level barriers to disclosure. Sociocultural factors such as stigma and negative stereotypes should be addressed through effective stigma reduction interventions. This will improve caregivers' perception of control to carry out HIV disclosure to their children. Many participants said they did not know how to disclose for their children to understand. Disclosure interventions should target building the self-efficacy of caregivers to disclose while decreasing barriers. Finally, the finding that caregivers have intentions to disclose is consistent with the fourth construct of the TPB and the research objective. There should be the development of an intervention to promote change of attitude, increase self-efficacy, and positive normative influence. In conclusion, the TPB allowed an in-depth exploration of caregivers' intention to disclose and all the factors that are likely to influence the disclosure decisions of caregivers. Li et al. (2015) recommended that disclosure change theories should be used in the assessment and development of interventions on HIV disclosure for children. This research which was guided by a behaviour change theory offers important implications and rich culturally sensitive evidence for the development of tailored interventions to facilitate disclosure to CLHIV in this context.

5.6. Summary

Summarily, this chapter presented a detailed discussion of the findings of the study. It was found that existing sociocultural beliefs about HIV and negative stereotypes in this setting may have influenced caregivers' disclosure attitudes. Stigma related to HIV is prevalent in every community in Ghana. Also, many negative stereotypes which view persons infected with HIV as sexually promiscuous and fear of contracting HIV from infected persons through casual interactions may have contributed to the decision of caregivers to conceal a child's diagnosis and defer disclosure to an older age. Caregivers also raised specific concerns about the school environment and teachers. Consistent with the literature, there were also other barriers inhibiting disclosure such as lack of self-efficacy, poor knowledge of HIV and disclosure, bereavement, misconceptions about ART, and family differences. Corroborating previous research, the current study found that healthcare professionals’ support, disclosure counselling, guidelines, and perceptions on the maturity of the child are the perceived facilitators of disclosure according to the caregivers. A notable finding of this study is the influence of religion on caregivers’ intention and decision to disclose.

Finally, for caregivers who intended to disclose, the age they cited for disclosure was higher than the WHO-recommended age for disclosure. This is likely because most caregivers viewed disclosure as a discreet event and lacked knowledge of the progressive and evolving nature of disclosure. In conclusion, the findings underscore the need for GAC, NACP, and other stakeholders to urgently develop tailored disclosure protocols to facilitate disclosure to children living with HIV in this setting. It is also important to explore the factors influencing disclosure from the perspectives of all stakeholders such as Healthcare professionals and schoolteachers.

Chapter six will present the summary of the study, implications of the study for practice, research, education and policy, limitations of the study, conclusion, and recommendations. The chapter ends with a summary of the chapter.

CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

This chapter presents a summary of the research, the implications for practice, research education, and policy. The limitations of the study and conclusions have also been presented. Recommendations were then made based on the findings of the study.

6.1. Summary of the Study

Disclosure of HIV status to children living with HIV who acquired HIV via perinatal transmission is a vital component of their management and a highly recommended intervention. Evidence suggests that a well-planned disclosure event is beneficial for children, caregivers, and their families. Despite this, several researchers have found that disclosure rates are low in LMICs. The current study employed a qualitative exploratory design to explore the experiences of caregivers on the disclosure of HIV-positive status to their children with HIV at two health facilities in the Ho Municipality of the Volta Region of Ghana.

A total of 13 caregivers of CLHIV participated in the study. The purposive sampling technique was used to recruit caregivers who met the inclusion criteria of the study. Data were collected using a semi-structured interview guide which was developed based on the constructs of the theory of planned behaviour. Data saturation guided the actual sample size as saturation was achieved on the thirteenth participant. The interviews were audiotaped, transcribed, and translated into English. Thematic analysis was used in analyzing the data collected. Four major themes were developed from the theoretical framework of the study which answered the research questions. The sub-themes were developed directly from the data and they are twelve (12) in number. The major findings of the study indicated that most caregivers possessed a negative attitude towards disclosing HIV-positive status to children between the ages of 6-12. However few participants expressed positive attitude and attitude ambivalence about HIV positive status disclosure to children. It was found that caregivers were apprehensive of the negative consequences of disclosure and the inability of the children to keep HIV diagnosis a secret.

Furthermore, the caregivers demonstrated insufficient knowledge of the disclosure process for children. Almost all caregivers felt their children were too young to understand HIV diagnosis and the implications of secondary disclosure to their peers. Besides, many caregivers considered paediatric HIV disclosure as a discreet event. It was also found that caregivers perceived negative normative influence from significant others and HCPs to disclose. Some HCPs actively discouraged caregivers from disclosing early. There was also concealment of the child's status from significant others such as grandparents, uncles, and spouses. Family members also inhibited disclosure due to the child's age.

Additionally, the data showed that several barriers at different levels were inhibiting the disclosure intention of caregivers. The major barriers found included fear of stigma and discrimination, school-related concerns about stigma, inadequate HIV and disclosure knowledge, lack of self-efficacy to initiate disclosure process, perceptions of the immaturity of the children, the family type, bereavement, telling source of infection, lack of disclosure teaching and adult-focused HIV clinics. Caregivers expressed the need to be taught how to disclose to children, and the need for guidelines and the support of HCPs to be able to disclose. Despite all these barriers, caregivers revealed that they have the intention to disclose to their children when they reach an older age. Most of them cited 17-18 years as the preferred age of disclosure. While the actual disclosure is being delayed, caregivers employed deceptive strategies to compel children to adhere to medications. They also gave their non-disclosed children instructions on lifestyle modification to prevent the transmission of infection to others. Caregivers' narratives indicated that most of the children were not adherent to their ARV medication. Children persistently questioned their caregivers about their medications, but fear of negative consequences and stigma prevented caregivers from disclosing.

It was also found that caregivers believe in God's ability to prevent negative disclosure consequences and expressed the need to pray about the correct timing of disclosure to their children. The findings suggest that factors inhibiting disclosure in the setting are multiple, complex, and unique to each family. All these findings have relevant implications for nursing practice and other health professionals directly involved in the care of CLHIV. Nurses and other HCPs should adopt a holistic and family-centred approach in managing caregivers and their CLHIV. There is an urgent need to develop tailored interventions and protocols to facilitate early HIV disclosure to children perinatally infected with HIV in the municipality and the entire Volta Region of Ghana.

6.2. Implications of the Study

The study has vital implications for nursing and midwifery practice, nursing education and nursing research, and policy formulation.

6.2.1. Implication for Nursing Practice

The current study has important implications for nursing practice and other HCPs directly involved in the care of children living with HIV. The study findings suggest that healthcare providers have to actively support caregivers and prepare them early for disclosure to their children. The data showed that most caregivers lacked knowledge of the disclosure process for children. There is a need for caregivers to be educated on the developmental process of children and how to identify signs of disclosure readiness in their children. Caregivers should also be educated on the evolving nature of paediatric HIV disclosure as recommended by WHO guidelines. As discussed previously, attitude is an important element of intention to disclose the HIV-positive diagnosis to CLHIV. However, the study findings revealed that most caregivers hold negative attitudes towards HIV disclosure and are unwilling to disclose early. This suggests the need for HCPs to educate caregivers on the numerous benefits of paediatric HIV disclosure. Interventions for reducing HIV stigma should target general community members and school children. Stigma and discrimination were major reasons cited by caregivers for delaying disclosure.

It was found that some HCPs discouraged caregivers from disclosing and suggested to them to postpone disclosure to an older age. The HCPs should positively influence caregivers to disclose to their children early by emphasising to caregivers the long-term benefits of HIV disclosure. Most caregivers revealed that they will be willing to disclose only if the recommendation comes from their primary healthcare professionals at the ART clinics. Additionally, the data showed that non-disclosure of either child or caregivers' HIV-positive status to some significant others such as spouses and older uninfected siblings is also influencing the decision to disclose to the infected child. As previously discussed, literature shows that disclosure of a child's HIV status to household members facilitates disclosure to the infected child. Hence, HCPs should support caregivers to safely disclose either their own or their child's HIV-positive status to their significant others.

Also, caregivers opined that significant others would disapprove of their decision to disclose HIV-positive status to their children. The HCPs need to encourage caregivers to secure the support of their significant others who can help in the disclosure process for their children. Besides, it was found that factors influencing disclosure are multiple, complex, and peculiar to each family. This suggests that HCPs should regularly assess individual families to identify and address specific factors inhibiting disclosure in each family. Individualised but family-centred intervention should be adopted in addressing these issues to promote safe disclosure of HIV-positive status to infected children. Finally, the findings of this study underscore the need for peer support groups for caregivers of children living with HIV at both clinics. This will facilitate sharing of experience among caregivers and provide them with other psychological benefits. It is also important that HCPs incorporate spiritual assessment and care in the disclosure planning of children living with HIV and their caregivers.

6.2.2. Implication for Nursing Research

The findings suggest that further research on paediatric HIV disclosure should be conducted among healthcare providers. The current study revealed that HCPs may be influencing the HIV disclosure intention of caregivers at both clinics. Therefore, future research must explore the barriers and facilitators to paediatric HIV disclosure from the perspective of HCPs in this setting. Also, a qualitative study is required to explore the disclosure experiences of the children living with HIV in the Municipality and the entire Volta Region of Ghana. The caregivers' narratives showed that some children were exhibiting suspicious behaviour and mood changes due to the delay in the disclosure of their HIV-positive status.

Again, a quantitative study is recommended to estimate the actual prevalence of HIV disclosure to infected children in the municipality and the Volta Region at large. This is because almost all the caregivers recruited did not disclose. This finding suggests that disclosure rates may be very low in the setting. Also, numerous factors have been found to be influencing caregivers' intention and decision-making to disclose HIV status to their children. Therefore, a quantitative study is necessary to determine the extent to which these individual factors are influencing the disclosure intentions of caregivers. Additionally, the school environment was also found to be influencing the disclosure intention of caregivers. Therefore, future research should explore the perception of school teachers and school children about children living with HIV. Finally, cross-disciplinary research is needed to explore the factors influencing HIV disclosure to children of ages 6 and 12 years from the perspectives of all stakeholders. There is also the need to assess the school health programme in the country and its effectiveness in caring for children with chronic illnesses such as HIV in schools. Finally, interventional studies that focus on building the caregivers' self-efficacy for disclosure are recommended.

6.2.3. Implications for Policy Formulation

The findings of the study offer important implications for policy development on paediatric HIV management. First, a tailored protocol on paediatric HIV disclosure is required urgently and it is necessary to assist both HCPs and caregivers in the disclosure process for children in this context. The unavailability of protocols on disclosure has been one of the main cited barriers to disclosure. Secondly, the findings of the current study revealed that many caregivers were unwilling to disclose HIV-positive status to their children due to fear of being stigmatized and discriminated against in their community. The GAC, NACP, and other stakeholders should develop new rigorous interventions to help reduce HIV stigma in communities. The findings suggest that a reduction in stigma levels in schools and communities may promote disclosure of HIV-positive status to infected children in the setting.

Furthermore, the findings indicated that there were specific concerns related to the school environment which are inhibiting HIV-positive status disclosure to CLHIV. Therefore, the school health programme should be strengthened to support school children who are living with HIV. Teachers and other health workers in schools should be equipped with the knowledge and skills to provide effective psychological support to CLHIV in the school environment. There should be a multi-sectoral collaboration between the health and education sectors, and other governmental and non-governmental stakeholders to help improve the health and educational needs of school children living with HIV. Importantly, new policies on paediatric HIV infection should consider integrating this care into general paediatric care to help destigmatize the clinic environment.

6.2.4. Implication for Nursing Education

The data showed that the care provided at both clinics is more focused on adults living with HIV. The unavailability of specialist paediatric nurses and other healthcare professionals at the clinics may be partly cited as the reason for the aforementioned. There is therefore the need to train more specialist paediatric nurses for the provision of optimum care to these children. Also, further training of qualified paediatric nurses in paediatric HIV management may be required in the near future. There is a need to include paediatric HIV management with emphasis on early disclosure to children in the curricula of all cadre of nurses in the country. Finally, nurses working at ART clinics should be trained periodically in paediatric HIV management to help improve their knowledge.

6.3 Limitations

This study has some limitations. First, most of the caregivers are from the Ewe tribe so the sample has limited diversity in terms of ethnicity of the participants. This was because it is the dominant tribe in the study setting. Secondly, most (11) of the interviews were conducted in Ewe (local language). Also, the translation of the interviews was done from Ewe to English. Meanings that do not have an exact interpretation in English may have created some variations in the meanings of the interviews. Also, more females (10) than males (3) were involved in the study. However, this study included the experiences of two (2) biological fathers and an uncle. The study also involved both biological and non-biological caregivers of CLHIV. Although the researcher initially intended to recruit several caregivers who disclosed HIV status to their children, the low rate of disclosure in the study settings made this impossible. Hence, this report included the experience of only one caregiver who disclosed HIV status to her child. The Covid-19 pandemic and lockdown caused a delay in data collection and created communication barriers with participants.

6.4. Conclusion

This current study explored the experiences of caregivers on disclosure of HIV-positive status to children living with HIV at two public health facilities in the Ho Municipality in the Volta Region of Ghana using the TPB. The findings revealed that disclosure of HIV-positive status to children living with the infection may be very low in this setting. Also, the findings indicated that almost all caregivers possessed a negative attitude towards HIV-positive status disclosure to infected children. Besides, several personal and interpersonal level barriers such as fear of stigma and discrimination, fear of negative psychological reactions, economic consequences, lack of HIV and disclosure knowledge, lack of self-efficacy, perception of immaturity, family type, serodiscordance, and bereavement are the main factors inhibiting the disclosure intention and decision of caregivers to disclose HIV positive to their children early in this setting. Some of the barriers identified are related to the HCPs and the institutions.

The study findings indicated that the factors influencing caregivers' intention to disclose are complex, multiple, and unique to each family. Caregivers need to be actively supported in the disclosure process and their decision-making by trained HCPs for them to disclose early. The findings of this study offer important implications for all stakeholders who care for CLHIV in developing interventions that will facilitate HIV disclosure to children infected with the virus. There is an urgent need for tailored and contextualised protocols on paediatric HIV disclosure in this setting. There is a need for HCPs to be trained on the recommended disclosure process for children.

6.5 Recommendations

Based on the study findings and field notes taken during the research, the following are the specific recommendations made to the GAC, GES, GHS, Nursing and Midwifery Council of Ghana (NMC), and ART clinics of Ho teaching hospital and Municipal Hospital.

6.5.1 GAC/GHS/NACP

These governmental organisations should:

1 Work collaboratively to develop tailored protocols to facilitate HIV-positive status disclosure by caregivers to their infected children of ages 6-12.

2 Develop new policies that target stigma reduction in the community

3 Collaborate with GES to formulate new school health policies that will take care of the needs of school-aged children living with HIV in Ghana.

4 Conduct intensive tailored training for all nurses, doctors, and counsellors at the ART clinics on paediatric HIV care and the disclosure process for children.

6.5.2. ART Clinics of HTH / HMH and Management

The ART clinics should:

1. Include disclosure counselling in the routine care provided to the children and their caregivers at the clinics and emphasise the benefits of early progressive HIV disclosure to caregivers to promote their change of attitude towards disclosure.
2. Introduce special paediatric HIV clinics for children living with HIV and their caregivers. This will facilitate the provision of child-focused care for CLHIV and their caregivers. Specialist paediatricians and paediatric nurses should be involved in the care of children at the ART clinics.
3. Employ the concept of family-centred care, culturally sensitive disclosure planning in actual disclosure to children.
4. Work collaboratively with key stakeholders to establish a support network for both CLHIV and their caregivers to promote interaction and sharing of experience.
5. The service of a clinical psychologist should be made available to support HIV-positive status disclosure to children living with HIV.

6. Incorporate spiritual care into disclosure planning and general care of children living with HIV and their caregivers
7. Conduct urgent training for all HCPs involved in HIV care on Paediatric HIV management and the recommended disclosure process of children.

6.5.3. Nursing and Midwifery Council of Ghana

The NMC should do the following:

1. Collaborate with other governmental agencies to train more specialist nurses in paediatric care.
2. Review the curriculum of basic nursing programmes and include paediatric HIV management and HIV disclosure.
3. Include the concept of family-centred care and spirituality in the curriculum for nurses.

6.5.4. Ghana Education Service (GES)

The GES should:

1. Develop interventions that target HIV/AIDS stigma reduction among school children.
2. Review the curriculum to include a component on HIV/AIDS and Stigma reduction for school children.
3. Improve school health programmes to support the health and educational needs of children living with HIV.
4. Collaborate with other governmental agencies to train all school workers and teachers to update the knowledge and skills of these important referents on paediatric HIV/AIDS and new policies.

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APPENDICES

Appendix A: Participant's Consent Form

STUDY TITLE: **Experiences of Caregivers on disclosure of childhood HIV-positive status to affected children in the Ho municipality.**

PARTICIPANTS' STATEMENT

I declare that I have read or have had the information and the purpose of this study explained to me in a language ……………… that I understand and I am fluent in.

I fully understand that my participation in this study is completely voluntary and I have the right to withdraw from this study at any time even after signing the consent form.

Also, the benefits and potential risks have been well explained to me in a language I fully understand.

I consent to the recording of the interview and note-taking. The interview will include open-ended questions about revealing HIV diagnoses to affected children. However, your name and personal identifying information will be removed from the transcript. The information provided will be accessed by the principal researcher and her research supervisors and authorized persons only.

Every hard copy of the transcripts will be kept under lock and electronic versions will be protected with a password. The electronic and hard copies of transcripts will be kept for five years after which they will be destroyed.

I voluntarily consent to participate in this research. Please tick Yes ☐ No ☐

Name or Initials………………………….. ID Code …………………..

Signature ……………………... Thumb Print…………………………

Date:…………………

INTERPRETERS' STATEMENT

I declare that I have interpreted all the information on the Participants' Information Sheet to the aforementioned participant to the best of my ability in the Ewe [ ], Twi [ ], English [ ] language to his proper understanding. All questions, appropriate clarifications sort by the participant, and answers were also duly interpreted to his/her satisfaction.

Name of Interpreter……………………………

Signature of Interpreter………………………..

Date:…………………………………………...

Contact Details:……………
Address:

Tel:

STATEMENT OF WITNESS

I declare that I was present when the information about this research was read and explained adequately to the aforementioned participant in his/her language of choice; Ewe [ ], Twi[ ] English[ ].
I certify that the participant was encouraged to ask questions for clarifications and these questions were adequately and correctly answered to his/her understanding before he/she willingly consented to participate in this research.

Name:…………………………………………..

Signature…………………………... Thumb Print ……..............................

Date:……………………………………….

INVESTIGATOR'S STATEMENT AND SIGNATURE

I declare that the aforementioned participant has been provided adequate information on all aspects of this research and allowed enough time to understand the research. I also encouraged the participant to ask questions and all clarifications have been given to the participant in simple language that he/she understands, Ewe [ ], Twi [ ] English[ ].
.
Researcher's name……………………………………

Signature ………………………………………………

Date………………………………………………………

Appendix B: Semi-Structured Interview Guide

Date…………………………………………………………………………
Pseudonym……………………………………………………………….
Duration of interview……………………………………………………

Section A: Demographic characteristics of participants

Please tell me more about yourself.

a) Age of Caregiver………………
b) Gender………………………….
c) Caregiver's HIV status………..
d) Marital status …………………..
e) Number of children…………….
f) Duration since HIV diagnosis…
g) Employment …………………..
h) Highest level of education…….
i) Relationship to child…………..
j) Age of child…………………….
k) Age at diagnosis………………..
l) Duration of ART use…………..

Section B: Perception of caregivers about HIV status disclosure

1. What do you know about HIV-positive status disclosure to children?
    - What is disclosure?
    - At what age should children be told their status
    - What exactly do you have to tell the child?
    - Who should be responsible for telling the child?
    - How should they (children) be told? (early, progressive process, no disclosure, partial, full disclosure)

Section C: Attitude of caregivers towards disclosure

1. Have you ever tried disclosing your ward's HIV status to him/her?
2. How do you feel about discharging this responsibility?
3. In your opinion what is good about disclosing HIV-positive status to children?
    - Benefits of disclosure
    - Medication adherence
    - Prevention of infection
    - Prevention of accidental disclosure
    - Others
4. What is bad about revealing HIV-positive status to children?

Section D: Normative beliefs of caregivers on HIV disclosure

1. What do you think other people will think and say about disclosing children's HIV status to them?
    - Spouse/sexual partners
    - Healthcare workers (nurses, Doctors, counsellors)
    - Close relatives

- Support groups
- Friends

2. How willing are you to comply with their influences?

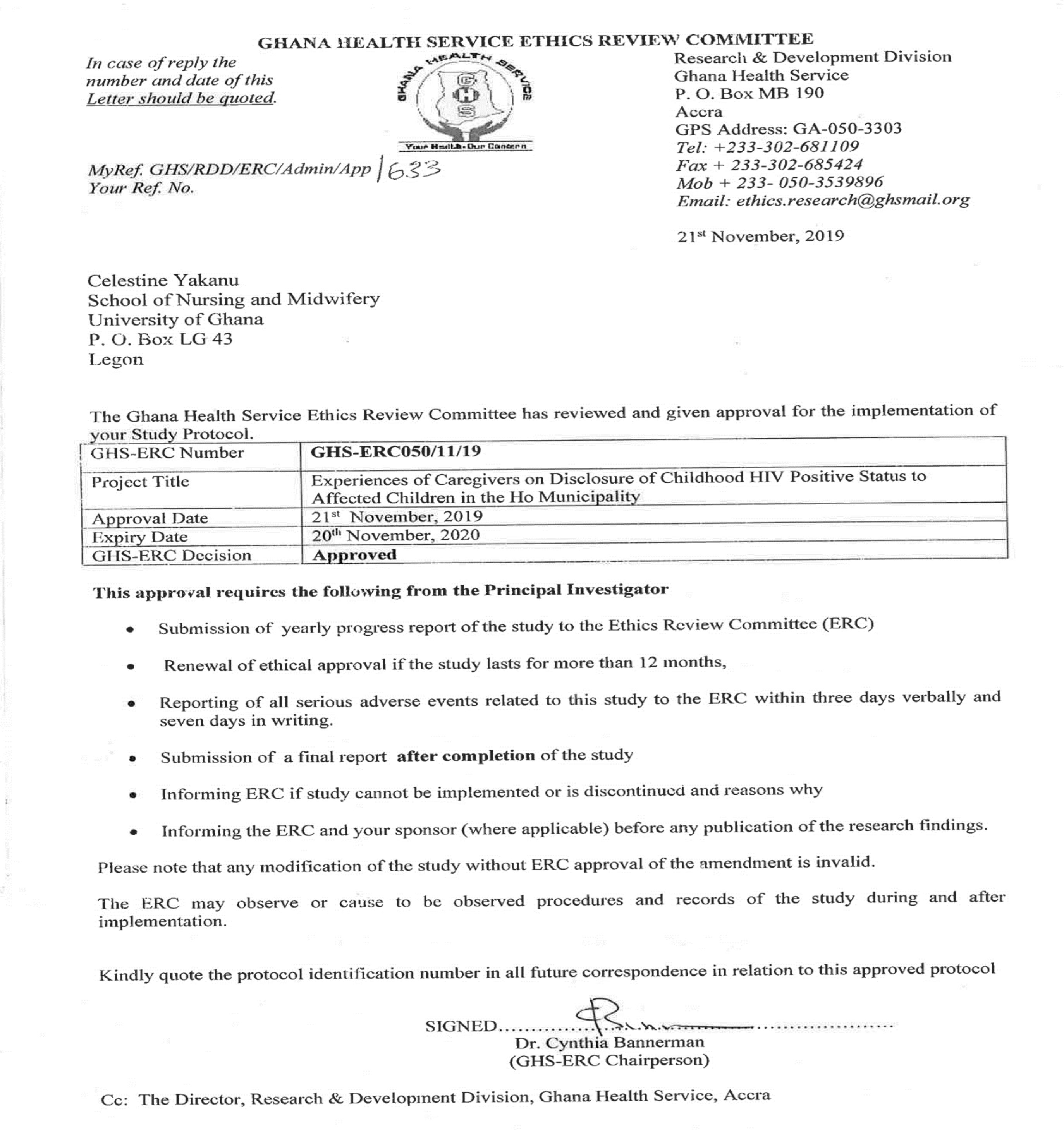
Section E: Perceived self-efficacy beliefs (perceived behavioural control)

1. Do you feel capable of disclosing your ward's HIV status to him/her?
    - If yes, why do you feel so?
    - If no, why do you feel so?
    - If no, what assistance do you think you need to enable you to do so?
    - What do you think you need to disclose your ward's status to him/her?
2. **What do you think will make it easy for you to tell your child he/she has HIV?**
    - HIV Knowledge
    - Available guidelines
    - Caregiver Counselling
    - Time (disclosure planning)
    - Self-efficacy
    - Communication skills with child
    - Culture norms
    - Healthcare provider Assistance
    - Support groups (disclosed caregivers)
    - Stigma
3. **What makes it difficult for you to tell your child he/she has HIV?**
    - HIV Knowledge
    - Available guidelines
    - Caregiver Counselling
    - Time (disclosure planning)
    - Self-efficacy
    - Communication skills w
    - Cultural norms
    - Healthcare provider Assistance
    - Support groups (NGO, disclosed caregivers)
    - Stigma

Section F: Intention of caregivers

1. What are your intentions towards disclosing your child's HIV positive status to him or her?
    - When do you think children should be told their HIV status
    - How are you planning to do that?

Appendix C: Ethical Approval Letter



GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

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

Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
GPS Address: GA-050-3303
Tel: +233-302-681109
Fax + 233-302-685424
Mob + 233- 050-3539896
Email: ethics.research@ghsmail.org

MyRef. GHS/RDD/ERC/Admin/App / 633
Your Ref. No.

21st November, 2019

Celestine Yakanu
School of Nursing and Midwifery
University of Ghana
P. O. Box LG 43
Legon

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	**GHS-ERC050/11/19**
Project Title	Experiences of Caregivers on Disclosure of Childhood HIV Positive Status to Affected Children in the Ho Municipality
Approval Date	21st November, 2019
Expiry Date	20th November, 2020
GHS-ERC Decision	**Approved**

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report **after completion** of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

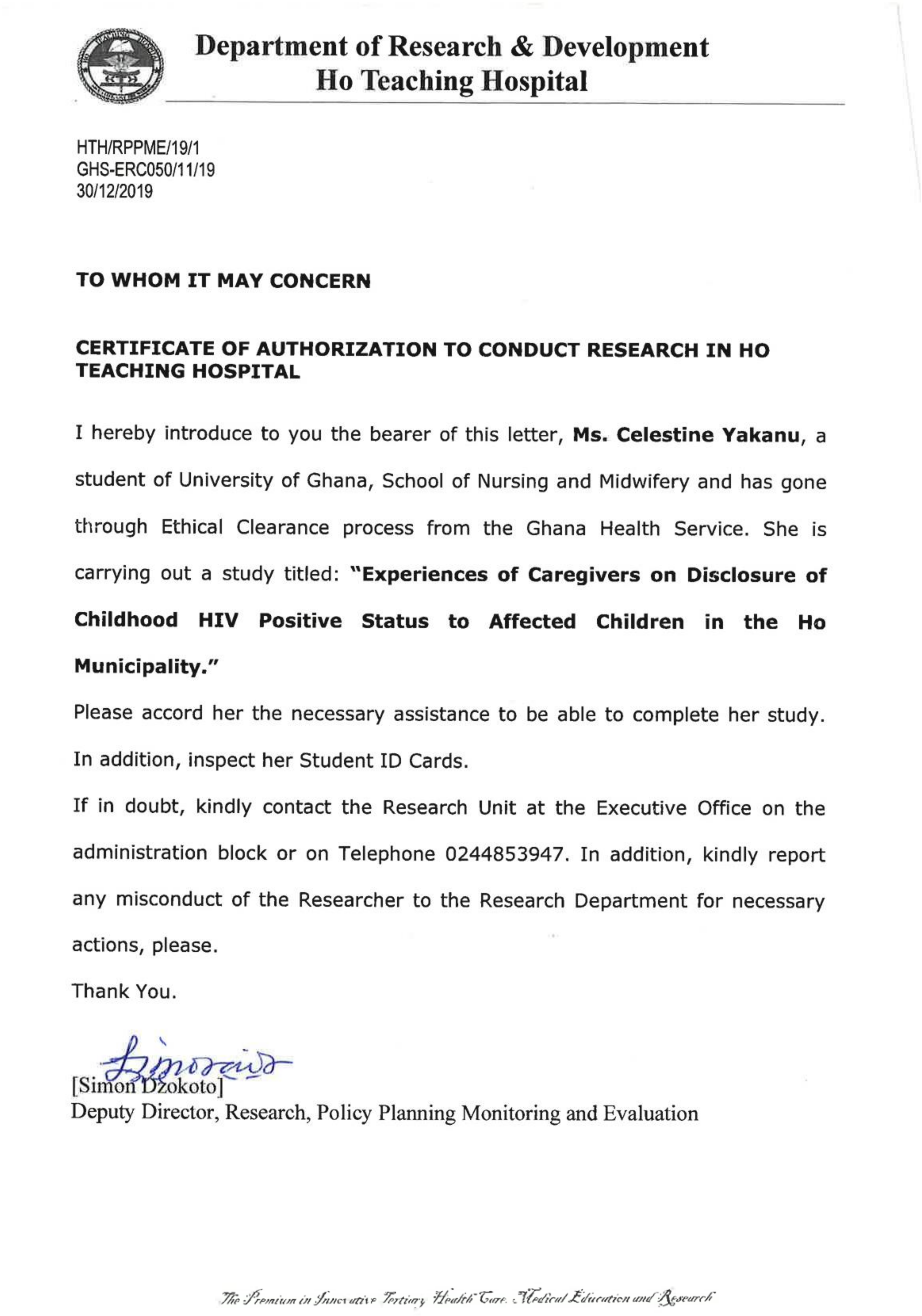
The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED……………………………………………………
Dr. Cynthia Bannerman
(GHS-ERC Chairperson)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

Appendix D: Certificate of Authorization from Ho Teaching Hospital



Department of Research & Development
Ho Teaching Hospital

HTH/RPPME/19/1
GHS-ERC050/11/19
30/12/2019

TO WHOM IT MAY CONCERN

CERTIFICATE OF AUTHORIZATION TO CONDUCT RESEARCH IN HO TEACHING HOSPITAL

I hereby introduce to you the bearer of this letter, **Ms. Celestine Yakanu**, a student of University of Ghana, School of Nursing and Midwifery and has gone through Ethical Clearance process from the Ghana Health Service. She is carrying out a study titled: **"Experiences of Caregivers on Disclosure of Childhood HIV Positive Status to Affected Children in the Ho Municipality."**

Please accord her the necessary assistance to be able to complete her study. In addition, inspect her Student ID Cards.

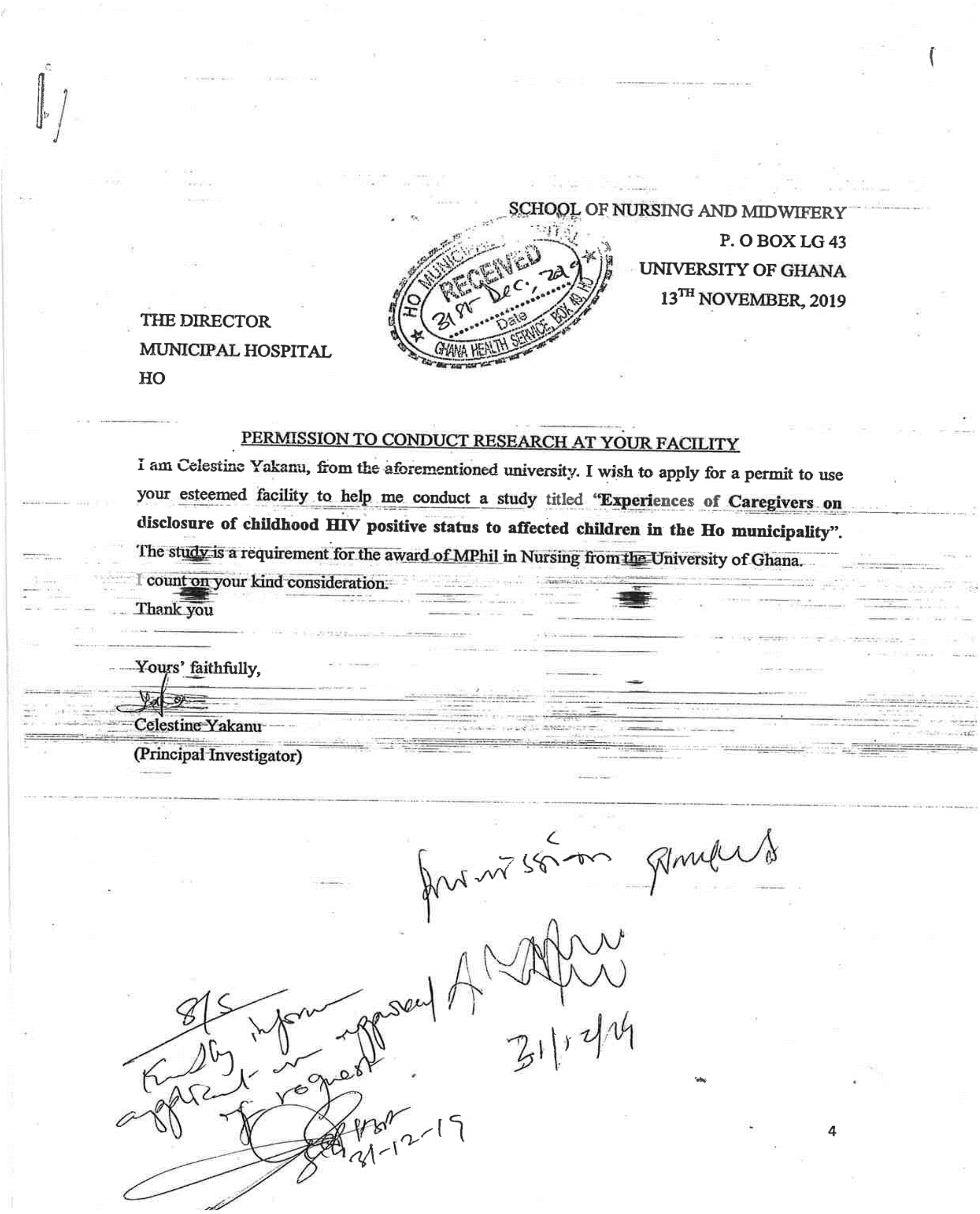
If in doubt, kindly contact the Research Unit at the Executive Office on the administration block or on Telephone 0244853947. In addition, kindly report any misconduct of the Researcher to the Research Department for necessary actions, please.

Thank You.

[Simon Dzokoto]
Deputy Director, Research, Policy Planning Monitoring and Evaluation

The Premium in Innovative Tertiary Health Care, Medical Education and Research

Appendix E: Approval of Study from Ho Municipal Hospital



SCHOOL OF NURSING AND MIDWIFERY
P. O BOX LG 43
UNIVERSITY OF GHANA
13TH NOVEMBER, 2019

HO MUNICIPAL HOSPITAL
RECEIVED
31st Dec, 2019
Date
GHANA HEALTH SERVICE, BOX 49, HO

THE DIRECTOR
MUNICIPAL HOSPITAL
HO

PERMISSION TO CONDUCT RESEARCH AT YOUR FACILITY

I am Celestine Yakanu, from the aforementioned university. I wish to apply for a permit to use your esteemed facility to help me conduct a study titled **"Experiences of Caregivers on disclosure of childhood HIV positive status to affected children in the Ho municipality".** The study is a requirement for the award of MPhil in Nursing from the University of Ghana.

I count on your kind consideration.

Thank you

Yours' faithfully,

Celestine Yakanu
(Principal Investigator)

Permission granted

31/12/19

8/S
Kindly inform applicant on approval of request

31-12-19

4

Appendix F: Language Translation Certificate

GHANAIAN LANGUAGES EDUCATION AND TRANSLATION CONSULT

P. O. Box CT 6532
Accra-Ghana
Tel: +233 (0) 207333161
+233 (0) 243971300
Email: gletco2@gmail.com

Our Ref: GLETCo/C/03/18

Your Ref:

Date: 6th July, 2018

CERTIFICATION OF RESEARCH TOOL

This is to certify that the **Ghanaian Languages Education and Translation Consult (GLETCo)** translated research tool (interview) for Celestine Yakanu regarding her Mphil in Nursing study project entitled "**Experiences of caregivers on disclosure of childhood HIV positive status to affected children in the Ho Municipality.**"

G. Agbemehia

GABRIEL K. AGBEMEHIA
DEPUTY EXECUTIVE DIRECTOR
GHANAIAN LANGUAGES EDUCATION AND TRANSLATION CONSULT
P. O. BOX CT 6532
ACCRA – GHANA

SCHOOL OF NURSING AND MIDWIFERY,
COLLEGE OF HEALTH SCIENCES,
UNIVERSITY OF GHANA, BOX LG 43, LEGON
EMAIL: cyakanu@st.ug.edu.gh

LANGUAGES:

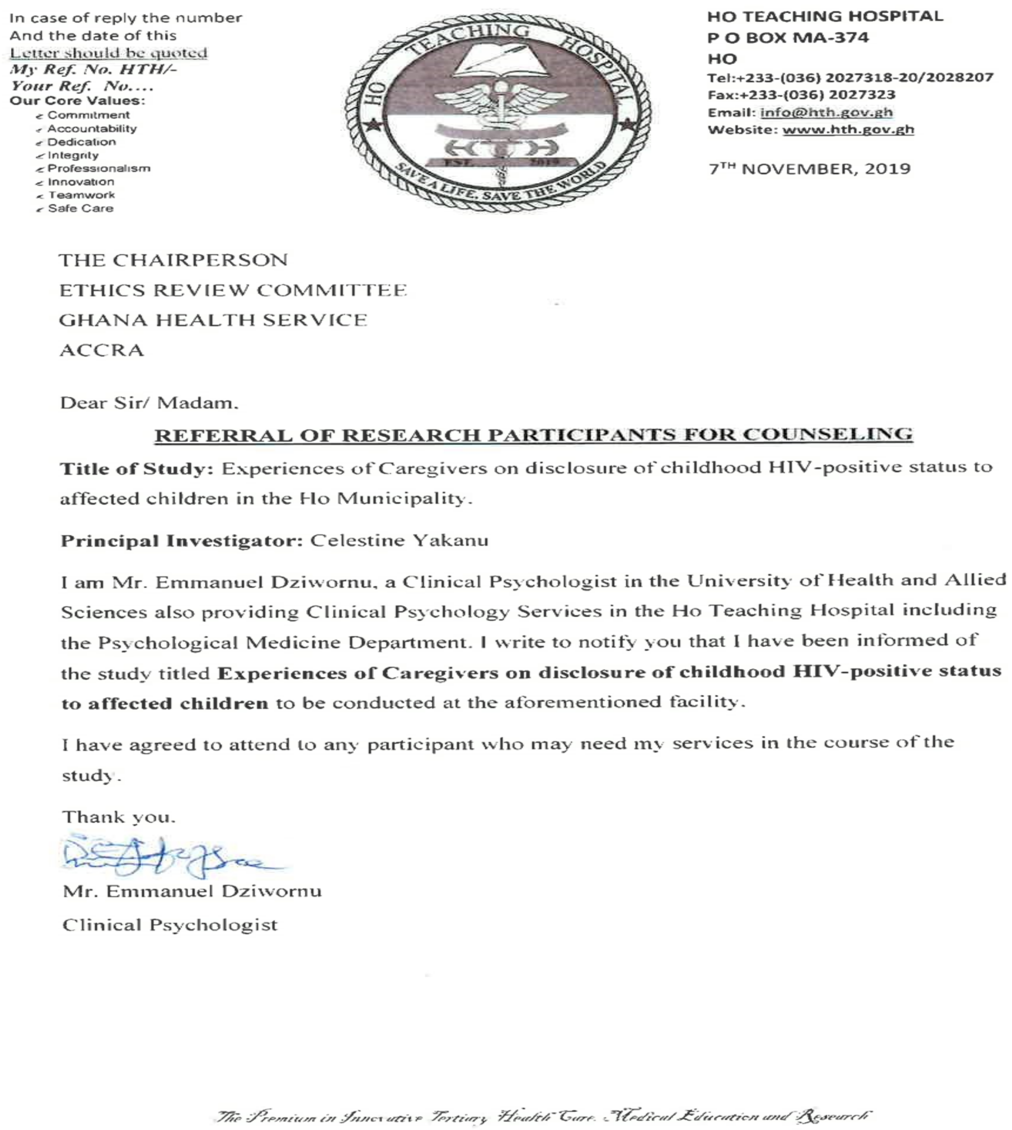
- Akuapem Twi
- Asante Twi
- Dagaare
- Dagbani
- Dangme
- Eve
- Ga
- Gonja
- Kasem
- Mfantse
- Nzema

etc.

OUR SERVICES:

- Material Development
- Translation
- Transcription
- Assessment of manuscripts
- Editing
- Proofreading
- Tutorials
- Research and more

Appendix G: Psychologist's Letter



In case of reply the number
And the date of this
Letter should be quoted
My Ref. No. HTH/-
Your Ref. No....
Our Core Values:
- Commitment
- Accountability
- Dedication
- Integrity
- Professionalism
- Innovation
- Teamwork
- Safe Care

HO TEACHING HOSPITAL
P O BOX MA-374
HO
Tel:+233-(036) 2027318-20/2028207
Fax:+233-(036) 2027323
Email: info@hth.gov.gh
Website: www.hth.gov.gh

7TH NOVEMBER, 2019

THE CHAIRPERSON
ETHICS REVIEW COMMITTEE
GHANA HEALTH SERVICE
ACCRA

Dear Sir/ Madam.

REFERRAL OF RESEARCH PARTICIPANTS FOR COUNSELING

Title of Study: Experiences of Caregivers on disclosure of childhood HIV-positive status to affected children in the Ho Municipality.

Principal Investigator: Celestine Yakanu

I am Mr. Emmanuel Dziwornu, a Clinical Psychologist in the University of Health and Allied Sciences also providing Clinical Psychology Services in the Ho Teaching Hospital including the Psychological Medicine Department. I write to notify you that I have been informed of the study titled **Experiences of Caregivers on disclosure of childhood HIV-positive status to affected children** to be conducted at the aforementioned facility.

I have agreed to attend to any participant who may need my services in the course of the study.

Thank you.

Mr. Emmanuel Dziwornu
Clinical Psychologist

The Premium in Innovative Tertiary Health Care, Medical Education and Research

Appendix H: Demographic Characteristics of Study Participants

PSEUDONYM	**Baba**	**Fafali**	**Ablator**	**Esinu**	**Tsoenamawu**	**Afeafa**	**Ameyo**	**Amewosina**	**Kofi**	**Mawumenyo**	**Mawutor**	**Kwadzo**	**Sefakor**
AGE (YEARS)	40	34	45	39	39	63	45	65	48	45	66	63	40
LEVEL OF EDUCATION	Secondary School	Tertiary	Primary	JHS 3	JSS	Middle School	No formal education	Primary	Middle school	Middle school	Middle school	Middle school	Primary
TYPE OF WORK	Self-employed	Teacher	Trader	Trader	Trader	Retired Teacher	Farmer	Farmer	Unemployed	Trader	Bakery	Retired	Trader
LEVEL OF MONTHLY INCOME (GH₵)	Nil	400	100	150	240	300	200	100	50	300	200	400	200
NATIONALITY	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian
RELIGION	Muslim	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian
MARITAL STATUS	Married	Single	Separated	Widowed	Married	Married	Married	Married	Widowed	Married	Widow	Separated	Married
RELATION TO CHILD	Uncle	Sister	Foster Mother	Mother	Aunt	Grand-mother	Mother	Grand-mother	Father	Mother	Grand-mother	father	Mother
AGE OF CHILD	6 years	11 years	10 years	11 years	12 years	10 years	12 years	12 years	7 years	7 years	6 years	10 years	10 years
AGE OF DIAGNOSIS	4 ½ years	5years	3months	7 years	8 years	7months	9 years	8 ½ years	5 years	3 years	3 ½ years	5 years	4 years
DURATION OF ART	1 ½ year	6years	9 ½ years	4 years	4 years	9years	3 years	3 ½ years	2 years	4 years	2 ½ years	5 years	6 years