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Disclosure of HIV status to infected children in Ghana: a north-south comparison of enablers and barriers

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Disclosure

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II. Abstract

Background

Understanding the living experiences of HIV+ children of disclosed status is necessary for intervention design. This study examined the living context of HIV status disclosed children and compared the barriers and facilitators to HIV disclosure across the Upper East, Northern and Ashanti regions of Ghana.

Methods

A concurrent mixed method design guided the interviewer-administered collection of data from 180 caregivers of HIV+ children 5-18 years from 12 antiretroviral treatment (ART) centres. A bivariate and binary multiple logistic regression analysis tested child and caregiver related variables associated with disclosure. A total of 30 HIV+ disclosed children 9-19 years were purposively selected for an interpretative phenomenological qualitative design and analysis.

Results

A total of 42 (23.3%) of the children knew their HIV status. The median age at disclosure of HIV status to the children was 9.5 (IQR=6-11) years. The median age of undisclosed children (n=138) was 7 (IQR=5-11). Caregivers of undisclosed children proposed age 16 as the intended age of disclosure, though children with disclosed status preferred 10 years as ideal age. Child age, age at ART start and caregiver resident region showed significant association with disclosure. Preference for disclosing child‟s HIV status to only child‟s family differed significantly between caregivers from Northern and Southern Ghana (17% vs 83%, $p<0.03$). In the multivariate binary logistic regression, a child questioning caregiver frequently about continuous medication intake (AOR = 19.0, $p< 0.01$) increased the odds of disclosure. From the qualitative evidence, disclosure often occurred with little or no preparation. It was either deliberately delayed or prolonged due to caregiver dilemma or took place based on the illness severity. Despite improved medication experiences post disclosure, the children reported financial difficulty and food insecurity.

Conclusions

Understanding the experiences of post-disclosed HIV+ children to inform the development of a national culturally sensitive and age specific disclosure guideline remains timely.

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IV. Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
HAART	Highly Active Antiretroviral Therapy
ARV	Antiretroviral
HIV	Human immunodeficiency virus
WHO	World Health Organization

1. Introduction

Globally, increased availability to Highly Active Antiretroviral Therapy (HAART) has led to an improvement in paediatric and adolescent HIV care and prevention among children and adolescents (1). Out of the global number of persons who live with HIV and AIDS, 3 million are children and adolescents aged 0-19 years. It is estimated that 87% of all HIV+ children in the 0-19 years bracket are living in sub-Saharan Africa (2).

There are growing numbers of HIV+ children surviving and growing into adolescents (3-5). This has implication for the sustainability of future HIV responses. Unfortunately, disclosure of HIV status to children who are infected considered as treatment gateway, has lagged (5-7). It is estimated that between 62-90% of children do not know their HIV status. Some systematic review evidence reports disclosure rates to be between 8.4 and 79% depending on the age of the child. In other studies, only 1.7% of very young children and 41% of adolescents were fully disclosed to about their HIV status (8-10).

In Ghana, HIV/AIDS prevalence is estimated to be 2.4% within the general population (11). Children between 0-14 years are about 30,000 representing 9% of all persons living with HIV and AIDS in Ghana (12). A total of 12,985 HIV+ persons are estimated to be on ART coverage in Ghana representing 36% of all persons living with HIV. Children on ART constitute a very marginal proportion (2). In the wake of increasing ART availability, and mixed reports of adherence, issues about child disclosure has emerged strongly as the possible causal link to shape medication adherence and psycho-social wellbeing. Some evidence suggests that child ART compliance and child improved health are positively related and this link is further enhance by child status disclosure (13).

However, most children are challenged with not knowing their HIV/AIDS status leading to low adherence to HIV medication with unexplained purpose. In Ghana, many adolescents initiate sex at very early ages of their life. Many young Ghanaians engage in sexual behaviour much earlier before turning age 19 (14-16). This presents an increased risk to new infection rates (16,17).

While concerns around child status non-disclosure exist, there are reported fear among caregivers that the children, when told about their HIV status, may not be able to keep the diagnosis to themselves (18). Similar reasons for non-disclosure have been established by Vreeman et al. and by Wiener et al.(19,20). There had been a paucity of data on the disclosure patterns for HIV+ children and the enablers and barriers across different geographical regions in Ghana.

The few studies that had been conducted on child disclosure by Kallem et al. and Kenu et al. used a relatively small sample size of 71 and 34 (21,22). More to that, all the studies conducted on disclosure in Ghana had been researched in the southern part of the country. The few studies had adopted either quantitative or qualitative approaches. The missing link that required further scientific inquiry was how HIV+ children will be able to know their HIV status to take measures aimed at improving their health.

The barriers that prevent care givers from disclosing the status to the children remains scanty and anecdotal in Ghana, with little known only from the urban and southern belt of the country. The unanswered question of the influence of multi-players - parents, caregivers and healthcare providers on child disclosure continues to exist. This is in addition to concerns on the suitable approaches to disclosure child age. In the midst of the espoused relevance of status disclosure to children, compliance to treatment protocols becomes a challenge as children have to battle with why they have to comply with such daily medical requirements daily.

There was a need to conduct a study to provide data, that is easily generalizable to the rest of the Ghanaian paediatric HIV population, and to provide a geospatial perspective of the factors that serve as obstacles to disclosing HIV status to status positive children across Northern regions, Upper East regions and Ashanti regions of Ghana. This study investigates the determinants for the disclosure of HIV status to positively diagnosed HIV children from their main or primary caregivers and also from the HIV+ children themselves across three regions in Ghana.

2. Rationale and Objectives

2.1 Rationale

HIV disclosure to HIV positive children in sub-Saharan Africa region remains very challenging. This is corroborated by very low reported disclosure figures. The reported studies show low disclosure prevalence of 17% in Ethiopia (22), 29% in Uganda, to between 21%-52.9% in Ghana (21,22) through to 39.6% in South Africa (23).

One potential explanation for having such differences in disclosure might be the year of publication or the age of the children. All these studies relied on relatively small sample size compared to studies in developed countries. This observation comes at the background of evidence that links several health benefits connected with the disclosure of the HIV status to HIV positive children. Complete disclosure has been reported to promote good medication adherence (24).

Non-disclosure may pose serious public health challenges with regard to viral transmission to the uninfected population as a result of possible risky sexual behaviour among adolescents. Risky behaviours may promote the transmission of drug-resistant strains of the virus (20). In Ghana, of the number of children who live with HIV, there is little data about the proportion of them who know their HIV status though a greater number of them are on ARV medication without knowing the reasons for taking the HIV medication.

The WHO argues that hiding of HIV status of children from them can increase their depression levels and ultimately lead to mental health outcomes(4). While some studies have been conducted on child disclosure, a careful analysis has shown that many of the studies lacked sound theoretical framework to situate those studies. In an exceptional case, the study by Paintsil et al. emerge as one of the foremost studies on child HIV disclosure to be theoretically grounded (15). The “Sankofa” study was a two-arm randomized controlled clinical trial conducted among HIV-infected children between aged 7 and 18 years without knowledge of their seropositive status (15).

The study was grounded in the bioecological systems theory, and supported by the Information, Motivation, and Behavioural Skills (IMB) model of Health Behaviour Change (25). This study was grounded on a theory and established an association between HIV negative status and lower levels of education with poor scores recorded on HIV knowledge questionnaire. Similarly, HIV+ status disclosed children showed higher levels of stigma. This demonstrates the utility of situating similar studies in a theoretical framework.

In many instances, theories serve as the underpinning or building blocks for evidence-based practice. There are several sociological and health-based theories that offer explanations for disclosure of HIV patient status. Serovich reports that one of the widely held theory‟s in accounting for HIV disclosure is disease progression theory. Serovich however shares the opinion that disease progression may not necessarily be a component of the disclosure process (26). This theory explains that disclosure of HIV status by individuals occurs only at the point when patients have recognized that the HIV has progressed to become AIDS and as a result cannot be kept as a secret any further. The aftermath of disease progression is hospitalizations and physical deterioration causing some people to unavoidably disclose their illness (26).

Not only would hospitalization require explanation, but if death of a patient becomes imminent for him or her or the patient feels the need for extra support, disclosure may take place to access the needed resources. This theory has been used extensively with several scholars documenting the association between disease progression and disclosure (27,28). The other often applied theory which serves as an alternative theory to the disease progression theory is premised on disclosure taking place after thoughtful deliberations on the outcomes of the disclosure whether positive or negative.

The progression of the disease brings stress, resulting in the need to appraise the disease on the consequences of disclosure. Disclosure will therefore take place if a person evaluates that revealing the HIV status to the significant others and sexual partners brings rather rewards than the cost. In such instance, the basic assumptions of the social exchange theory are at play. The consequences the HIV status disclosure is very paramount in whether to disclose or otherwise. The present study was therefore situated in the context of the two theories to justify their utility in understanding HIV status disclosure to children, especially in the setting where the study was conducted. The conduct of this study is justified in respect of the prospects the generated evidence offers to caregivers and healthcare workers to addressing child disclosure dilemma. The results of this study emerge as reliable scientific information that can be used in the future for design and formulation of context appropriate paediatric HIV counselling in Ghana.

2.2 General Objective

To investigate the disclosure barriers and enablers of children who are HIV positive from the HIV+ children and main caregivers across regions from the Northern and Southern belts of Ghana

2.3 Specific Objectives

The study's specific objectives are:

1. To determine and compare the prevalence of disclosure and identify the factors associated with disclosing HIV positive children status to them from the Northern region, Upper East region and Ashanti regions of Ghana.
2. To describe caregiver's perspective on the perceived barriers and benefits of informing children about their own HIV status from Northern and Southern Ghana.
3. To find out the lived experiences of HIV positive children, including ART adherence and treatment compliance among children living with HIV (C/LWAIDS).

3. Methods

3.1 Research Design

This was a cross-sectional facility-based study adopting qualitative and quantitative approaches in 12 ART centres located in rural and urban antiretroviral treatment (ART) centres in Ashanti region, Upper East region and Northern regions of Ghana. The convergent mixed method approach was used to complement each other (29). The study considered children between 5-18 years as participants and caregivers as respondents.

The study was conducted between April 2017 and February 2018. There were 29 and 14 ART centres in the Ashanti and Northern regions of Ghana at the period. In the Upper East, and 16 ART centres existed during the time of the study. A total of four ART centres/clinics were purposively selected from each of the three regions. Each region had two of the selected ART clinics located in an urban and rural centre respectively. Respondents comprised caregivers of HIV infected children attending the various ART centres for care. Included in the study participants were children themselves, who knew their HIV status. In the Ashanti region, the Kumasi South and Suntreso Government Hospitals was selected for the urban sites. The Offinso St Patrick Catholic Hospital and the Agogo Hospitals were recruited as the rural district ART sites.

The ART clinic of Tamale Teaching Hospital and the ART clinic of the Tamale Central Hospital were selected as the urban ART sites in the Northern region. The rural ART sites selected were Savelugu Hospital-ART and Walewale district hospital"s ART unit. The Upper East region had Bolgatanga regional hospital ART and War Memorial Hospital ART unit as the urban sites. Bongo district hospital"s ART centre and the Tongo district ART centre were enrolled as the rural sites.

The collection of data from the different parts of the country provided a national representative depiction of research problem and the results and allowed for the generalisation of the results. More so, the comparison among the regions aimed at bringing to the fore the socio-cultural and contextual factors that played a role in shaping paediatric HIV status disclosure.

3.2 Sampling

A multi-stage sampling procedure was adopted. This study focused on two groups of study participants. These were the HIV+ children with known status and caregivers of HIV+ children. In the attempt to reduce selection biases using the multi-stage cluster/area sampling, comprehensive sampling frame of HIV+ children from each of the ART centres selected was accessed from the data managers in each facility. The regions were selected due to the difference in HIV/AIDS prevalence and unique cultural backgrounds. The stratified sampling technique guided in stratifying ART centres into two strata (urban and rural). Additionally, through purposive sampling, four ART sites (2 urban and 2 rural) from each region were selected to add up to a total of 12 ART sites. The study randomly selected caregivers who met the inclusion criteria. This done by using both the patient registry of the children and their folders.

The inclusion criteria were:

1. Caregivers of HIV/AIDS positive children as confirmed in the medical folder of the child.
2. Primary caregivers who have taken care of the children since the first diagnosis of the HIV/AIDS infection or who had had regular charge of the children in at least the last three months since infection/diagnosis.
3. Children with known HIV/AIDS status, as confirmed by caregiver and also the records from the ART centre.

3.2.1 Sample size

Based on a previous study on HIV disclosure to infected children by Kallem et al and using 21% prevalence, the sample size was calculated by using the following formula (22):

where d=p =0.21; q=0.79; z= 1.96; d=0.05, thus

= (1.96)2 * (0.21x0.79)/(0.05)2 = 254.9= 255.

However, 180 interviewer administered questionnaires (representing 71%) were able to be performed due to unavailability of target population resulting from long medical review schedule before visiting the ART centres.

The qualitative interviews involved 30 children with known HIV/AIDS status. Respondents for the quantitative data were selected by simple random sampling method using random numbers. After obtaining a list of paediatric attendants at each of the clinics, a number was assigned to each entry in the list. Caregivers of children with numbers corresponding to the generated random numbers were included in the study. A meeting was arranged with the caregiver with the assistance of the data managers of the ART centre. The interview was held upon agreeing to be involved in the study.

3.2.2 Study variables

Outcome/dependent variable

The dependent variable was measured as „„disclosed‟‟ or „„not disclosed. The operational definition of disclosure was defined as whether primary caregiver of the child answered Yes or No in response to the question of "has the child been told his or her HIV status".

Independent variables

The predictor variables were demographic variables of the primary caregiver which included their age, HIV status, sex, relationship with child. Other caregiver variables consider considered were caregiver educational and levels of income, caregiver marital status and occupation. The child related independent variables were age of the child, sex, and ART medication reception. Other child linked independent variables were status of child‟s mother whether alive or dead, age at child HIV diagnosis and length on ART). The additional variables on the medical and clinical history of the child were considered. Other variables elicited information on the perspective of caregivers on the perceived barriers and benefits to HIV status disclosure.

Definitions used in this study

- **Caregiver**: any adult who is responsible for the day-to-day health care related needs of the child. It is extended to include someone who brings the child to clinic often, is directly responsible for the health and safety of the child, and has the information about the child behaviours (e.g., response to diagnosis, adherence to ART, social movement in the home etc).

- **Child**: any young person within the ages of 5 years to 18 years.
- **Disclosure**: having explained to the children the HIV/AIDS diagnosis
- Definition of **HIV** infection was limited to a confirmed positive HIV ELISA antibody, that had been documented in the clinical folder of the child or a positive HIV PCR test
- The study chose the minimum age of 5 for the disclosure. This was chosen after consulting the literature. The evidence suggested that age-tailored disclosure information beginning from five years was appropriate. Age 19 was chosen as maximum age to cater for children and adolescents (10-19 years), the group around which this study revolved.

3.3 Data Collection

Structured questionnaires were provided to caregivers of the children. This was done during regular clinic hours of visit. This was done by principal researcher and trained staff at the various health facilities. This was done in English, Asante Twi, Frafra and Talen. Scheduled appointments were arranged for caregivers who satisfied the inclusion criteria and were randomly pre-selected. Interviews were done without the presence of children. This was done to avoid any possibility of inadvertent disclosure of status to the children who had not yet been told about their own HIV status.

Questionnaires were made up of both closed ended and open-ended questions. They comprised caregiver information on their demographic characteristics and HIV status, child's demographic characteristics, child's diagnosis and HIV disclosure status, child's disclosure age, benefits of disclosure as perceived by the caregiver as well as the barriers to disclosure. Information included the type of support healthcare workers required in the disclosure process. In-depth interviews were conducted to elicit information from the caregivers. These interviews bordered on the broader theme of post disclosure experiences of HIV+ children. This was done using interview guides.

3.3.1 Pre-testing

Prior to the start of the study, pre-testing was done on the developed questionnaire at the Kwadaso hospital located in Kumasi. The hospital share similar population characteristics with the selected ART study sites. This help in identifying the flaws and ambiguities in the questions after which all necessary corrections were made prior to the actual data collection.

3.4 Data handling and analysis

The collected data were entered into Microsoft Excel and imported into STATA version 12 and SPSS 21. Descriptive statistical analysis was carried out to explore the socio-demographic distribution of the children and their association with status disclosure of the children. This was presented frequencies and percentages. The numerical variables were presented in in the forms of means and standard deviations. Disclosure prevalence for the children was calculated for all children and also for within age sub-categories. The main outcome variable of disclosure or non-disclosure of HIV diagnosis was compared with each of the exposure variables using chi square analysis.

The univariate analysis was executed with the Pearson‟s chi squared (x2) tests to investigate the relations between disclosure status, child-level and caregiver demographic, clinical and other related factors. Further to that, the binary logistic multivariate analyses was done with odds ratios (OR) and 95% confidence intervals (95%CI) reported. The variables that demonstrated significant association with child disclosure status at $p<0.05$ in the univariate analysis were further entered into the multivariate model.

The qualitative data was collected through interviews and was transcribed and categorized into themes and analyzed thematically. The qualitative results was reported in themes using constant comparative method after transcription from field notes, direct interviews and tape recordings (30).

3.5 Ethical considerations and limitation of the study.

Ethical approval for the study was secured from the Ghana Health Service through its Ethics Review Committee. The Ethics approval number was GHS-ERC: 05 /06/17. Additional Ethical approval was taken from the University of Munich. The Ethical Committee of LMU Munich approved the study. The Ethics number is (Project Number 18-018). Participation in the study was voluntary. Caregivers provided written informed consent. After ethical approval had been given, introductory letters were sent to the Ghana Health Service and to the various ART clinics selected for management approval. Informed consent that had been written was secured from each caregiver. This was done before questionnaires administration.

The limitation of this study stemmed from the admission that some caregivers may have provided responses which were not accurate. This might have led to possible social desirability biases. Caregivers were however engaged outside the hospital wards to allow them the free space to give responses that were deemed accurate to represent their exact knowledge on the disclosure status of their children.

Another possible limitation of this study is the inability of the researchers to verify the content of the disclosure messages that were given to the children.

This could not be authenticated whether the children had been disclosed to fully or partially in terms of their HIV+ status. There was also the possibility of recall bias. The adoption of the triangulation approach to the study helped address this potential challenge. The originally estimated sample size from the northern region of Ghana could not be achieved due to several data collection challenges. This may have impacted the study in terms of the multivariate level analysis. This was however addressed by recategorising the sample from upper east and northern region to northern Ghana for statistical analysis purposes.

4. Results

4.1 Study 1

A Phenomenological Account of HIV Disclosure Experiences of Children and Adolescents from Northern and Southern Ghana

Appiah, SCY. Kroidl, I.; Hoelscher, M.; Ivanova, O*. and Dapaah, J.M*. (Published at *Int. J. Environ. Res. Public Health* **2019**, *16*, 595)

Abstract:

Background: Disclosure of HIV status to infected children, though challenged by caregiver dilemma, remains central in achieving the United Nations Programme on HIV and AIDS (UNAIDS) and global goal of 90/90/90. This study explores children‟s HIV disclosure experiences Northern and Southern Ghana.

Methods: A qualitative interpretative phenomenological design facilitated the recruitment of 30 HIV+ disclosed children and adolescents aged 9–19 years in 12 antiretroviral treatment (ART) centres in Northern and Southern Ghana between January 2017 and June 2018. Data was collected via in-depth interviews. We used phenomenological analysis applying concepts and categories identification, patterns and interconnections searching, mapping, theme building and constant comparative technique to draw conclusions

Results: Disclosure of HIV status to children occurred with little or no preparation. Caregivers intentionally or out of dilemma often prolonged or postpone disclosure to when children aged older. Illness severity and disease progression principally defined the need for disclosure. Children preference for early status disclosure averaged at age 10 was demonstrated despite the initial disclosure experience of shock and disappointment. There was improved medication adherence despite the challenge of limited knowledge about HIV transmission, financial difficulty and food insecurity.

Conclusion: Context and culturally adapted pre- and post- disclosure guideline laced with social protection package is needed to support HIV+ children.

4.2 Study 2

Disclosure of HIV/AIDS status to infected children in Ghana - a north-south comparison of barriers and enablers

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Abstract

Introduction Disclosure of HIV status to infected children plays critical role in child health and wellbeing. This study identifies and compares child HIV disclosure barriers and facilitators in Upper East, Northern and Ashanti regions of Ghana.

Method Prospective data was collected through a questionnaire on 180 caregivers of HIV-infected children 5-18 years from 12 antiretroviral treatment (ART) hospitals from May 2017 to November 2018 enrolling 89 (49.5%) males and 91 (50.5%) females. A bivariate and binary multiple logistic regression analysis was performed to test child and caregiver related variable with disclosure.

Results: A total of 42 (23.3%) children with a median age of 12 years had been disclosed to. The median age of 138 undisclosed children was 7 (IQR =5-11) years. The median age at disclosure was 9.5 (IQR =6-11) years in contrast to 16.3 years, which was proposed as the intended age of disclosure by caregivers. Approval for child status disclosure to be facilitated by only child‟s family member differed significantly between caregivers from northern Ghana and southern Ghana (17% vs 83%, p <0.03). In the multivariate binary logistic regression, a child questioning caregiver frequently about continuous medication intake (AOR =19.0, p <0.01) increased the odds of disclosure. Enablers to disclosure were child age, ART start age and resident region of the care giver. The barriers to disclosure involved limited caregiver knowledge and caregiver notion of non-disclosure as a best interest and child protection decision. Difference in region of residence of the child contributes to enhance or impede child HIV disclosure.

Conclusion: This calls for developing appropriate age specific child disclosure-promoting guideline to facilitate disclosure.

5. Discussion

This study was a concurrent mixed-methods study adopting both cross-sectional design and phenomenological approach. The study examined the differential enablers and barriers to HIV disclosure among children in northern and southern Ghana an explored context and the lived experiences of post HIV disclosed children and adolescents. In this study, children who had been informed the children about they being HIV positive was 23.3% of the total number of children studied.

The finding from the quantitative data shows that, children were informed about being HIV positive at a median age of 9.5 years. This age is lower than the 10.39 years median age at which children became aware they were HIV as confirmed in the studies of in Kallem et al. and other single facility and region specific studies conducted elsewhere in Ghana (21,22,31,32).

Ghana may have to interrogate further its continued low rates of paediatric HIV disclosure practice. This stems from the findings that child disclosure rates continue to remain relatively low (21% to 34%) despite progress in HIV care and management in Ghana by the Ghana AIDS Commission and the Ministry of Health(12,22,31).

The average age of all the children in the quantitative data with known/disclosed status was 12 years while the average age for children enrolled in the post-disclosure interview session was 14 years. With caregivers of disclosed children indicating disclosing to their children at a mean age of 9.5 while children interviewed for the post disclosure experience reported coming to know their status at 13 years, there is some recognition for consensus on the need for disclosure though the ideal age for disclosure remained unclear. Some delays in disclosure remains to be addressed.

The mean age of disclosure among the children interviewed for their post disclosure experiences was much higher. It was also late compared to 9.5 years among those reported by caregivers to have been informed of their status. The findings suggest that, some caregivers of HIV+ children are beginning to appreciate the concerns and respect the voices of their children for early status disclosure. This is against the background that, among the children interviewed, the ideal or preferred age for disclosure was 10 years while the findings from the caregivers of status disclosed children show a median age at disclosure to be 9.5 years for status disclosed children. The continuing challenge however has to do with caregivers of the majority undisclosed children who think the intended or ideal age of disclosure to their children should be 16.3 years.

The two data which were gathered independent of each other shows a consensus between children"s preferred age of disclosure (10 years) and the current practice of an average 9 and half years. Notwithstanding these observed marginal progress in the timing of disclosure, caregivers are challenged as they s continue to experience uneasiness disclosing the positive status of the child to them notwithstanding the promising benefits that process oriented child HIV status disclosure brings to the children(19,33).This study comes as the first study conducted in Northern Ghana to examine the patterns of HIV disclosure. The study further has the additional distinctive feature of being the first comparative study in Ghana to examine HIV disclosure patterns between the two distinct geographical and cultural zones in Ghana (Northern Ghana and Southern Ghana) and to further explore the lived experiences of post-disclosed HIV+ children across the two regions.

In terms of the enablers, our study showed that not only does caregiver related factors influence disclosure but also child related factors. Frequent asking of caregivers the reasons for medication intake by children was found to significantly and independently predict the disclosure of the HIV status of child in the multivariate analysis. The place of stay of the children in the case of northern or southern Ghana was not significantly associated with child disclosure. Notwithstanding, out of the total number of disclosed children (n=42), those who lived in Northern Ghana (Upper East and Northern region - 59.5%, n=25) had higher HIV disclosure rates compared to children living in Southern Ghana (40.48%, n=17), who knew their HIV status.

This finding is important taking into considering the uneven and inequitable distribution of health resource in the Upper East region as compared to the Northern and Ashanti regions. There was not one of the ART sites selected from the Upper East region that was considered as a specialised or dedicated ART clinic for HIV care compared to the Tamale Teaching hospital HIV/STI clinic in the Northern region or when compared to the specialized children clinic and adolescent HIV clinics such as the Suntreso hospital in the Ashanti in Southern Ghana. Moreover, the Upper East region is a resource disadvantaged region with underprivileged health outcomes. This includes an under-five mortality of 128 per 1000 live births which is worse when compared to 75 per 1000 births in Southern Ghana (34). The reasons accounting for the disparities in the disclosure patterns with higher rates of disclosure in the Upper East region compared to the Northern region and Ashanti region remains yet to be identified. It is however possible that some clinic and health professionals specific factors including but not limited to the motivation of the staff and diversity of cultural caregiver groups may play a role in the observed difference (35). It is unclear as to whether religion had any impact on the somewhat low rates of disclosure in the northern region; a region that is predominantly Muslim.

In terms of the disclosure barriers to HIV positive children, marked differences existed between Northern and Southern Ghana. The differences were established around caregiver beliefs and perceptions which were found to be associated with disclosure. Significantly, the differences lie in caregiver"s fear of accidentally disclosing status to their children accompanied by a belief that the health status of their children will worsen or deteriorating and the conviction that only child family members should facilitate disclosure to the children. Despite the difficulty in establishing the cause of these disparities as reported by Vreeman et al. in Kenya, understandably, several difference exist between the Northern part of Ghana and Southern part Ghana in diverse trajectories including culture and language. In terms of religion, health access and health seeking behaviour , such differences also exist (35,36).

Another barrier to the telling children their HIV status was the clear absence of comprehensive plan by ART centres and caregivers themselves. Among the caregivers of undisclosed children nearly a half (49.28%, n=68) did not yet have a definite age of the child at which they were prepared and able to inform the child of his or her status. This brings to the fore about beliefs of caregiver"s in the significance of early disclosure to the health of their children. While this observation was made with results from the qualitative component, this is corroborated by the lived experiential account of post-disclosed children.

These children narrate in their experiences that majority of the disclosure encounters they had occurred when they were not prepared as disclosure occurred instantaneously. This is because, their caregivers did not actually have a plan in mind when they would disclose, how it would be done and the preparation they needed to ready the children for that encounter. Similar observations have been reported as barriers to disclosure in Zambia, where 6% of children and adolescents were informed of their HIV status by both parents. Parents/caregiver weak-preparedness and poor skills predisposition to disclose are justified on the excuse stigma and blaming of the children and the possibility of child self-disclosure to colleagues and peers (13,37-39).

The absence of comprehensive plan and or preparation on the part of the caregiver does not necessarily constitute a deliberate intention. However, the daily jostling between illness substitutions, hiding the truth to the children and in some cases incremental disclosure were underpinned by lack of skill to disclose. This observation is consistent with the establishment of significant association between disclosure and caregiver limited knowledge about how to go about with disclosure ($p<0.003$)(31,40). This study did not establish the influence of caregiver‟s level of education on disclosure though Kenu et al. and Paintsil et al. had reported such association. The importance of adequacy of knowledge on illness associated with HIV and knowledge about HIV disclosure importantly shapes and informs disclosure patterns (15,21). The dominant disclosure barrier had to do with inadequate caregiver skill to disclose to the child; an attribute which was observed to be independent of the educational level of caregiver which was found not to be a significant predictor of disclosure.

Caregiver notion of child best interest also contributed to non-disclosure of child status. Best interest of child wellbeing was identified to have been wrongly interpreted and this has contributed to delays in disclosure of child HIV status to them. Caregiver unwillingness to seek child disclosure skill support to disclose at an earlier child age under the notion of protecting the child rather constitute a violation of the child best interest and the child‟s right, a view that has strongly been highlighted elsewhere (41,42). In such context, when the children are told at later age, as reflected in the narratives of those engaged in the interviews, they blame their caregivers.

There is the need for an interpersonal communication plan or strategy that is very interpersonal for both between the children and their caregivers built on mutual trust and empathy in the disclosure process (43). Caregivers practice of late disclosure and postponement to late years rather deprive the children and amounts to a violations of the rights of the children in several domains contrary to the stipulations of international treaties and national laws (44,45). Although previous studies have not examined the direct relationship prolonged non-disclosure as a child right issue, stretching disclosure amounts to a clear child right violation and the many international child right conditions in the Convention on the Rights of the Child (CRC) and of the African Charter on the Rights and Welfare of the Child (ACRWC) (44,45).

6. Conclusions

Our study reports on the first study ever to report on the exploration of the disclosure experiences among children and adolescents across Southern and Northern Ghana. The findings demonstrate that child status disclosure of HIV to the positive HIV children in Ghana is characterised by unpreparedness of the children while occurring at very late years of the children a situation that impairs child"s development. The study established further the unique association found between disclosure status of the child and their region of residence. Children recruited from less resourced areas in terms of health facility and ART clinics had comparatively higher chances of being disclosed to about their HIV status showing higher rates of disclosure.

This finding is important because it provides baseline information and on the need to identify the unique factors may have been responsible for improvement in health care delivery. This reiterates the call for an improvement on health strengthening approaches going beyond the health facility and the personnel factors to integrate client focused and community-based factors. The factors that were found to have an associated with child status disclosure were the age of a child, ART start and caregiver willingness to disclose, but with limited “know-how”. Children who frequent queried their caregivers about medication intake were independently more likely to know or be told their HIV status

A special training programme is expected to be designed for both caregivers and healthcare workers who are at the centre of HIV positive disclosure to infected children to improve the disclosure process.

7. References

1. Dako-Gyeke P, Dornoo B, Addo SA, Atuahene M, Addo NA, Yawson AE. Towards elimination of mother-to-child transmission of HIV in Ghana: an analysis of national programme data. Int J Equity Health. 2016;15(1):5.
2. HIV/AIDS JUNP on. Global AIDS Monitoring 2018. Indicators for monitoring the 2016 United Nations Political Declaration on Ending AIDS. Geneva: UNAIDS; 2017. 2018.
3. Thorne C, Newell M, Peckham CS. Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. Child Care Health Dev. 2000;26(1):29-40.
4. WHO. Guideline on HIV disclosure counselling for children up to 12 years of age. - Google Search [Internet]. WHO Geneva. 2011 [cited 2019 Feb 18]. Available from: https://www.google.com/search?client=firefox-b-d&q=Guideline+on+HIV+disclosure+counselling+for+children+up+to+12+years+of+age.+
5. AIDS C on P. Disclosure of illness status to children and adolescents with HIV infection. Pediatrics. 1999;103(1):164–6.
6. UNAIDS. Criminalisation of HIV Non-Disclosure , Exposure and Transmission: Background and Current Landscape. 2012;(February).
7. WHO. Global update on HIV treatment 2013: results, impact and opportunities. 2013 [cited 2019 Feb 5]; Available from: http://apps.who.int/iris/bitstream/handle/10665/85326/978?sequence=1
8. Nichols J, Steinmetz A, Paintsil E. Impact of HIV-status disclosure on adherence to antiretroviral therapy among HIV-infected children in resource-limited settings: a systematic review. AIDS Behav. 2017;21(1):59–69.
9. Britto C, Mehta K, Thomas R, Shet A. Prevalence and correlates of HIV disclosure among children and adolescents in low-and middle-income countries: A systematic review. J Dev Behav Pediatr JDBP. 2016;37(6):496.
10. Vreeman RC, Gramelspacher AM, Gisore PO, Scanlon ML, Nyandiko WM. Review article Disclosure of HIV status to children in resource-limited settings : a systematic review. 2013;
11. Ghana AIDS Commission. Ghana AIDS Commission [Internet]. GhanaS"s HIV Fact Sheet 2019. Accra; 2019. Available from:

https://www.ghanaids.gov.gh/mcadmin/Uploads/2019 FACT SHEET 22 06 2020 revised(1).pdf

12. Ghana AIDS Commission. Ghana AIDS Commission National and Sub-National HIV and AIDS Estimates and Projections 2017 Report [Internet]. Accra; 2017. Available from: http://www.ghanaids.gov.gh/gac1/pubs/2017-2022_national_and_sub national_Estimates_Report.pdf
13. Vaz LME, Maman S, Eng E, Barbarin OA, Tshikandu T, Behets F. Patterns of Disclosure of HIV-Status to Infected Children in a Sub-Saharan African Setting. J Dev Behav Pediatr. 2011;32(4):307–15.
14. Appiah SCY, Badu E, Dapaah JM, Harriet T, Abubakar M. Youth friendliness of sexual and reproductive health service delivery and reproductive health service utilization in Ghana. Int J Innov Appl Stud. 2015;10(2):716–25.
15. Paintsil E, Renner L, Antwi S, Dame J, Enimil A, Ofori-Atta A, et al. HIV knowledge, stigma, and illness beliefs among pediatric caregivers in Ghana who have not disclosed their child"s HIV status. AIDS Care - Psychol Socio-Medical Asp AIDS/HIV. 2015;
16. Dapaah J, Appiah S, Amankwaa A, Ohene L. Knowledge about sexual and reproductive health services and practice of what is known among Ghanaian Youth, a mixed method approach. 2016 [cited 2019 Mar 11]; Available from: http://dspace.knust.edu.gh/handle/123456789/8724
17. Norman I, Awiah B, … FN-A in A, 2016 undefined. Homosexuality in Ghana. file.scirp.org [Internet]. [cited 2019 Mar 11]; Available from: https://file.scirp.org/pdf/AASoci_2016012014100379.pdf
18. Boon-Yasidhi V, Kottapat U, Durier Y, Plipat N, Phongsamart W, Chokephaibulkit K, et al. Diagnosis disclosure in HIV-infected Thai children. J Med Assoc Thai. 2005;88(Suppl 8):S100–5.
19. Vreeman RC, Nyandiko WM, Ayaya SO, Walumbe EG, Marrero DG, Inui TS. The Perceived Impact of Disclosure of Pediatric HIV Status on Pediatric Antiretroviral Therapy Adherence, Child Well-Being, and Social Relationships in a Resource-Limited Setting. AIDS Patient Care STDS. 2010;
20. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: history, current research, and future directions. J Dev Behav Pediatr JDBP. 2007;28(2):155.
21. Kenu E, Obo-Akwa A, Nuamah GB, Brefo A, Sam M, Lartey M. Knowledge and

disclosure of HIV status among adolescents and young adults attending an adolescent HIV clinic in Accra, Ghana. BMC Res Notes. 2014;7(1):844.

22. Kallem S, Renner L, Ghebremichael M, Paintsil E. Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. AIDS Behav. 2011;15(6):1121–7.
23. Madiba S. Patterns of HIV diagnosis disclosure to infected children and family members: data from a paediatric antiretroviral program in South Africa. World J AIDS. 2012;2(03):212.
24. Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., ... & Bunnell R. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. AIDS Behav [Internet]. 2006 [cited 2019 Feb 6];1(10):85. Available from: https://link.springer.com/article/10.1007/s10461-006-9141-3
25. Fisher WA, Fisher JD, Harman J. The information-motivation-behavioral skills model: A general social psychological approach to understanding and promoting health behavior. Soc Psychol Found Heal Illn. 2003;22:82–106.
26. Serovich JM. A TEST OF TWO HIV DISCLOSURE THEORIES.
27. Hays RD, Cunningham WE, Ettl MK, Beck CK, Shapiro MF. Health related quality of life in HIV disease. Assessment. 1995;2(4):363–80.
28. Marks G, Bundek NI, Richardson JL, Ruiz MS, Maldonado N, Mason HRC. Self-disclosure of HIV infection: Preliminary results from a sample of Hispanic men. Heal Psychol. 1992;11(5):300.
29. Creswell J, Poth C. Qualitative inquiry and research design: Choosing among five approaches. 2017 [cited 2019 Feb 18]; Available from: https://scholar.google.com/scholar?hl=en&as_sdt=0%2C5&q=Creswell+JW.+Qualitative+inquiry+and+research+design%3A+Choosing+among+five+traditions.+thousand+oaks%2C+ca%3A+Sage%3B+1998.+&btnG=
30. Merriam SB. Qualitative Research and Case Study Applications in Education. Revised and Expanded from" Case Study Research in Education.". ERIC; 1998.
31. Hayfron-Benjamin A, Obiri-Yeboah D, Ayisi-Addo S, Siakwa PM, Mupepi S. HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central Region of Ghana. BMC Pediatr [Internet]. 2018 Dec 22 [cited 2019 Mar 11];18(1):365. Available from: https://bmcpediatr.biomedcentral.com/articles/10.1186/s12887-018-1330-5

32. Gyamfi E, Okyere P, Enoch A, Appiah-Brempong E. Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. BMC Int Health Hum Rights. 2017;17(1):8.
33. Arrivé E, Dicko F, Amghar H, Aka AE, Dior H, Bouah B, et al. HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. PLoS One. 2012;
34. Ghana Statistical Service. 2010 Population and Housing Census, National Analytical Report. 2013;1-117.
35. Vreeman RC, Scanlon ML, Mwangi A, Turissini M, Ayaya SO, Tenge C, et al. A cross-sectional study of disclosure of HIV status to children and adolescents in Western Kenya. PLoS One. 2014;9(1):1–10.
36. GSS. 2010 population and housing census: summary report of final results. Ghana Statistical Service Accra; 2012.
37. Mburu G, Hodgson I, Kalibala S, Haamujompa C, Cataldo F, Lowenthal ED, et al. Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. J Int AIDS Soc. 2014;17(1):18866.
38. Okawa S, Yasuoka J, Ishikawa N, Poudel KC, Ragi A, Jimba M. Perceived social support and the psychological well-being of AIDS orphans in urban Kenya. AIDS Care. 2011;23(9):1177–85.
39. Mweemba M, Musheke MM, Michelo C, Halwiindi H, Mweemba O, Zulu JM. “When am I going to stop taking the drug?” Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia. BMC Public Health. 2015;15(1):1028.
40. John-Stewart GC, Wariua G, Beima-Sofie KM, Richardson BA, Farquhar C, Maleche-Obimbo E, et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. AIDS Care [Internet]. 2013 [cited 2019 Apr 4];25(9):1067–76. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23256520
41. Reynolds NR, Ofori-Atta A, Lartey M, Renner L, Antwi S, Enimil A, et al. SANKOFA. AIDS [Internet]. 2015 Jun [cited 2019 Mar 11];29:S35–45. Available from: http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00002030-201506001-00004
42. National Department of Health SA. Disclosure Guidelines for Children and

Adolescents in the context of HIV, TB and non-communicable diseases [Internet]. Johanesburg: National Department of Health; 2016. p. 1–82. Available from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=2ahUKEwjn4_uFpMnhAhWzTBUIHbRXDyMQFjAAegQIAxAC&url=http%3A%2F%2Fwww.health.gov.za%2Findex.php%2Fhiv-aids-tb-and-maternal-and-child-health%3Fdownload%3D1696%3Ahiv-disclosure-

43. Vaz LME, Eng E, Maman S, Tshikandu T, Behets F. Telling Children They Have HIV: Lessons Learned from Findings of a Qualitative Study in Sub-Saharan Africa. AIDS Patient Care STDS [Internet]. 2010;24(4):247–56. Available from: http://www.liebertonline.com/doi/abs/10.1089/apc.2009.0217
44. African Charter on the Rights & Welfare of the Child (ACRWC). ACERWC: African Committee of Experts on the Rights and Welfare of the Child. (1999). The African Charter on the Rights and Welfare of the Child [Internet]. 1999. Available from: http://acerwc.org/wp-content/uploads/2011/04/ ACRWC-EN.pdf
45. Nations Human Rights: Office of the High Commissioner for Human Rights. (2014). Convention on the rights of the child,. Available from: http://www.ohchr.org/en/professionalinterest/pages/crc.aspx, retrieved on the 04 march 20199

Publications

8.1 Publication 1

A Phenomenological Account of HIV Disclosure Experiences of Children and Adolescents from Northern and Southern Ghana Int. J. Environ. Res. Public Health 2019, 16, 595.

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A Phenomenological Account of HIV Disclosure Experiences of Children and Adolescents from Northern and Southern Ghana

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Abstract: Disclosure of HIV status to infected children, though challenged by caregiver dilemma, remains central in achieving the United Nations Programme on HIV and AIDS (UNAIDS) global goal of 90/90/90. This study explores children's HIV disclosure experiences across Northern and Southern Ghana. A qualitative interpretative phenomenological design facilitated the recruitment of 30 HIV positive disclosed children and adolescents aged 9–19 years in 12 antiretroviral treatment (ART) centers in Northern and Southern Ghana between January 2017 and June 2018. Data was collected via in-depth interviews. We used phenomenological analysis applying concepts and categories identification, patterns and interconnections searching, mapping, theme building and constant comparative technique to draw conclusions. Disclosure of HIV status to children occurred with little or no preparation. Caregivers intentionally or out of dilemma often prolonged or postponed disclosure to when children aged older. Illness severity and disease progression principally defined the need for disclosure. Children preference for early status disclosure averaged at age 10 was demonstrated despite the initial disclosure experience of shock and disappointment. There was improved medication adherence despite the challenge of limited knowledge about HIV transmission, financial difficulty and food insecurity. Context and culturally adapted pre- and post- disclosure guideline laced with social protection package is needed to support HIV positive children.

Keywords: HIV; AIDS; disclosure; children; adolescence; phenomenology; experiences; Africa; Ghana

1. Introduction

The HIV/AIDS epidemic has spread across continents, during the last three decades, with about 36.9 million people living with the infection out of which 1.8 million are children less than 15 years old [1]. Sub-Saharan Africa contributes to about 70% of the global HIV infection burden [2]. About 74% of all 1.5 million AIDS-related deaths in 2013 were recorded in Sub-Saharan Africa, despite the substantial progress in access to antiretroviral therapy (ART) [2]. In 2017, it was estimated that 21.7 million were receiving ART globally, representing 59% of the 36.9 million people living with HIV and AIDS [3].

Out of the global number of persons receiving ART, only 43% of HIV infected children are on ART due to many factors, but partly also because their status has been kept secret by caregivers denying children's access to ART [3]. Despite the low HIV prevalence in most West African countries, there has been recent increase in new infections in Ghana. Though the prevalence in Ghana was stable with 1.7% in 2008, 1.3% by 2013 and 1.4% in 2014; the recent past has witnessed increase in new infections with prevalence rising to 2.4 % in 2016, according to the 2016 HIV sentinel report [4].

There were over 310,000 Ghanaians infected with HIV in 2017, out of which 28,000 were children aged 0 to 14 years [4]. ART coverage in Ghana remains very low at 34%, especially in children, though ART coverage for children had increased from 22% since 2014 [5,6] to 26% (8545 children) in 2015 and is estimated to reach 85% of all children and adolescents according to the recent data from National Paediatric Acceleration Plan for HIV 2016–2020 [5].

An estimated 350,000 HIV children were infected through mother-to-child HIV transmissions at birth (MTCT) across many low- and middle-income countries [6] before Prevention of Mother to Child Transmission of HIV (PMTCT) services were introduced. A scale up in PMTCT activities has been implemented in Ghana since 2009.

In 2008, Ghana in particular witnessed a high prevalence of 2.9 % among women attending antenatal clinics with 3700 children newly infected with HIV compared to the national prevalence of 1.7 % that same year [6]. PMTCT has led to a decline in the number of children born who are HIV infected. Additionally, early ART initiation has led to the improved survival of HIV-infected children, notwithstanding new challenges have emerged as children grow into adolescence.

Many children grow into adolescents without knowledge of their HIV infection. This situation endangers many of these adolescents and their potential partners as it promotes physiological distress among those who might have heard of the danger part of the infection in school [7]. Increased risk behaviour such as medication non-adherence, substance use and sexual risk taking have been associated with adolescent HIV infection for status naïve children [7,8]. Secrecy surrounding HIV treatment coupled with limited control over the living environment are significant barriers to adherence.

Disclosure to children remains critical for addressing drug adherence and pre-knowledge of HIV transmission risk for adolescent on first sexual initiation. The goal of paediatric disclosure is for children to know their own HIV status [9]. Many caregivers fear disclosing the status of positive children to the children because of the anticipated distress that may come along with it for both the child and the caregiver. Child HIV status disclosure is complex and brings about hesitancy and ethical dilemmas taking into consideration the socio-cultural and stigma related issues and secrecy surrounding HIV infection [10]. As a result, caregivers have a dilemma whether to disclose or not to to a child the child's own HIV/AIDS status, principally due to their inability to trade-off between the benefit and challenges that comes with paediatric disclosure considered to contribute to increasing child survival [11,12]. Disclosure offers a psychological boost, facilitates better coping strategies for the child and gives a protection mechanism for potentially early sexual initiation and risky sexual behaviour [11,13].

According to the American Academy for Paediatrics, disclosure of child HIV status ought to be individualized. This should consider all issues surrounding the child's cognitive ability, developmental stage, HIV clinical status and social circumstances after adequate counselling of parents and caregivers of HIV-infected children by a health professional about disclosure to the child that their infection has occurred [14].

According to WHO, children of school age should be told of their HIV status; and this should be done incrementally. This is to accommodate the age and child development specific needs of the child. Children cognitive skills and emotional maturity have implications for a full disclosure [15]. Age of child, perceived cause of HIV, child's inability to keep diagnosis to self, the stigma attached to HIV and fear of physiological harm has been noted to prevent caregivers and, in some instances, health care providers from disclosing HIV status to infected children and adolescents [16,17].

Theoretically, the phenomenological approach anchors the study. Phenomenology is considered as a reflective analysis of life-world experiences and situations [18]. The justification for situating this study within this theoretical context is because, the perspective helps chart an understanding of and meanings to human experiences [19] and/or explore concepts from new and fresh perspectives [20,21].

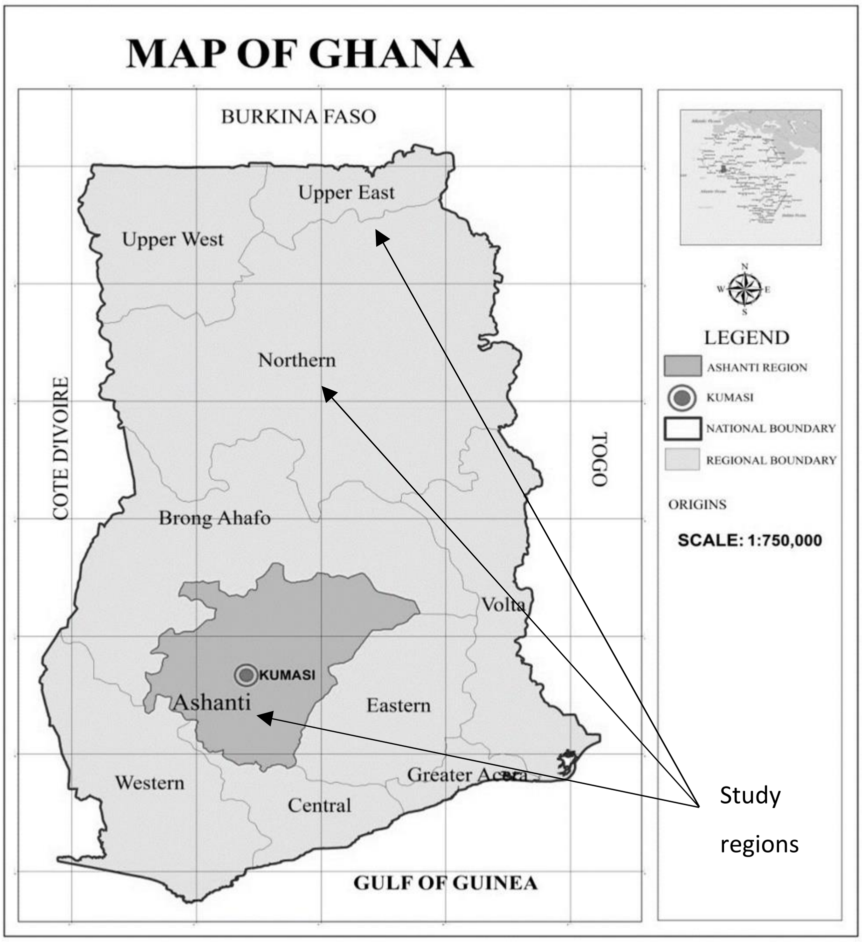
The nature of this study is better be explained by the phenomenological theoretical position. It is anticipated that it will allow the researchers gain insights into social phenomenon of living with HIV and AIDS post disclosure and reveal the "essence of things" in real world.

In Ghana, guidelines on child/adolescent chronic disease disclosure remains sketchy and almost non-available despite the continued physiological distress that confronts children and adolescent living with HIV. There is inadequate information about experience and challenges adolescent encounter prior and post disclosure. This study explores the lived account and narratives of HIV disclosed children and adolescents from diverse backgrounds, cultures and context and geographically distinct locations in the Northern and Southern Ghana. The findings of this study contributes both to theory and practice of post disclosure experience of children moving beyond caregiver account to lived experiential account by infected children.

2. Materials and Methods

2.1. Study Setting

The study was conducted in three regions in Ghana. These are the Ashanti, Northern and Upper East regions of the country. By the operational definition of this study, the Ashanti region is considered as the southern part of Ghana whilst the two remaining regions are classified as Northern Ghana. In 2017, the Ghana AIDS Commission reported the regional HIV prevalence, of which the Ashanti region had a share of 3.2%. The HIV prevalence rate recorded for the Upper East region was 1.7%, with the Northern region recording the lowest national prevalence of 0.7% [4]. The regions and the study areas are indicated in Figure 1. The study areas are categorized under each of the regions as both urban and rural.



Upper East Region:
Tongo
Bongo
Bolgatanga
Navrongo

Northern Region:
Tamale (Tamale Teaching Hospital-TTH)
Tamale Central
Walewale
Savelugu_

Ashanti Region:
Kumasi (Suntreso)
Tafo
Offinso
Agogo

Figure 1. Map of the study area.

The sites were the HIV clinics of the Bongo and Tongo district hospitals as rural sites and the War Memorial Municipal Hospital in Navrongo and the Bolgatanga Regional Hospital as urban sites in the Upper East region. In the Northern region, the selected urban sites were the Tamale Teaching Hospital (TTH) and the Tamale Central Hospital. The Walewale district and the Savelugu district hospitals were selected as the rural sites for the Northern region. In the Ashanti region, the urban hospitals selected were the ART units of the Suntreso and Tafo government hospitals whilst the rural sites chosen were the ART units of the St Patrick Hospital (Offinso) and the Presbyterian Hospital at Asante Akyem Agogo.

2.2. Study Design

The study utilized entirely qualitative methods employing in-depth interviews (IDI) to have a comprehensive understanding of the lived experiences of HIV positive disclosed children. Qualitative study primarily focuses on the meanings and hinges on the conceptual level rather than on numbers or statistics [22,23]. Thus the design's focus is more meaning oriented. Using phenomenology [21] as a qualitative research approach, the focus of the study was to understand the meanings and the experiences positive HIV status disclosed children from their own perspective. This ranged from individual to situational experiences through to their coping strategies and personal transformation after their status disclosure. The notion of transition from a state of unknown status to a state of known status constitute, what Prescotte and Hellstén [24] explain as an advancement from the known or familiar to the unknown and the acceptance of new cultural, social, and mental challenges. This reflects the situation of HIV positive children in the study setting.

2.3. Sampling and Participant Recruitment

Recruitment of study participants was carried out by means of purposive sampling methods facilitated by the first author with the assistance of the trained ART unit heads. In total, 30 children and adolescents aged 9–19 were recruited from 12 ART sites from northern and southern Ghana. The 12 ART sites were selected to represent the diversity in the HIV prevalence, understanding and context. The rural and urban sites were representative of the size of the ART units and variation in the number of clients and distance from study site to the regional capital. Pre-meeting arrangements were made by the principal researcher and the facility managers with children who met the eligibility criteria, thus children with known status and caregiver consent in a convenient location.

2.4. Data Collection

Data collection spanned from January 2017 to June 2018. Due to the difficulty in reaching out to the children mostly in their rural communities, participants were often engaged during the clinic visit days when the children came to the ART clinic for their drugs and for general check-up. In centres where drugs were given in advance of three months to accommodate for the financial difficulty of caregivers coming to the facility on weekly or fortnightly, the principal researcher had to wait for three months intervals to be able to reach the children on their clinic days.

A trained focal person supported the conduct of the interviews using structured interview guides. The focal person in each clinic additionally served as a translator for children who could not understand English. The language used was principally English, followed by Asante Twi, with other diverse languages which included Grune, Mampruli and Dagaare. In the northern parts of Ghana (Northern region and Upper East region), the principal investigator spent 10 days on average in each of the eight ART centres. Field notes were taken by the principal investigator with the support of a trained research assistant.

In the Southern part, the materials were translated into the Asante Twi language. In the Northern regions, the translations were made verbally into the local dialects that were unique to each ART site. The interviews were conducted using direct discussions, focusing on local explanations for the causes of HIV, explanations given to the cause of the illness condition prior to disclosure, process of disclosure, post disclosure experience, ART adherence and social support. Stigmatization encounter, community and household level attitudes towards the children were also explored.

2.5. Data Processing, Coding and Analysis

The phenomenological analysis characterized by its intuition and reflective nature and anchored on reading textual narratives intensively and repetitively [20,24]. The interviews were audio-recorded and supported with field notes and later transcribed. Two trained qualitative researchers were engaged to perform an independent transcription which were compared and corrected to guarantee the reliability of the data. This was followed by introspection and an eidetic reduction process [24]. The transcription followed a constructivist approach through the viewing of reality and experience from the perspectives of the children.

This approach according to Creswell and Miller [25] allows for the quality of collected data and accurate reporting of the findings of the study. The constructivist approach was supported with a content analysis. The content analysis followed O'Leary's [25] six steps or procedure for analyzing qualitative data. This included: reading through data; organizing and coding; searching for patterns and interconnections; mapping and building themes; building thematic data; and, drawing conclusions. The raw data was read more than once and in some cases several times by two researchers initially. Agreed upon codes were used to delineate common observations. The common patterns were identified independently by the two researchers. The emerging themes were then searched for by each researcher after which they were all grouped. In building the thematic data, four of the researchers were engaged to examine the theme data built. The conclusion drawing involved a constant revisit to the field notes, identified and matched patterns, replay of the audio recordings and constant feedback from the researchers. The researchers developed the coding scheme to help maximize the breadth and depth of the analysis.

After transcription, there was the adoption of open coding technique. The open coding procedure involved concept identification and categories segmentation of data to smaller units after which they were labelled, and their conceptual properties described. Though this can be done word-by-word, line-by-line, by paragraphs, or by perusing of the entire transcripts, we adopted an eclectic approach by combining different approaches [21].

Emerging new subthemes which were constantly compared with the data. Any inconsistencies in coding identified were resolved by going back to play the audio, re-read the transcripts and checking of records from the field notes. Identical quotes supported the major or sub-themes on the basis of similarities and contrasts. The new themes that emerged were presented as the study findings through interpretative reasoning and narration, whilst constantly linking codes to the sub-themes. The posteriori inductive approach primarily guided the analysis by making inference on the implications the findings have for the phenomenological theory [26–28].

2.6. Quality Control and Data Rigor

The data were collected by trained social scientist/medical sociologist using qualitative phenomenological data collection techniques with the help of language translators in clinics where study participants could not either speak or understand English or Asante Twi (dominant language spoken in Ghana). Field supervisors who supported the data collection were trained persons working within the ART clinics. An additional person recorded the interview, whilst field note-taking continued.

2.7. Ethical Statement

The ethical approval for the study was granted by the Ghana Health Service Ethics Review Committee with ethics approval number GHS-ERC: 05/06/17 and the Ethical Committee of LMU Munich (Project Number 18-018). Parent/caregiver consent was obtained for all study participants. Child assent was also sought. This was led by the principal researcher and the research assistants who sought for study participants willingness and explored how they preferred to be interviewed using the information sheet and consent/assent form.

3. Results

3.1. Participant's Background Information, Current Preoccupation and Living Arrangement

Thirty HIV positive disclosed children aged between 9 and 19 were enrolled in the study: 17 females (57%) and 13 (43%) males. The average age of the children and adolescents was 14 years. Many children [13] mainly lived with their mothers. Four of the children stayed exclusively with their grandparents and the remaining lived with their siblings and distant relatives. Five children did not have their biological mothers, whilst eight had both parents' dead, with three having their father demised.

Across the geographical belts, thus both northern, southern, rural and urban, there was no child who reported of currently staying with a father. Table 1 presents an overview of the characteristics of study participants in terms of site or recruitment, urban rural dwelling and the region where child lives.

Table 1. Child age, geographical setting and region.

No	Region	Urban/Rural	Age (yrs)	Village/Town	ART Site Name	Northern/Southern Ghana
1	Upper East	Rural	11	Fiya	Tongo/	Northern Ghana
2	Upper East	Urban	11	Bolga town	Bolgatanga RH	Northern Ghana
3.	Upper East	Urban	12	Navrongo	Navrongo WMH	Northern Ghana
4.	Upper East	Urban	13	Zuale	Bolgatanga RH	Northern Ghana
5	Upper East	Urban	13	Gambiago	Bolgatanga RH	Northern Ghana
6	Upper East	Rural	14	Sawla	Bongo	Northern Ghana
7	Upper East	Rural	14	Namong Awale	Bongo	Northern Ghana
8	Upper East	Urban	16	Fiya	Tongo	Northern Ghana
9	Upper East	Rural	18	Gamborige	Bongo	Northern Ghana
10	Northern	Rural	10	Savelugu	Walewale	Northern Ghana
11	Northern	Urban	11	Kanvin	Tamale TTH	Northern Ghana
12	Northern	Urban	11	Kanvin	Tamale TTH	Northern Ghana
13	Northern	Rural	11	Walewale	Walewale	Northern Ghana
14	Northern	Urban	12	Central	Tml Central	Northern Ghana
15	Northern	Rural	13	Savelugu	Savelugu	Northern Ghana
16	Northern	Urban	13	Central	Tml Central	Northern Ghana
17	Ashanti	Rural	9	Kyekyebiase	Agogo	Southern Ghana
18	Ashanti	Urban	12	Suntreso	Suntreso	Southern Ghana
19	Ashanti	Urban	13	Bantama	Suntreso	Southern Ghana
20	Ashanti	Rural	14	Agogo free Town	Agogo	Southern Ghana
21	Ashanti	Rural	14	Asaante Akyem Adomfe	Agogo	Southern Ghana
22	Ashanti	Urban	15	Atimatim	Tafo	Southern Ghana
23	Ashanti	Urban	15	Breman Nkontwoma	Tafo	Southern Ghana
24	Ashanti	Urban	16	Pankrono	Tafo	Southern Ghana
25	Ashanti	Rural	16	Asante Akyem	Agogo	Southern Ghana
26	Ashanti	Urban	17	Tafo Medoma	Tafo	Southern Ghana
27	Ashanti	Rural	17	Konongo Odumase	Agogo	Southern Ghana
28	Ashanti	Urban	17	Fawoade	Tafo	Southern Ghana
29	Ashanti	Rural	18	Offinso	Offinso	Southern Ghana
30	Ashanti	Rural	18	Konongo Zongo	Agogo	Southern Ghana

All the children were preoccupied mainly with two domains. Either children or adolescents were currently in school (25/30) or were engaged in apprenticeship or offering support to their parents/caregivers owning shops and small businesses. One adolescent was enrolled in tertiary education, two in secondary schools with the remaining currently enrolled in basic education (junior high school and primary school).

Field and participant observations of the children and adolescents show most of the children to be physically lean and looking impoverished. Generally, among those in school, majority of them were far late in their educational grade. When we asked the children about their classes matching it against their age (average age of beginning basic school being 6 years in Ghana), the following responses were offered:

> *" ... I am 14 years ... I live with my mother and siblings ... I am in school and in class 4".* (Female, 14 years, Agogo, Southern Ghana)

> *"I am 16 years; from [ ] ... I am in school; and in class 4; will be progressing to class 5".* (Female, 16 years, Agogo, Southern Ghana)

Similar observations were made among participants who were in the junior high school level:

> *" ... I am 17 years ... I am in school, in junior High School Year 3".* (Female, 17 years, Tafo, Southern Ghana)

Few of the children were in the class which corresponded to their age.

3.2. Study Emerging Themes

Central to the themes that emerged were: (i) Pre-disclosure knowledge on HIV and AIDS, (ii) the disclosure approach and process; (iii) earliness or lateness of disclosure nested in preferred ideal age of disclosure; (iv) reaction and response to disclosure news; (vi) self- disclosure of status to peers; (vii) medication intake and adherence and (viii) coping with HIV and AIDS. The themes are displayed in Table 2.

Table 2. Emerged themes and related quotes.

Theme	Sub Theme	Quotes
Pre-disclosure knowledge on HIV and AIDS	Knowing how children became infected with HIV and AIDS	*-Male, 13 years from Gambiago:" I don't know anything about it"* *-Female, 16 years from Agogo: " ... HIV/AIDS is a disease which manifests in the blood; and once there is a blood contact between an infected and non-infected person, the non-infected person will be infected with the virus"* *- Male, 16 years from Tafo:" HIV/AIDS is a disease which manifests in the blood; and once there is a blood contact between an infected and non-infected person, the non-infected person will be infected with the virus"* *-Female, 13 years from Bolgatanga:" I have heard about it but no one has explained to me in details"* *-Female, 15 years from Nkwontwoma:" ... yea, there is difference, HIV/AIDS ... HIV is not very dangerous but AIDS is very dangerous ... Yes, HIV is a virus ... Yes, I know my status, ok, I will say HIV is a........it looks like someone who is having a malaria parasite and went for medicine to reduce the level of malaria.......but the AIDS when you get it, it's the disease"*

Table 2. *Cont.*

Theme	Sub Theme	Quotes
The disclosure approach and process		*-Male, 18 years from Tamale:" I had 'kooko' and came to the hospital. Upon diagnosis by the Doctor, he disclosed to me about my HIV status. He asked me whether I am aware and I said; no. I have not been informed by anyone … When I was young, I didn't know the reason for coming for the drugs always. Later I read about the drugs and realized that I have HIV. Again, my mother confirmed to it and some of the nurses later disclosed to me. I got ill and was admitted so was later told"* *-Male, 18 years from Offinso: "When I got ill and was admitted then my parents were also diagnosed"* *- Male, 13 years from Bolgatanga: "I was informed by a nurse"* *-Female 14 years from Agogo: "My grandmother disclosed to me at home. I was not happy about it at all. I came to seek medical attention and never expected to be tested for HIV/AIDS. So, when I was told about it, I could not believe it. It was later that I came for a lab test and it was confirmed"*
Earliness or lateness of disclosure nested in preferred ideal age of disclosure		*-Male, 18 years from Tamale: "When I was 17 that they informed me, … yes, what they did was paining me, getting old and telling me about it, … oh am okay with that"* *-Female, 16 years from Agogo: "They waited for me to take the drugs for some time before disclosing it to me … I was pleased with the process of disclosure"* *-Female, 16 years from Tongo: " … Three years … I was informed too early"* *-Male, 17 years from Sangnerirukuku:" … months, my uncle sent me to the hospital … felt that the doctor has prescribed him the medicines so that's all. all I know that it has been given to me by doctors, so I think that's the right thing to do so they know what they are doing … Anytime I ask they tell me those things they always tell me, that I have something in my stomach"*
Reaction and response to disclosure news		*- Female, 16 years from Agogo: "I felt sick and when I was sent to the hospital, it came out that I am HIV/AIDs positive … The doctor first informed my mother and she cried. When I asked her why? she failed to respond to me. Then a nurse called me and asked me whether I have had an intimacy with someone before and I said 'No'. Then she asked my mother whether she has really found out from me concerning having intercourse with someone and she replied 'Yes'. Later, the nurse called me and informed me privately. She told me not to feel sad … I felt sad and I still think about it … My mother should have informed me … I tried several times, but she failed to disclose to me"*
Medication intake and adherence	Coping strategy and food insecurity	*-Male, 15 years from Tafo: "I take every day. Morning and evening … I feel healthy when I take the drugs … sometimes when I travel. I remember I went to Accra and stayed for about 8 months of which I did not take the drugs along"* *-Female, 16 years from Agogo:" I take every day—in the mornings and in the evenings … I know that it will strengthen my immune system and the viruses will be destroyed … Yes. Sometimes, I feel I am taking the drugs too frequently so I pulse in some cases. Again, taking the drug is not a pleasant experience, hence I sometimes take in the morning and skip the evening and vice versa … I feel comfortable taking drugs at home. At the work place, I take the drugs secretly so that people will not know"*

3.3. Pre-Disclosure Knowledge on HIV and AIDS

Despite the relevance of knowledge on HIV and AIDs, many participants demonstrated limited understanding on HIV and AIDS with circumstances forcibly compelling their parents and guardians to disclose HIV status to the young ones at a later stage.

> *"My grandmother informed me after I persistently ask her why I have been taken [this] medicine every time and going to hospital almost every week. At first, she told me that my disease is scary and that if I don't take the medicine, there will be rashes all over my body and I will die prematurely. Then I ask her the name of the disease. She calls me privately in her room and then disclose to me".* (Female, 14 years, Agogo, Southern Ghana)

There was however, a disparity in in low and high knowledge of HIV and disclosure related information between participants from southern and the northern parts of the country respectively. The observation is illustrated in Table 3.

Table 3. Comparing HIV and AIDS knowledge levels of study participants.

Interview Issue	Southern Ghana	Northern Ghana
What do you know about the HIV/AIDs disease?	*Child 1: "HIV/AIDs is a disease which manifests in the blood; and once there is a blood contact between an infected and non-infected person, the non-infected person will be infected with the virus"* *Child 3: "HIV/AIDs is a disease which affects the immune system"* *Child 4: "It is a disease that is very disturbing"* *Child 5: "HIV/AIDs is a disease which manifests in the blood; and once there is a blood contact between an infected and non-infected person, the non-infected person will be infected with the virus"* *Child 9: "I have heard about it before . . . I know difference . . . The difference is that if the HIV comes on you, you can have very quick treatment for it but the AIDS can easily kill you early"* *Child 10: "yea, there is difference, HIV/AIDS, . . . HIV is not very dangerous, but AIDS is very dangerous"*	*Child 6: "I have heard HIV lives in the body"* *Child 7: "I can't tell"* *Child 8: " . . . they say it is a deadly disease but for me I don't see it as a deadly disease"* *Child 11: "I know it's a disease"* *Child 13: "I have heard about it but no one has explained to me in details"* *Child 14: "I don't know anything about it"*

The sub-theme of how children contracted HIV emerged prominently. Two dominant narratives that featured in their attempts to provide response to how they became HIV positive were either "*I do not know*" or an incidental explanation that concerned the response given to them by their caregivers in their attempt to find answers.

> " . . . *I don't know*". (Child 1, Child 3, Child 4, Child 7, Child 8, and Child 14)

Only one participant knew about how she got infected with HIV:

> " . . . *actually from my step mum* [was narrated to child by a step mother], *they say it was through my mum and my dad*". (Female, 18 years, Tamale, Northern Ghana)

Most of the children indicated circumstances around their illness as the time around which they got to know about their HIV infection. Giving incidental account of participant's recollection of their first conscious encounter with HIV and AIDS related illness some shared.

> *" . . . During the time I was in school, I felt sick and was rushed to the hospital. Then the doctor discovered it, I was about 12 years by that time"*. (Female, 18 years, Tamale, Northern Ghana)

> *"I can't remember. But I had a boil and came to hospital. It was then that it was discovered by the doctor"*. (Male, 13 years, Tamale, Northern Ghana)

Some of the children were knowledgeable on the potential source of HIV infection despite being unable to isolate which among the sources could be linked with their own infection. When asked, few of the participants were accurate with their responses:

> *" . . . by having unprotected sex and secondary taking used blade, and transfer from parent to children"*. (Female, 16 years, Tafo, Southern Ghana)

3.4. Disclosure Approach and Process

Disclosure of HIV status to the participants was often postponed to later years, deferred, lied to about, replaced with excuses or partially performed and at best without any child preparation. In most instances, disclosure became possible when the illness aggravated and there was the urgent need to tell the child. With the exception of few participants whose disclosure had taken place at very young age specific to their development, majority of the children had unprepared disclosure and felt very disappointed. The participants explained how their status was disclosed to them:

> *"The health official disclosed to my grandmother. My grandmother instructed me not to take oily foods, rice and corn related foods. I asked her why . . . Then she replied that it is because of my sickness. I asked what sickness? . . . But she refused to tell me. She then told me that if I should use razor blade and, as a result, there is a cut on me. Then if someone else uses the blade and gets a cut, the person will also be affected with my disease. So, I started thinking about it since I was taught by my science teacher that the use of infected blades or needles could cause HIV/AIDS. Then I realized I am HIV positive, but my grandmother felt adamant and uncomfortable to disclose to me"*. (Female, 17 years, Tafo, Southern Ghana)

There were few instances where children appeared to be prepared for the disclosure. In such few instances, disclosure occurred in private between caregivers and children. Some children expressed satisfaction about the approach and privacy of the disclosure amidst minor reservations about the timing (lag between diagnosis and disclosure), while others remained less worried with the time (age) of disclosure:

> *"My mother disclosed to me privately, in the room. I was informed too late. I think I should have been informed earlier than the time I was actually informed"*. (Female, 14 years, Bongo, Northern Ghana)

> *"When my father died, my mother came to take me away from my father's home, my mother sent me to do the lab at the hospital and I was told about 8 years ago* [disclosure took place when the child was 7] *It was the doctor who told me at the hospital. I did not react in any way because I was young"*. (Male, 15 years, Tafo, Southern Ghana)

3.5. Earliness or Lateness of Disclosure Nested in Preferred Ideal Age of Disclosure

In the considered opinion of the children, status disclosure to them was late. The reported mean age of disclosure among all the 30 children was 13 years. Some of the children had grown into later years of adolescence before being told about their HIV positive status. Among some participants aged

17 and 18, they had only been told of their status a year ago prior to the conduct of the study. Many of them showed resentment and disappointment with the age at which status disclosure took place. This resonated with participants across Southern and Northern Ghana and urban and rural sites:

> *"I think it should be above 3 years now . . . I feel I should have been informed earlier than the time I was informed"*. (Male, 17 year, Agogo, Southern Ghana)

> *"When I was 17 that they informed me*". (Male, 18 years old male, Tamale, Northern Ghana)

> *"I was informed in 2012; which is 5 years ago . . . was too late. My mother should have informed me. I tried several times, but she failed to disclose to me"*. (Female, 16 years, Tafo, Southern Ghana)

> *"I am 17 years; from Tafo Medoma. My parents are dead. I know is a dreadful disease, I can't remember. But I had boil and came to hospital. It was then that it was discovered by the Doctor . . . Not long ago. Not even more than a month"*. (Female, 17 years, Tafo, Southern Ghana)

Notwithstanding, four of the children whose disclosure occurred particularly at ages 9,7,8, and 6 were comfortable with the timing of disclosure since they had their status disclosed to them at relatively younger age despite sharing varied opinion on what early age meant to each participant:

> *"When I was in class 2, I was six years . . . It was normal, if they did not tell me in the earlier stage maybe I would not have been alive by now, my aunty knows about it, my aunt's first daughter, they treat me well"*. (Female, 16 year, Tafo, Southern Ghana)

> *"I can't recall but it will be about 2-3 years now . . . I said to her its ok . . . Yeah, the timing was ok"*. (Female,12 years, Navrongo, Northern Ghana)

Participants were of the view that disclosure needed to be carried out privately. Though children the ideal age of disclosure were non-uniform mostly ranging between 8-12 years, participants laid significant emphasis on four principal requirements: (1) early disclosure, (2) serene environment-social and physical for disclosure, (3) parent/caregiver frankness with information on child illness, (4) holistic preparedness of child prior to disclosure.

> *" . . . I think disclosure should be made by examining the person's psychological state and should not be done unexpectedly like what they did to me"*. (Female, 17 years, Tafo, Southern Ghana)

> *"Privately like what my mother did; but the information should come early after status is known"*. (Male, 14 years, Agogo, Southern Ghana)

> *"I think disclosure should be made immediately it is known but the patient should be made aware that HIV test is to be done. When the person gives the approval, then it can be tested and disclose to him or her"*. (Female, 17 years, Agogo, Southern Ghana)

> *" . . . I think disclosure should be made by first encouraging the person, then you tell the person about the importance of the medication. After that, you can gradually unfold the information to the person. Whilst you tell the person, you still encourage the person that all is not lost"*. (Male, 18 years, Offinso, Southern Ghana)

Figure 2 presents an overview of the pre-post disclosure context of children and adolescents studied.

Figure 2. Child/adolescent disclosure pathway context.

3.6. Immediate Reaction and Response to Disclosure News

Among nearly all the participants, sadness and disappointment greeted them with the news of hearing being HIV positive. In many instances, participants further explained that, the context under which they became knowledgeable of their illness condition worsened their reaction. Illness severity appeared to be the trigger to their being told about their HIV status.

> *"It pained me so I wept that very day . . . . . . I felt unhappy"*. (Female, 14 years Bongo, Northern Ghana)

> *" . . . I felt very sorrowful. It really pained me"*. (Female, 17 years, Agogo, Southern Ghana)

> *" . . . yes, what they did was paining me, getting old and telling me about it, . . . oh am okay with that"*. (Female, 18 years, Tamale, Northern Ghana)

Those who could not make any visible reaction, explained that they had been suspicious of what their illness could be:

> *"So I read the label on the box and realise that it was HIV"*. (Female, 14 years, Bongo, Northern Ghana)

A common theme that emerged was the silence of the children /adolescents to inquire from their care givers/ mothers how they became infected. In what appeared quite surprising, none of the children questioned their care givers but for two relatively old adolescents (16 and 18 years) whose disclosure by health professionals appeared to them extremely unanticipated and unprepared. One reported:

> *"During the time I was in school, I felt sick and was rushed to the hospital. Then the Doctor discovered it, I was about 12 years by that time . . . I had 'kooko(boils)' and came to the hospital. Upon diagnosis by the Doctor, he disclosed to me about my HIV status. He asked me whether I am aware and I said no.*

> *I have not been informed by anyone . . . It really pained me. My mother then told me they shouldn't have informed me at that very time. It should have been later. Then later, my mother approach me privately and explained everything to me concerning how I became HIV positive. She says she doesn't know, whether it was a spiritually purchased illness for me or a blade that I might have used . . . Not at all. The doctor unexpectedly disclosed to me. In fact, I did not believe it but later I realized it was true. The disclosure was too instantaneous"*. (Female, 18 years, Agogo, Southern Ghana)

Participants further explained that they had not self-disclose by concealing their status from their peers:

> *"No, I don't even have friends; I have somehow restricted myself from people around . . . and its something my mother has warned me about it It is sensitive situation. I have boyfriend but have never disclosed to him. My mother told me if I tell him, the relationship will break and I also don't want to lose him. I don't want to tell him because he will leave me"*. (Female, 18 years, Agogo, Southern Ghana)

3.7. Medication Intake, Adherence and Coping Strategy

HIV medication intake among participants was often scheduled daily between morning and evening dose. Nearly all children were affirmative in being adherent to the taking of their medications with few defaulting. During circumstances of missing medication resulting from forgetfulness or busy work schedule, children often came to take the medication or called for it to be brought to them wherever they were to be taken. Nearly all the children took their medication in the home with few taking it at school or workplace. Few of the children shared their experience of abdominal pains associated with the HIV medication intake. The strongest motivation for the continuous taking of the medication was the desire to be healthy:

> *"I take every day—in the mornings and in the evenings it is my grandmother who encourages and ensures that I take the drugs well, sometimes I forget. I feel comfortable taking drugs at home since people do not say anything bad about the drug............. It is the abdominal pains"*. (Female, 16 years, Tongo, Northern Ghana)

> *" . . . one in morning and evening...... it's my life, and I have to depend on it, I just realize it's a duty There was a day I forgot that I did not take, so they had to bring it to me, when I forgot, they had to bring it to me at work...... when I forget, I quickly go and take but now I take it 7:00 in the morning . . . when you take the drugs, like, I don't know how to put it, the drug is strong . . . No....... I don't feel anything. I don't take the drugs at the worksite.......no worse experience but when I don't take then I have some bad experience"* (Female, 18 years, Agogo, Southern Ghana)

The continuous consumption of the HIV medications does not come as a pleasant experience to the children at all times. In some instances, children questioned their own action of daily taking the HIV medication. Other children contend with the bitter taste of the drug and vomit alongside a situation that has caused some to change their initially prescribed medication:

> *"I take morning two . . . evening two. At first, I used to vomit. That was the first drugs....... Yes. I used to vomit when I take that drug. But this new one, I am feeling good with it: I take every day—in the mornings and in the evenings....... I know that it will strengthen my immune system and the viruses will be destroyed............ Yes. Sometimes, I feel I am taking the drugs too frequently, so I pulse in some cases. Again, taking the drug is not a pleasant experience, at the work place, I take the drugs secretly so that people will not know"*. (Female 18 years, Agogo, Southern Ghana)

The taking of the medication demanded adequate food intake which was mentioned as a challenge among many amidst financial difficulties.

> *"Sometimes, I am forced to skip my weekly visits to the hospital due to limited funds . . . Sometimes, I don't eat in the afternoon due to financial problems. I have financial problem, the food we eat sometimes faces shortages; so I eat in the morning and in the evenings only. I eat twice a day. I wish that government will give positive HIV and AIDS children money to go to school. I have limited finance which affects my eating, transport and general living condition"*. (Female, 18 years, Tamale, Northern Ghana)

4. Discussion

This study explored the HIV and AIDS disclosure and post-disclosure experiences among children and adolescents from Northern and Southern Ghana using phenomenological lenses. We critically examined the disclosure experiences, reactions and response to the disclosure and identified the context appropriate for disclosing HIV and AIDS based on the child lived experiences. This study to the best of our knowledge is the first qualitative attempt at characterizing children and adolescent post HIV and AIDS disclosure experiences in Ghana. Previous studies reporting on whether disclosure of HIV status to infected child was early or late elicited the perspectives of caregivers and not children [29,30]. Reports from caregivers on the age of disclosure have ranged from 9.3 years in South Africa, 10.39 years and between 6-10 years in Ghana [29–31].

The mean age of disclosure as reported by the children in this study was 13 years. Notwithstanding, the children expressed dissatisfaction with the timing of disclosure and opined that the timing for disclosure was late. Some had been informed only a few months before reaching their eighteenth birthday, despite the few who got to know their status as early as six years. An earlier study in Ghana by Gyamfi et al. reports that the preferred ideal age for status disclosure to infected children according to the care givers was 15 years. This was however quantitative and an elicited opinion of caregivers.

Our study reports of age 10 as the ideal age children and adolescents preferred to be disclosed their status with the range being 8–12 years. Certainly, differences exist in preferred mean age of disclosure (10 years vs 15 years) between caregivers and children themselves, though in practice care givers disclosed to children at age 13 [17]. This appears to be midway age ideal for caregivers though many of the children did not demonstrate acceptance of the age therefore rating the timing of their disclosure as late. Caregiver/child crush of interest and preference appears to be emerging. This calls for the creation of friendly and open avenues for parent/caregiver–child dialogue. The topic of disclosure remaining silent until time is becoming imminent and inevitable.

Similar to the sentiments expressed by other adolescents in different African countries like South Africa, Zambia and Zimbabwe, Ghanaian children and adolescents showed initial distress, reacted shockingly when disclosure was initiated, yet the children desired to be told and offered the correct information about their illness [32,33]. The initial shocks were accommodated by the children with the passage of time and development of resilience. There is the need for the development of a structured pre- and post-disclosure care and support intervention for adolescents and children with their primary care givers to facilitate the acceptance of their new status. Further investigation may be needed to explore the unique child characteristics that shaped their resolute disposition to the news of their status disclosure [28,33,34].

Our study found that in majority of the disclosure encounter children were not prepared, and not ready as disclosure happened instantaneously. In Zambia, similar finding has been confirmed with only 6% of children and adolescents being informed by both parents of their HIV status. The possible reason for this occurrence may be due to parents/caregiver weak-preparedness and unskilled predisposition to disclose amidst the fear of blame and stigma towards the children and child self-disclosure to peers [33–36]. This often prolonged the years or time to disclosure. This heightened fear is however allayed as evidence from the Cluver et al. study has shown how medication-adherent children with early status disclosure of less than age 12 become [29].

Moreover, the findings in this study emerge as a respite to caregivers for heightened fear since an estimated 97% (29/30) of the children and adolescents had never self-disclosed their HIV status to their peers or any other person outside the confines of their nucleus family nor did they report of felt or community level stigma [36].

The difference in disclosure approach could be attributable to the non-availability of a paediatric disclosure guideline in Ghana compared to South Africa. Caregivers have had to trade off a balance between having to lie to children, non-disclosure, incremental disclosure and full disclosure. Our findings are consistent with the picturesque narrative on paediatric HIV disclosure landscape across Sub-Saharan Africa where evidence from 180 sites in six global regions from 31 countries, only a third of the sites to have existing standardized protocol for paediatric disclosure [37]. In this study, early disclosure was to be interlaced with serene social and physical environment, frankness with their illness condition and holistic preparation of the children towards receiving disclosure news.

Consistent with findings in Kenya, Zambia and South Africa, some children blamed their caregivers except that the reasons for the parental blame by children differed from the present study compared to earlier report [28]. In the current study, children blamed their parents/caregivers by reason of their inability to have disclosed their status to them earlier and not by reason of parent/caregiver transmitting the virus to the children as reported in previous study. None of the children studied reported being bold enough to ask the source of their HIV infection. From the study findings, caregivers gently and smartly refused to tell the children how they got infected with HIV or children were not interested in knowing.

One in three of the children lived with their mothers as primary caregivers with the remaining staying exclusively with their grandparents or distant relatives. This observation is consistent with other studies in Ghana where the family structure of Ghana has contributed to relatively huge numbers of children without parental care which is estimated at 4.7% of Ghana's population and 10.4% of the entire children and adolescent population in Ghana [38–41].

Despite the limitedness of social support for the children in the study, it served to moderate the effect of the illness on child health. This finding has received similar expression in previous cross-sectional studies in East Africa and Latin America [35,42,43] and meta-analysis studies in Latin America and Asia [44,45], where family social support had improved health outcomes for children living with HIV and AIDS. On the contrary, the study findings are inconsistent with Doku et al. from Lower Manya Krobo District of Ghana where a weakened traditional system contributes to lower social support by families to HIV positive children in earlier study [46].

None of the school children reported disruptions in school attendance due to financial difficulties as compared to the recent findings from Cambodia et al [42], though peer support group was absent among the Ghanaian children despite its availability among positive children elsewhere. Generally, the children had delayed in academic progression. Children from the northern part of the country had delayed more compared to those southern Ghana. This may reflect a national situation where school enrolment among children in the northern part are less compared to that in the southern part of Ghana. This finding is in tandem with the overall general educational outlook in Ghana where less than 50% of the population in the three northern regions aged 11 years and older are literate compared to a minimum of at least 69% in other regions with the southern Ghana inclusive [47].

Our findings offer an additional rationale for improving the knowledge of the children and adolescents living with HIV and AIDS. Knowledge on HIV infection and mode of transmission among the children and adolescents was limited and varied between high and low for children from Southern and northern Ghana respectively. High knowledge on HIV and AIDS have been reported by previous studies in Ghana [48], whilst studies by Enimil et al. have established limited understanding of and knowledge on HIV transmission modes among 13–22 aged adolescents in urban Ghana [49]. The limited knowledge of children on HIV and AIDS might partly explain why caregivers remained reluctant in disclosing their status to children. Similarly, it may explain why in many instances, disclosure occurred at the hospital and by health care providers [17], contrary to the evidence from

Zambia, Kenya and Zimbabwe, where disclosure took place in the either at home or hospital with a preference for at home by parents [50]. This did not vary among children living in rural or urban locations, despite the difference in prevalence and variations in the odds of infection for urban (2.3%) and rural (7%).

Our study results argue that efforts towards managing the pre- and post-disclosure interface as well as the transition from childhood to adolescence—a phase of high vulnerability, will require designing adolescent-focused interventions with multiple layers of the sociological context that is need based with comprehensive social protection packages. The call for these interventions is timely and consistent with earlier study recommendations by Enimil et al. with our findings making a case for the inclusion of the phenomenological context of the children in the intervention design [49].

Limitations

This study is limited by the possibility of social desirability biases. It remains unclear whether children and adolescents offered explanations that reflect the truth about their prior and post disclosure experience or gave responses they considered as what interviewers wanted to hear though this was limited by asking questions that filtered the responses and elicited consistency. The eclectic phenomenological approach used in this study aimed at presenting a lived experiential account of what participants considered as the truth on disclosure narratives worth exploring. As a result, the authors did not attempt at determining whether participant's world view and experiences presented were the 'truth' as the responses given by participants were considered their version of the truth on their disclosure experience. Consistent with qualitative studies, our findings are limited by being context specific for which interpretation may have to be done with some care. Though several attempts were made to ensure accurate and pure bracketing—an essential requirement essential when using a phenomenological design study—the adoption of research translators, different study sites selection with unique cultural context, may not have been able to ensure a full compliance with pure bracketing.

5. Conclusions

Our study, the first ever on post-disclosure experiences among children and adolescents across Southern and Northern Ghana, demonstrates HIV and AIDS disclosure in Ghana has often occurred with children being unprepared and at very late period in the child's development. The findings of this study provide in-depth and nuanced understanding of unexplored area of child and adolescent HIV and AIDS post-disclosure experiences from the child's own account. Furthermore, it provides that despite the emotional, remorseful and pain that are immediately associated with HIV and AIDS disclosure among children and adolescents, they preferred to be told their HIV and AIDS status at very early stage and preferably between age 8 to 12.

The near absence of evidence of child self-stigma, non- self-status-disclosure to peers and improved medication adherence comes as a relief to parents and primary caregivers who are often in a dilemma and cite these factors as predominant reasons for delayed status disclosure to infected children. The findings of this study highlight the varying limitedness in child adolescent knowledge on their own illness and disease aetiology across southern and Northern Ghana. The findings on the near absence of social protection packages and support groups compared to the adult population [51] coupled with financial difficulties have implications for child and adolescence engaging in risky sexual behaviour and transactional sex. Effective care for post-disclosed children and adolescents will require that care givers of HIV and AIDS infected children be provided with social, financial and income generating resources coupled with programs that aim at strengthening the resilience of the children to improve their wellbeing post-disclosure.

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References

1. UNAIDS. Fact Sheet—Latest Global and Regional Statistics on the Status of the AIDS Epidemic. Available online: http://www.unaids.org/en/resources/documents/2018/UNAIDS_FactSheet (accessed on 17 February 2019).
2. Kharsany, A.B.M.; Karim, Q.A. HIV infection and AIDS in Sub-Saharan Africa: Current status, challenges and opportunities. *Open AIDS J.* **2016**, *10*, 34. [CrossRef] [PubMed]
3. WHO. *HIV/AIDS*; WHO: Geneva, Switzerland, 2017; p. 1.
4. Ghana AIDS Commission. Summary of the 2016 HIV Sentinel Survey Report. 2016. Available online: http://ghanaids.gov.gh/gac1/aids_info.php (accessed on 18 February 2019).
5. Unicef, National Aids Control Programe GHS. *National Paediatric Acceleration Plan for HIV 2016–2020*; National Aids Control Programe GHS: Accra, Ghana, 2016.
6. Dako-Gyeke, P.; Dornoo, B.; Addo, S.A.; Atuahene, M.; Addo, N.A.; Yawson, A.E. Towards elimination of mother-to-child transmission of HIV in Ghana: An analysis of national programme data. *Int. J. Equity Health* **2016**, *15*, 5. [CrossRef] [PubMed]
7. *Progress Report: Global HIV/AIDS Response: Epidemic Update and Health Sector Progress towards Universal Access*; World Health Organization: Geneva, Switzerland, 2011.
8. Mutumba, M.; Bauermeister, J.A.; Harper, G.W.; Musiime, V.; Lepkowski, J.; Resnicow, K.; Snow, R.C. Psychological distress among Ugandan adolescents living with HIV: Examining stressors and the buffering role of general and religious coping strategies. *Glob. Public Health* **2017**, *12*, 1479–1491. [CrossRef]
9. Wiener, L.; Mellins, C.A.; Marhefka, S.; Battles, H.B. Disclosure of an HIV diagnosis to children: History, current research, and future directions. *J. Dev. Behav. Pediatr. JDBP* **2007**, *28*, 155. [CrossRef] [PubMed]
10. Watermeyer, J. 'Are we allowed to disclose?': A healthcare team's experiences of talking with children and adolescents about their HIV status. *Health Expect* **2015**, *18*, 590–600. [CrossRef] [PubMed]
11. Kabogo, J.; Muniu, E.; Wamunyokoli, F.; Musoke, R.; Songok, E. Evidence of reduced treatment adherence among HIV infected paediatric and adolescent populations in Nairobi at the onset of the UNAIDS Universal Test and Treat Program. *BMC Res Notes* **2018**, *11*, 134. [CrossRef]
12. Dapaah, J.M. Attitudes and behaviours of health workers and the use of HIV/AIDS health care services. *Nurs. Res. Pract.* **2016**, *2016*, 5172497. [CrossRef] [PubMed]
13. Appiah, S.C.Y.; Badu, E.; Dapaah, J.M.; Harriet, T.; Abubakar, M. Youth Friendliness of Sexual and Reproductive Health Service Delivery and Service Utilization in the Kwadaso Sub-Metro of the Ashanti Region, Ghana. *Int. J. Innov. Appl. Stud.* **2015**, *10*, 716–725.
14. Brown, S.D.; Truog, R.D.; Johnson, J.A.; Ecker, J.L.; American Academy of Pediatrics Committee on Pediatrics AIDS. Disclosure of Illness Status to Children and Adolescents with HIV Infection. *Pediatrics* **1999**, *103*, 164–166.
15. World Health Organization. Guideline on HIV Disclosure Counselling for Children up to 12 years of Age. WHO: Geneva, Switzerland, 2011. Available online: https://www.who.int/hiv/en/ (accessed on 18 February 2019).
16. Paintsil, E.; Renner, L.; Antwi, S.; Dame, J.; Enimil, A.; Ofori-Atta, A.; Alhassan, A.; Ofori, I.P.; Cong, X.; Kyriakides, T.; et al. HIV knowledge, stigma, and illness beliefs among pediatric caregivers in Ghana who have not disclosed their child's HIV status. *AIDS Care* **2015**, *27* (Suppl. 1), 18–27. [CrossRef] [PubMed]
17. Gyamfi, E.; Okyere, P.; Enoch, A.; Appiah-Brempong, E. Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC Int. Health Hum. Rights* **2017**, *17*, 8. [CrossRef] [PubMed]

18. Von Eckartsberg, R. *Life-World Experience: Existential-Phenomenological Research Approaches in Psychology*; University Press of America: Lanham, MD, USA, 1986.
19. Creswell, J.W. *Qualitative Inquiry and Research Design: Choosing among Five Traditions*; Sage: Thousand Oaks, CA, USA, 1998.
20. Sanders, P. Phenomenology: A new way of viewing organizational research. *Acad. Manag. Rev.* **1982**, *7*, 353–360. [CrossRef]
21. Cohen, M.Z.; Kahn, D.L.; Steeves, R.H. *Hermeneutic Phenomenological Research: A Practical Guide for Nurse Researchers*; Sage Publications: Thousand Oaks, CA, USA, 2000.
22. Davidsen, A.S. Phenomenological Approaches in Psychology and Health Sciences. *Qual. Res. Psychol.* **2013**, *10*, 318–339. [CrossRef] [PubMed]
23. Paley, J. *Phenomenology as Qualitative Research: A Critical Analysis of Meaning Attribution*; Routledge: London, UK, 2016.
24. Moustakas, C. *Phenomenological Research Methods*; Sage: Thousand Oaks, CA, USA, 1994.
25. Creswell, J.W.; Miller, D.L. Determining validity in qualitative inquiry. *Theory Pract.* **2000**, *39*, 124–130. [CrossRef]
26. Angen, M.J. Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qual. Health Res.* **2000**, *10*, 378–395. [CrossRef] [PubMed]
27. Bryman, A. *Social Research Methods*; Oxford University Press: Oxford, UK, 2016.
28. Okawa, S.; Mwanza-Kabaghe, S.; Mwiya, M.; Kikuchi, K.; Jimba, M.; Kankasa, C.; Ishikawa, N. Adolescents' experiences and Their suggestions for hiV serostatus Disclosure in Zambia: A Mixed-Methods study. *Front. Public Health* **2017**, *5*, 326. [CrossRef]
29. Cluver, L.D.; Hodes, R.J.; Toska, E.; Kidia, K.K.; Orkin, F.M.; Sherr, L.; Meinck, F. 'HIV is like a tsotsi. ARVs are your guns': Associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa. *AIDS* **2019**, *29*, S57–S65. [CrossRef]
30. Moodley, K.; Myer, L.; Michaels, D.; Cotton, M. Paediatric HIV disclosure in South Africa-caregivers' perspectives on discussing HIV with infected children. *S. Afr. Med. J.* **2006**, *96*, 201–204.
31. Kallem, S.; Renner, L.; Ghebremichael, M.; Paintsil, E. Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS Behav.* **2011**, *15*, 1121–1127. [CrossRef]
32. Abebe, W.; Teferra, S. Disclosure of diagnosis by parents and caregivers to children infected with HIV: Prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia. *AIDS Care* **2012**, *24*, 1097–1102. [CrossRef]
33. Vaz, L.M.E.; Maman, S.; Eng, E.; Barbarin, O.A.; Tshikandu, T.; Behets, F. Patterns of disclosure of HIV-status to infected children in a sub-Saharan African setting. *J. Dev. Behav. Pediatr. JDBP* **2011**, *32*, 307. [CrossRef] [PubMed]
34. Mburu, G.; Hodgson, I.; Kalibala, S.; Haamujompa, C.; Cataldo, F.; Lowenthal, E.D.; Ross, D. Adolescent HIV disclosure in Zambia: Barriers, facilitators and outcomes. *J. Int. AIDS Soc.* **2014**, *17*, 18866. [CrossRef] [PubMed]
35. Okawa, S.; Yasuoka, J.; Ishikawa, N.; Poudel, K.C.; Ragi, A.; Jimba, M. Perceived social support and the psychological well-being of AIDS orphans in urban Kenya. *AIDS Care* **2011**, *23*, 1177–1185. [CrossRef] [PubMed]
36. Mweemba, M.; Musheke, M.M.; Michelo, C.; Halwiindi, H.; Mweemba, O.; Zulu, J.M. "When am I going to stop taking the drug?" Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia. *BMC Public Health* **2015**, *15*, 1028. [CrossRef] [PubMed]
37. Arrivé, E.; Ayaya, S.; Davies, M.A.; Chimbetete, C.; Edmonds, A.; Lelo, P.; Fong, S.M.; Razali, K.A.; Kouakou, K.; Duda, S.N.; et al. Models of support for disclosure of HIV status to HIV-infected children and adolescents in resource-limited settings. *J. Int. AIDS Soc.* **2018**, *21*, e25157. [CrossRef] [PubMed]
38. UN General Assembly. UN General Assembly-Second Committee-Economic and Financial-List of Draft proposals United Nations. 2016. Available online: http://www.un.org/en/ga/second/67/proposals.shtml (accessed on 18 February 2019).
39. Bettmann, J.E.; Mortensen, J.M.; Akuoko, K.O. Orphanage caregivers' perceptions of children's emotional needs. *Child. Youth Serv. Rev.* **2015**, *49*, 71–79. [CrossRef]

40. Darkwah, E.; Daniel, M.; Asumeng, M. Caregiver perceptions of children in their care and motivations for the care work in children's homes in Ghana: Children of God or children of white men? *Child. Youth Serv. Rev.* **2016**, *66*, 161–169. [CrossRef]
41. UNICEF. The State of the World's Children 2015:Reimagine the Future. Available online: http://sowc2015.unicef.org/ (accessed on 18 February 2019).
42. Toth, G.; Mburu, G.; Tuot, S.; Khol, V.; Ngin, C.; Chhoun, P.; Yi, S. Social-support needs among adolescents living with HIV in transition from pediatric to adult care in Cambodia: Findings from a cross-sectional study. *AIDS Res. Ther.* **2018**, *15*, 8. [CrossRef]
43. Wood, K.; Chase, E.; Aggleton, P. 'Telling the truth is the best thing': Teenage orphans' experiences of parental AIDS-related illness and bereavement in Zimbabwe. *Soc. Sci. Med.* **2006**, *63*, 1923–1933. [CrossRef]
44. Pinquart, M.; Sörensen, S. Correlates of physical health of informal caregivers: A meta-analysis. *J. Gerontol. Ser. B Psychol. Sci. Soc. Sci.* **2007**, *62*, 126–137. [CrossRef]
45. Ke, X.; Liu, C.; Li, N. Social support and Quality of Life: A cross-sectional study on survivors eight months after the 2008 Wenchuan earthquake. *BMC Public Health* **2010**, *10*, 573. [CrossRef] [PubMed]
46. Doku, P.N.; Dotse, J.E.; Mensah, K.A. Perceived social support disparities among children affected by HIV/AIDS in Ghana: A cross-sectional survey. *BMC Public Health* **2015**, *15*, 538. [CrossRef] [PubMed]
47. GSS. *2010 Population and Housing Census: Summary Report of Final Results*; Ghana Statistical Service: Accra, Ghana, 2012.
48. Kenu, E.; Obo-Akwa, A.; Nuamah, G.B.; Brefo, A.; Sam, M.; Lartey, M. Knowledge and disclosure of HIV status among adolescents and young adults attending an adolescent HIV clinic in Accra, Ghana. *BMC Res. Notes* **2014**, *7*, 844. [CrossRef] [PubMed]
49. Enimil, A.; Nugent, N.; Amoah, C.; Norman, B.; Antwi, S.; Ocran, J.; Kwara, A.; Barker, D.H. Quality of life among Ghanaian adolescents living with perinatally acquired HIV: A mixed methods study. *AIDS Care* **2016**, *28*, 460–464. [CrossRef] [PubMed]
50. Aderomilehin, O.; Hanciles-Amu, A.; Ozoya, O.O. Perspectives and practice of HIV disclosure to children and adolescents by health-care providers and caregivers in sub-Saharan Africa: A systematic review. *Front. Public Health* **2016**, *4*, 166. [CrossRef] [PubMed]
51. Laar, A.; Manu, A.; Laar, M.; El-Adas, A.; Amenyah, R.; Atuahene, K.; Quarshie, D.; Adjei, A.A.; Quakyi, I. Coping strategies of HIV-affected households in Ghana. *BMC Public Health* **2015**, *15*, 166. [CrossRef]

8.2 Publication 2

Disclosure of HIV/AIDS status to infected children in Ghana - a north-south comparison of barriers and enablers, *Children and Youth Services Review 122 (2021) 105753*

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Disclosure of HIV/AIDS status to infected children in Ghana – A north-south comparison of barriers and enablers

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ABSTRACT

Disclosure of HIV status to infected children plays critical role in child health and wellbeing. This study identifies and compares child HIV disclosure barriers and facilitators in Upper East, Northern and Ashanti regions of Ghana. Prospective data was collected through a questionnaire on 180 caregivers of HIV-infected children 5–18 years from 12 antiretroviral treatment (ART) centres from May 2017 to November 2018 enrolling 89 (49.5%) males and 91 (50.5%) female children. A bivariate and binary multiple logistic regression analysis was performed to test child and caregiver related variable with disclosure. A total of 42 (23.3%) children with a median age of 12 years had been disclosed to. The median age of 138 undisclosed children was 7 (IQR = 5–11) years. The median age at disclosure was 9.5 (IQR = 6–11) years in contrast to 16.3 years, which was proposed as the intended age of disclosure by caregivers. Approval for child status disclosure to be facilitated by only child's family member differed significantly between caregivers from northern Ghana and southern Ghana (17% vs 83%, $p < 0.03$). In the multivariate binary logistic regression, a child questioning caregiver frequently about continuous medication intake (AOR = 19.0, $p < 0.01$) increased the odds of disclosure. Enablers to disclosure were child age, ART start age and resident region of the care giver. The barriers to disclosure involved limited caregiver knowledge and caregiver notion of non-disclosure as a best interest and child protection decision. Difference in region of residence of the child contributes to enhance or impede child HIV disclosure. This calls for developing appropriate age specific child disclosure-promoting guideline to facilitate disclosure.

1. Introduction

The expanding access to Highly Active Antiretroviral Therapy (HAART) has made promising strides in the prevention and treatment of paediatric HIV and AIDS. In 2019, there were an estimated 38.0 million persons who lived with HIV globally out of which 1.8 million of them were children under age 14. Of this population, 33% [22–45%] representing 52 000[30000–83000] of the population reside in Western and Central Africa (UNICEF, 2018; UNAIDS, 2020). It has been reported that only a little over half (52%) of all HIV infected children aged 0–14 have access to antiretroviral therapy (ART). This development militates against achieving the UNAIDS global target of 90–90–90 (Mutanga et al., 2019; Joint United Nations Programme on Global HIV, 2018).

Disclosure serves the first step to achieving the global 90/90/90 goal. In Ghana, ART coverage for children below 14 years progressed from 24% in 2013 (WHO, 2013) to 52% in 2018. Gaps in paediatric HIV care continue to exist in Sub- Saharan Africa in terms of HIV diagnosis and treatment coverage (Joint United Nations Programme on Global HIV, 2018).

The World Health Organization (WHO) reports that disclosure of HIV status to infected children is the gateway to treatment. The WHO further recommends disclosure that is context bound and should be age appropriate. However, the practice of disclosure to children is lagging (UNAIDS, 2012). There has been mixed reports on how child disclosure improves medication adherence and retention in care. This calls for attention as many perinatally infected children grow into adolescence (Mutanga et al., 2019; Vaz et al., 2011; Bikaako-Kajura et al., 2006). Non-disclosure could lead to adolescents mal-adherence to ART and

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engaging in early age risky and unprotected sexual behaviour (Appiah et al., 2015).

Within the sub-Saharan Africa region, the challenge of HIV infected children not knowing their status appears striking. Several studies conducted in the region have reported very low prevalence of disclosure (Rosen et al., 2005). Studies conducted at relatively early years post national introduction of ART reported very low paediatric disclosure rates. The landscape of paediatric disclosure rates and patterns have however not changed much nearly two decades despite the improved treatment possibilities. In Uganda, Bibaako-Kajura *et al.* reported in 2006 a disclosure prevalence of 29% of infected children among children aged 5–17 years (Bikaako-Kajura et al., 2006). A multicentre study in Ethiopia by Biadgilign *et al.* focusing on children aged 1–14 years of age in 2011 found that 17% of children had been disclosed to about their HIV status (Biadgilign et al., 2011).

In South Africa, Madiba *et al.* established in 2012 a disclosure prevalence of 39.6% in children 4 to 17 years old. The mean age of disclosure was 10.4 years (Madiba, 2012). In the recent study by Mengesha *et al.* in Ethiopia a disclosure prevalence of 49.4% with a mean disclosure age of 11.2 years (Mengesha et al., 2018). Nearly all of these studies were conducted in either single study sites or in the case of multiple facilities/hospitals located within the same geopolitical zones and cultural settings. Notwithstanding, it remains possible for study location defined with different cultural context to influence disclosure. This is so particularly so when locations and cultures have been found to influence health attitudes and behaviours (Buor, 2004).

Recent evidence on HIV disclosure shows that the barriers and enablers to paediatric and adolescent disclosure keep modifying. A systematic review and *meta*-analysis of 22 studies by Britto *et al.* from 12 low- and middle-income countries depict consistent lower levels of disclosure among infected children. There was a reported 1.7% to 41% disclosure rate from the studies (Britto et al., 2016). According to WHO children of school age should be disclosed and provides support material for children up to the age of 12 years (https://www.who.int/hiv/pub/hiv_disclosure/en/).

Nearly 30% of Ghanaian adolescents are reported to have had first sexual initiation before turning 18 years. In Ghana, prevalence of HIV in 2016 stood at 2.4%, declined to 2.1% in 2017 though with an increased incidence from 1.1% to 1.5% and reduced to 2.0% in 2019(National AIDS Control Programme, 2017; Ghana AIDS Commission, 2019).

Out of a total 342,307 estimated Ghanaian living with HIV and AIDS, 25,955, representing 8%, are children less than 15 years (Ghana AIDS Commission, 2019; Dako-Gyeke et al., 2016; Ghana AIDS Commision, 2016). Globally there are about 960,000 children on ART. Globally, children on ART remain at 67% (ACRWC, 1999) (UNAIDS, 2020). In Ghana, only 30% of children have access to ART, while ART coverage for all adult persons living with HIV and AIDS stands at 34% (Joint United Nations Programme on Global HIV, 2018; Unicef et al., 2016). This has the propensity to increase new rates of HIV infection as majority of children do not know their HIV status (Appiah et al., 2015; Ghana AIDS Commision, 2016; Norman and Awiah, 2016; Hayfron-Benjamin et al., 2018). In Ghana, many adolescents continue to have sex at an early age (Dapaah, 2016; Paintsil et al., 2015). The unaddressed challenge remaining is the number of children who may have had sex before being disclosed to about their HIV status. Currently, though the ART guidelines in use by health professionals has been revised in its sixth edition, disclosure is mentioned only in passing with no specific reference to HIV status disclosure to adults ignoring HIV positive children (National AIDS Control Programme, 2017). There is currently no national disclosure guideline for HIV infected children. Disclosure occurs at the convenience of the ART counselors using their experience and discretion. The Korle-Bu and Komfo Anokye Teaching hospitals have rather benefitted from piloted child disclosure studies that led to the mainstreaming of child and adolescent disclosure processes into the HIV care at the HIV clinic (Ofori-Atta et al., 2019). The experience and discretion of ART counselors combined with other factors shape the disclosure landscape for Ghanaian children and adolescents living with HIV and AIDS. Whilst the area of child HIV disclosure had begun to receive research attention, Kallem *et al.* established a disclosure prevalence of 21% of children 8–14 years old in 2010 (Kallem et al., 2011). At the Korle-bu Teaching hospital, the largest tertiary hospital in the Accra, the capital of Ghana, Kenu *et al.* found that a little over half (52%) of adolescents and young adults 15–24 years of age had been told their HIV status (Kenu et al., 2014). The enrolled participants were very few. In a recent study by Hayfron-Benjamin et al. among 103 caregiver-child dyads in 3 facilities within the central region of Ghana, 23% of the children aged 6 to 17 were found to have had their HIV status disclosed to them. The mean age at disclosure 10.4 years (Hayfron-Benjamin et al., 2018).

A common semblance with all studies reporting on child disclosure in Ghana is that, all of the studies were conducted in the comparatively resource rich southern part of Ghana. In these areas, health facilities and health care delivery are comparatively advanced. Though some national efforts have been made in meeting the international goals on HIV and AIDS, results from few independent non-nationally representative studies conducted in Ghana have established that a limited number of Ghanaian HIV positive adolescent/children know their HIV status (Unicef et al., 2016; Kallem et al., 2011; Kenu et al., 2014)

Differences in barriers and enablers to caregiver disclosure of infected child status may exist between the Upper East region and Northern region in the northern parts of Ghana and Ashanti region in the southern part of Ghana (Buor, 2004). Similarly, health infrastructure, healthcare delivery, poverty, disease aetiology, school enrolment religion significantly differ (GSS, 2010).This study is grounded on a rigorous theoretical context similar to the maiden study on disclosure in Ghana "the Sankofa" study by Paintsil *et al.* (Paintsil et al., 2015). It has been argued that many HIV disclosure studies have not often been grounded in rigorous theoretical context (Reynolds et al., 2015; Serovich, 2001). Theories often cited in HIV disclosure studies are the disease progression theory (explains disclosure as HIV progresses to AIDS) and social exchange theory which builds on the assumption that disclosure only takes place after careful deliberation of the positive and negative consequences associated with disclosing ones status (Serovich, 20001). This study adopts an eclectic theoretical approach by combining the social exchange and the disease progression theory.

Factors such as caregiver uneasiness, guilt, blame and concerns about child psychological acceptance of the news of HIV status have been reported as disclosure barriers. There is however scanty information on the enablers or facilitators to paediatric disclosure though recent evidence from studies in parts of Africa have established that the enablers to disclosure are either the child questioning, caregiver discomfort and or advice from nurses (Vreeman et al., 2010; Madiba et al., 2013; Arrivé et al., 2012; Kalembo et al., 2019). Paediatric disclosure barriers reported in previous studies in Malawi included challenges revolving around disconnected interventions and a non-synergistic approach such that single model approaches have not yielded ultimate disclosure benefit to children (Kalembo et al., 2018). In Ghana, different barriers revolving around caregiver fear, limited skill for disclosure, non-standardized disclosure tools or manual and child age have been cited(Hayfron-Benjamin et al., 2018; Gyamfi et al., 2017). Skill inadequacy for disclosure is not only a barrier faced by caregivers but also healthcare workers. In Malawi eight out of every 10 health worker consider lack of training on disclosure and absence of disclosure tools to be a major barrier. These findings may differ across country context despite the generally common paediatric disclosure challenges. The enablers to HIV disclosure to children have rather remained minimally understood and researched within the Ghanaian context apart from a few studies that have been carried out in the recent past (Ofori-Atta et al., 2019; Gyamfi et al., 2017; Radcliffe et al., 2020; Appiah et al., 2019) A more reflecting and nationally representative data providing a clearer geospatial perspective of the barriers and enablers to paediatric disclosure across the Northern, Upper east and Ashanti regions is needed. This will shape and inform the development of a nationally inclusive, culturally sensitive and context defining paediatric HIV counselling and disclosure guideline. This study seeks to answer the question of what remains as the determinants of child HIV/AIDS status disclosure or non-disclosure from the primary caregivers of HIV infected children across southern and northern regions of Ghana. The aim of this study therefore is to examine the determinants of child HIV/AIDS status disclosure or non-disclosure across southern and northern regions of Ghana.

2. Materials and methods

2.1. Study design and sites

A facility-based cross-sectional design using quantitative approach at 12 antiretroviral treatment centres (ART) centres in rural and urban areas in three regions: Upper East, Northern region and Ashanti was adopted. The selected regions have different rates of HIV prevalence. The Upper East has a regional prevalence of 1.7% (Ghana AIDS Commision, 2016), the Northern region has the national lowest prevalence of 0.7%, whiles Ashanti region prevalence is 3.2% and there are 16, 14 and 29, ART centres in the Upper East, Northern and Ashanti, and regions of Ghana respectively. In each of the three regions, four ART centres/clinics - made up of two urban and two rural centres - were purposely selected and participants were enrolled. The study sites are pictorially depicted in Fig. 1.

2.2. Population and sampling

The study population was primarily caregiver of HIV positive children aged 5–18 years. A multi-stage sampling procedure was adopted guided by a multi-stage cluster/area sampling of three regions purposively selected due to the unique developmental, cultural and health seeking differences that exist among the sites. Twelve ART sites, four from each region were subsequently stratified and selected according to rural –urban locations. An inclusion criterion of a centre was based on whether the centre had paediatric HIV/AIDS clients and was not a recently opened centre (less than two years). The total number of HIV positive children distributed across the selected regions was not available at the time of the study partly because our study enrolled 5–18 years while national and regional data reporting for children living with HIV was aggregated for children 0–14 years with 15 years plus considered adult population. In terms of the regional distribution of Persons Living With HIV, the end of the year 2018, a total of 69,002 Persons Living With HIV were from the Ashanti region. There were 4090 Persons Living With HIV who stayed in the Upper East region. The total number of all Persons Living With HIV who stayed in the Northern region was 7706. The study focused on children 5–18 years. Caregivers/child dyads of 5–18 years HIV/AIDS positive children were randomly sampled using medical records (folder) and patient registry. This was done at random for children who were aged 5–18 years using their medical records, who had caregivers consenting to be recruited and who had not been diagnosed of HIV infection less than 3 months.

Primary caregiver was defined as the person who was responsible for bringing child to clinic for medication and review in the past 1 year preceding the conduct of the study. The primary caregiver answered the questions on behalf of child. Data collection took place between May 2017 and November 2018. The total sample size for caregivers was determined by using the formula for estimating a single proportion using previous study on paediatric disclosure prevalence of 21% (Kallem et al., 2011). Using a 95% level of significance and a 0.005 precision, and reliability co-efficient of (1.96), a total of 254. However, due to data collection challenges resulting from missed appointments, long distance travel restrictions and unavailability of the eligible children, selection/recruitment response rate was 71% giving a total of 180 caregiver /child

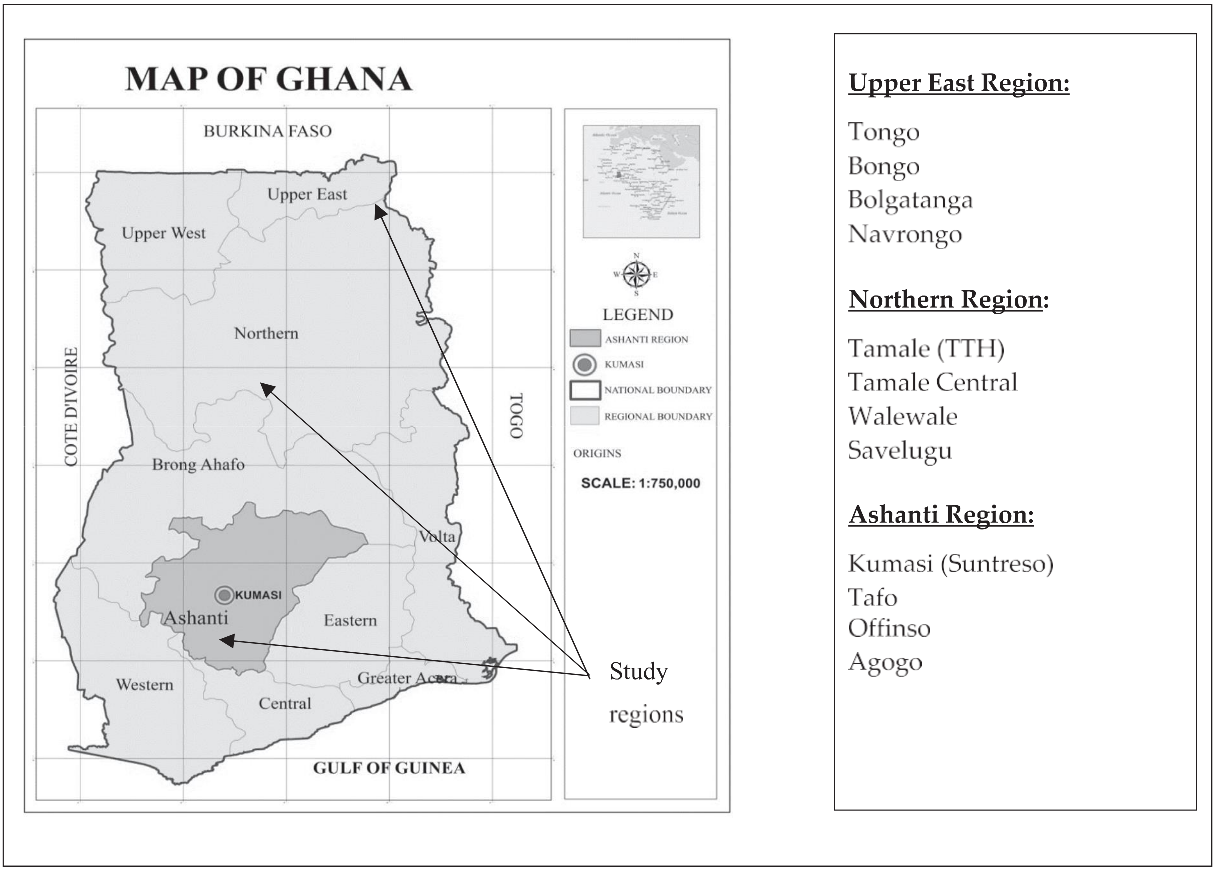

Fig. 1. Map of Ghana showing the study areas.

Table 1
Socio-demographic characteristics of caregivers.

Variable	Frequency (n = 180)	Percentage (%)
Age		
Up to 30 years	44	24.44
31 – 40 years	71	39.44
41 – 50 years	38	21.11
51 years and above	21	15.0
Median age of caregivers(yrs) IQR	39(31–46)	
- Region		
Ashanti	84	46.67
Northern	27	15.00
Upper east	69	38.33
- Geographical belt		
Northern Ghana		
Southern Ghana	96	53.3
Residence	84	46.7
Urban	101	56.11
Rural	79	43.89
- Distance to clinic		
Less than 20 km	87	48.33
More than 20 km	93	51.67
- Gender		
Female	152	84.44
Male	28	15.56
- Marital status		
Divorced	21	11.67
Living with partner	8	4.44
Married	84	46.67
Single	31	17.22
Widowed	36	20.00
- Monthly family income		
Less than 50 cedes	42	23.33
51 – 100 cedes	36	20.00
101 – 200 cedes	39	21.67
201 – 500 cedes	34	18.89
500 cedes and above	29	16.11
- Education background		
No formal education	50	27.78
Primary	33	18.33
Junior High School	35	19.44
Senior high school	35	19.44
Tertiary education	27	15.00
- Religion		
Christian	138	76.76
Muslim	29	16.11
Traditionalist	10	1.67
others	3	5.56
- Relation to child		
Adopted parent	8	4.49
Biological father	11	6.18
Biological mother	91	51.12
Foster parent	22	12.36
Grand father	1	0.56
Grand mother	25	14.04
others	20	11.24
- Children with biological mother alive		
Yes	109	60.56
No	71	39.44
- Child’s biological father alive		
Yes	92	51.11
No	88	48.89
- HIV status of caregiver		
Positive	96	53.33
Negative	56	31.11
Cannot disclose	6	3.33
Don’t know	22	12.22

dyad who were recruited.

2.3. Data collection

A structured questionnaire was administered to caregivers of selected children during their routine visits to the clinics. The questionnaire was prepared in English and orally translated into the different local languages of the caregivers. The questionnaire was administered with the support of a trained research assistant and facility data managers who could speak at least two of the local languages due to the multi-ethnic languages existing in the Upper East and Northern regions. The questionnaire used in the Ashanti region was translated into the Asante Twi language. The Asante Twi is the predominant language used in Ghana. The two regions in northern Ghana had their questionnaires translated into Frafra and Dagabani- two predominant languages in Upper East and Northern regions. The trained research assistant, a biomedical scientist had lived and worked in a hospital in the upper east region and had firm grasp of the language. The first author has adequate command over translating English to Asante Twi and and was responsible for translating the questionnaire into Asante Twi. The questionnaires were administered in an enclosed facility within the hospital or clinic premise but outside the general ART rooms or consulting room.

Scheduled appointments were booked with caregivers of children who met the eligibility criteria and had been selected for the study but have not reported to the hospital during the time of the interviews. The random sample was to be made from the pool of those who would turn up on a clinic day since different children came for their medication on different days. Caregivers were selected at random among those who were able to attend to the booked appointments until the expected sample size was reached. In this way, the stratified randomization approach was adopted such that the separate blocks that were required to be generated in the context of this study was the rural and urban block, northern and southern block and eligible child/caregiver dyads and non-eligible child/caregivers were used. This randomization was useful because all the potential subjects in terms of eligible person had been identified from the register before selecting them relative to those who attended to the booked appointments (Lachin et al., 1988; Weir and Lees, 2003). After this was done, simple randomisation was used. This approach helped in reaching out to the targeted sample size so that an appreciable number of caregivers with their children became eligible to be recruited in each selected facility.

The questionnaire used contained validated instruments on disclosure that had been used to carry out similar studies in different context but were contextualised to suit the current objective of the study (Kallem et al., 2011; Gyamfi et al., 2017; Vreeman et al., 2014).

The Questionnaires administration was carried out in the absence of the children in order to avoid inadvertent disclosure to children who have not yet been told their diagnosis. Questionnaire was pretested at the Animwaa medical centre in the Ashanti region whose population share similar characteristics as that of the urban and rural settings. The outcome variable was considered a binomial variable of “disclosed’’ or “not disclosed” status of the child defined by primary caregiver’s answer of “Yes” to the question about whether the child has been told about his HIV status or he or she is HIV positive by either the primary caregiver, ART nurse or medical doctor or any other person in the family or outside the family.

Caregiver response of “No” was confirmed from the medical records of the child to ascertain whether the child might have been disclosed to at the blind side of the caregiver by the ART nurses or doctors. However, a “Yes” response from caregiver was accepted even if the medical folder indicated “non-disclosed status” of the child since primary caregivers lived and interacted daily with the children and might have adequate information on disclosure. The independent variables included demographic characteristics of primary caregiver (age, sex, HIV status, relations with child, educational level, income level, occupation and marital status). Demographic characteristics of a child (age, sex, grade in school, whether or not child is receiving ART, whether or not child’s mother is alive or not, age at diagnosis, duration on ART) variables considered under child medical /clinical HIV/AIDS history, variables eliciting information on caregivers perspective on the perceived benefits and barriers to disclosure.

Table 5
Socio-demographic and medical history of children.

Variable	Freq (n = 180)	Percentage (%)
Age of all children		
5–7	79	43.89
8–10	37	20.56
11–13	44	24.44
14–18	20	11.11
Median age of children(IQR)	9 (5–12)	
- Gender		
Female	91	50.5
Male	89	49.5
- Currently attends school		
Yes	156	86.67
No	24	13.33
- Caregiver perceives child has self -knowledge of attending clinic for HIV care		
Yes		
No	64	35.56
	116	64.44
- Age child started ART medication intake		
≤ 5–7 years	144	80.00
8–10 years	22	12.22
11–13 years	11	6.11
14–18 years	3	1.67
- How long has child been on ART		
Less than 12 months	39	21.67
12 – 24 months	30	16.67
25 – 48 months	15	8.33
49 months and above	96	53.33
- Reason caregiver informed other person/s about the child's HIV status		
For assistance/support		
Because the person is child's relative	13	38.24
Because the person is the child's mother	6	17.65
Due to sickness	9	26.47
No reasons given	6	17.65
	65	65.66
- Whether child refuse to take HIV medication		
Yes	25	13.89
No	155	86.11
- All caregivers' opinion on the right person to disclose child status to children		
Father		
Mother	17	9.44
Grandmother	53	29.44
ART Nurse	7	3.89
Doctor	47	26.11
Caregiver other than all the above	36	20.00
	20	11.11
- WHO Clinical staging of child at the time of ART initiation		
Stage 1	94	52.22
Stage 2	24	13.33
Stage 3	36	20.00
Stage 4	2	2.11
No recorded	24	13.33
- Child has history of hospitalization		
Yes	71	39.44
No	109	60.56
- Is child on Anti-TB treatment		
Yes	23	12.78
No	157	87.22

2.4. Data analysis

Data collected were entered into Excel sheet and exported into STATA version 12. Descriptive statistics was carried out to explore the socio-demographic characteristics of caregivers and children. The bivariate analysis was performed with Pearson's chi squared tests χ^2 to investigate the associations between a child's disclosure status and child-level clinical and demographic in addition to caregiver background characteristics. The chi squared tests χ^2 of association was performed to examine the significant difference in caregivers living in either Northern or Southern Ghana perceived enablers and barriers to child disclosure. Tests of association between disclosure and the other characteristics was carried out using binary logistic regression. Significant variables with $p < 0.05$ in the binary logistic regression were entered in a stepwise backward format into a multivariate model to conduct multivariate logistic regression. This was reported in odds ratios (OR) at 95% confidence intervals (95% CI) with statistical significance in the model considered at p-values < 0.05.

2.5. Ethical consideration

The study obtained ethical approval from the Ghana Health Service Ethics Review Committee with Ethics approval number GHS-ERC: 05 /06/17 and the Ethical Committee of LMU Munich (Project Number 18–018). Study participation was voluntary and written informed consent was obtained from caregivers.

Table 3

Disclosure related characteristics of HIV + children.

Variable	Freq, N ¼ 42	Percentage
Disclosure status of HIV + Children		
- Yes	42	23.33
- No	138	76.67
Age range of disclosed children		
- 5–7 years	9	21.43
- 8–10 years	9	21.43
- 11–13 years	11	26.19
- 14–18 years	13	30.95
Median age at which disclosure was made to child (IQR)	9.5(IQR = 5–11)	
Median age of the current disclosed children	12 (IQR = 8–14)	
Ages of undisclosed children(n = 138)		
- 5–7	70	50.72
- 8–10	28	20.29
- 11–13	33	23.92
- 14–18	7	5.07
Median age of undisclosed children (IQR) 7 (5–11)		
Duration between diagnosis of HIV and child status disclosure (n = 42)		
- Same date	8	19.05
- Less than 3 months	20	47.62
3 – 6 months	2	4.76
7 months – 4 years	4	9.52
5 years and above	8	19.05
Who disclosed child HIV status to him/her?		
Father	7	16.67
Mother	9	21.43
Grandfather	2	4.76
Grandmother	3	7.14
Nurses	15	35.71
Doctor	3	7.14
Other	3	7.14
Reason for disclosure of child status (n = 42)		
- To obtain social/emotional support in caring for the child	17	40.48
- Out of moral obligation	5	11.90
- Someone found out the child status and I confirmed to child by disclosing	3	7.14
- The child found out and asked me	8	19.05
- The child kept troubling me with what was responsible for her medical condition	9	21.43
Age caregiver intends to disclose undisclosed child status to him/her (n = 138)		
10 years	5	3.62
12 y	3	2.17
13yrs	7	5.07
14yrs	1	0.72
15yrs	12	8.70
16yrs	1	0.72
17yrs	2	1.45
18yrs	8	5.80
19yrs	31	22.46
Don't have specific age of child in mind	68	49.28
Mean age with intention to disclose (SD) 16.48 (±2.96)		
Preference on whom to disclose undisclosed child status to when due (n = 138)		
ART counseling nurse	29	21.01
Biological father	7	5.07
Biological mother	38	27.54
Both parents	8	5.80
Caregiver neither biological mother nor father	11	7.97
Doctor	13	9.42
Don't know	32	23.19

3. Results

3.1. Background characteristics of caregivers

Table 1 present the socio-demographic characteristics of caregivers of the children studied. One-hundred and eighty caregiver/child dyads were included into this analysis. Median age of caregivers was 39 (Appiah, Kroidl, Hoelscher, Ivanova, & Dapaah, 2019; Arrivé et al., 2012; Finnegan et al., 2019; Gyamfi, Okyere, Enoch, & Appiah-Brempong, 2017; Kalembo, Kendall, Ali, & Chimwaza, 2019; Kalembo, Kendall, Ali, Chimwaza, & Tallon, 2018; Lachin, Matts, & Wei, 1988; Radcliffe et al., 2020; Vreeman et al., 2014; Weir & Lees, 2003; Serovich, 2001; Tadesse et al., 2015; WHO, 2011) with ages ranging between 16 and 80 years. Almost half (46.67%, n = 85) of the caregiver/ child dyads were from Ashanti region (Southern part of Ghana) were females (84.44%, n = 152) with more than half of caregivers (56.1%, n = 101) living in urban communities and travel beyond 20 km before accessing health facility for a child (51.7%, n = 93).

Caregiver/child dyads enrolled from Northern Ghana (Northern region and Upper East region) were a little over half (53.3, n = 96) of the total recruits comprising caregivers from Northern region (n = 27) and Upper East regions (n = 69) of Ghana with the remaining from Southern Ghana. Nearly half of primary caregivers (46.7%, n = 84) were married, with a little over one in five caregivers (22.8%, n = 41) being unemployed. Over half (51.1%, n = 91) of the caregivers were biological mothers of the HIV infected children. HIV positive status was reported among half of the caregivers (53.3%, n = 96). Table 1 presents the results.

Table 4
Association between caregiver and child characteristic and child status disclosure.

Variable	Child HIV status disclosed		X^2	P-value
	Yes	No		
Age of caregiver			3.93	0.27
Up to 30 years	11 (25.00)	33(75.00)		
31 – 40 years	14 (19.72)	57 (80.28)		
41 – 50 years	7 (18.42))	31 (81.59)		
51 years and above–	10 (37.04))	17 (62.96)		
Median age of caregiver 39(IQR = 31–46)				
- Child Age			25.80	<0.01*
5–7 years	9 (11.39)	70 (88.61)		
8–10 years	9 (24.32)	28 (75.68)		
11–13 years	11 (25.00)	33 (75.00)		
14–18 years	13 (65.00)	7 (35.00)		
- Gender of child			0.39	0.53
Male	23 (25.27)	68 (74.73)		
Female	19 (21.35)	70 (78.65)		
- Child currently attends school			3.48	0.06
Yes	40 (25.64)	116 (74.36)		
No	2 (8.33)	22 (91.67)		
- Age child started ART			21.54	<0.01*
5–7 years	25 (18.12)	113 (81.88)		
8–10 years	7 (30.43)	16 (69.57)		
11–13 years	7 (58.33)	5 (41.67)		
14–18 years	3 (100.00)	0 (0.00)		
- Child duration on ART			2.27	0.52
Less than 12 months	11 (26.83)	30 (73.17)		
12 – 24 months	4 (15.38)	22 (84.62)		
25 – 48 months	2 (11.11)	16 (88.89)		
49 months and above	25 (26.32)	70 (73.68)		
- Child refuses to take HIV medication			0.18	0.67
Yes	5 (20.00)	20 (80.00)		
No	37 (27.87)	118 (76.13)		
- Opinion on who to disclose child status to him/her			5.25	0.39
Father				
Mother	2 (11.76)	15 (88.24)		
Grandmother	13 (24.53)	40 (75.47)		
Nurse	1 (14.29)	6 (85.71)		
Doctor	8 (17.02)	39 (82.98)		
Other person	11 (30.56)	25 (69.44)		
	7 (35.00)	13 (65.00)		
- Region			8.14	0.02*
Upper East Region	23(33.33)	46(66.67)		
Northern Region	2 (7.41)	25 (92.59)		
Ashanti Region	17(20.24)	67 (79.76)		
Geographical belt				
Northern Ghana	25(26.04)	71(73.96)	0.84	0.36
Southern Ghana	17(20.24)	67(79.76)		
- Gender of caregiver			0.05	0.82
Female	35 (23.03)	117 (76.97)		
Male	7 (25.00)	21 (75.00)		
- Caregiver education background			0.74	0.95
No formal education	11 (22.00)	39 (78.00)		
Primary	7 (21.21)	26 (78.79)		
Junior High School	8 (22.86)	27 (77.14)		
Senior high school	8 (22.86)	27 (77.14)		
Tertiary education	8 (29.63)	19 (70.37)		
- HIV status of caregiver			2.96	0.36
Positive	21 (21.88)	75 (78.13)		
Negative	17 (30.36)	39 (69.64)		
Cannot disclose	1 (16.67)	5 (83.33)		
Don't know	3 (13.64)	19 (86.6)		

3.2. Child medical history, socio-demographic characteristics and child disclosure

The Table 2 provides an overview of the socio-demographic characteristics and medical history of the children studied. The median age of all the children was 9 years with majority (45.6%, n = 82) of the children between ages 5 and 7 years. Male (49.5%, n = 89) and female (50.5%, n = 91) children were almost equally enrolled. A total of 23 children were currently receiving anti-tuberculosis treatment. Clinical review and ART refill visit were mostly done on monthly basis (45%, n = 81) though more than a third (37.2%, n = 67) attended clinic visits in three months intervals. More than half (53.3%, n = 96) of the children had been on medication for over four years and were at stage one of the HIV infection according to WHO classification (See Table 2).

3.3. Child disclosure related characteristics specific to HIV + disclosed and non-disclosed children

In Table 3, the disclosure related characteristics of the children studied are provided. Overall, HIV status disclosure to infected children

Table 5
Association between caregiver perceived benefits and barriers to disclosure and child disclosure status.

Variable	Child HIV status disclosed		X^2	p-vale
	Yes	No		
- Child often ask questions for frequent medication intake			9.40	0.02*
Yes	23 (36.51)	40 (63.49)		
No	19 (16.24)	98 (83.76)		
- I have problem with giving child his /her medicines			1.67	0.20
Yes	10 (32.26)	21 (67.74)		
No	32 (21.48)	117 (78.52)		
- Caregiver believes disclosure will make child distressed and socially isolated			9.73	0.01*
Yes	12 (20.00)	48 (80.00)		
No	21 (37.50)	35 (62.50)		
Don't know	9 (14.06)	55 (85.94)		
- Caregivers believe that disclosure is a child's right issue and should be mandatory			11.59	0.03*
Yes	35 (31.82)	75 (68.18)		
No	4 (12.50)	28 (87.50)		
Don't know	3 (7.89)	35 (92.11)		
- Disclosure should only start when female child is about having onset of puberty			2.52	0.28
Agree	18 (23.08)	60 (76.92)		
Disagree	17 (29.31)	41 (70.69)		
Can't tell	7 (15.91)	37 (84.09)		
- Caregivers believe disclosure is not beneficial to children under age 15			3.40	0.07
Yes	16 (17.58)	75 (82.42)		
No	26 (29.21)	63 (70.79)		
- Caregiver supports the view that disclosure averts possible transmission among children who may have early sex (10–14 years)			4.67	0.10
Yes	30 (26.09)	85 (73.91)		
No	7 (31.82)	15 (68.18)		
Can't tell	5 (11.63)	38 (88.37)		
- Caregiver believes non-disclosure until adulthood is necessary to save caregiver from child blames and criticism			7.4	0.03*
Yes	20 (21.74)	72 (78.26)		
No	15 (38.46)	24 (61.54)		
Don't know	7 (14.29)	42 (85.71)		
- Whether caregiver shares the opinion that disclosure should be done by only family members			7.16	0.03*
Yes	14 (17.07)	68 (82.93)		
No	15 (22.73)	51 (77.27)		
Don't know	13 (40.63)	19 (59.38)		
- Whether caregiver believes disclosure improves child medication adherence?			4.81	0.09
Yes	24 (24.49)	74 (75.51)		
No	12 (33.33)	24 (66.67)		
Don't know	6 (13.04)	40 (86.96)		
Whether caregiver do not know how to go about status disclosure			11.61	0.03*
Yes	4 (7.55)	49 (92.45)		
No	16 (25.81)	46 (74.19)		
Don't know	22 (33.85)	43 (66.15)		

was 23.3% (n = 42). The median age of disclosed children was 12 years, with time of disclosure around the median age of 9.5 (5–11) years

The quest to secure social and emotional support in caring for children among other factors was cited as the main reason for child HIV status disclosure. The main persons who facilitated HIV disclosure to children were nurses 35.7% (n = 15) followed by mothers 21.3% (n = 9).

A total of 138 (76.7%) children did not know their HIV status. Median age of undisclosed children was 7 (5–11). Among undisclosed children, mean age at which caregivers intended disclosing their status to them was 16.28 years (n = 70). Majority of caregivers of children with undisclosed status preferred the biological mother (27.4%, n = 38) followed by the ART counselling nurses (21%, n = 29). Nearly half (49.3%, n = 68) of caregivers of undisclosed children did not have any specific age in mind to disclose child status to him or her.

3.4. Bivariate analysis of child and caregiver background characteristics and HIV disclosure status of infected children

The Table 4 gives a bivariate association between both child and caregiver variables and the disclosure status of the children. Child age, age child started ART, child and caregiver region of residence were significantly associated with disclosure. Among disclosed children, the majority (65%, n = 13) of them were disclosed between ages 14–18 years. Despite efforts to recruit even numbers from each of the regions, caregiver inaccessibility limited the number of recruits from Northern region (n = 27). The highest proportion of children with HIV disclosed status lived in Upper East region (33.3%, n = 23) followed by the Ashanti region (20.2%, n = 17) with the greatest proportion of children with undisclosed status living in Northern region (92.6%, n = 25).

Caregiver age was not associated with child status disclosure (p = 0.27) though older aged caregivers above 51 years appeared to disclose their children or wards status to them much more than younger aged caregivers of age 30 or below(37.0% vs. 25.0%). There was no significantly association between gender and disclosure status of males (25.27%, n = 23) and females (21.35%, n = 19). Caregiver HIV status did not have any significant association with the disclosure status of the child though compared to HIV positive caregivers (21.9%, n = 21), HIV status negative caregivers had higher child disclosure rate (30.4%, n = 17) See Table 4.

Table 6
Comparison of caregiver perceived barriers and enablers to child HIV disclosure with geographical location.

Variable	Region		X^2	p-value
	Northern Ghana (n = 96)	Southern Ghana (n = 84)		
- Caregiver believes child cannot understand HIV			2.08	0.15
Yes	60 (54.55)	50 (45.45)		
No	11 (39.29)	17 (60.71)		
- Caregivers fear accidental disclosure (n = 138)			4.62	0.03*
Yes	8 (32.00)	17 (68.00)		
No	63 (55.75)	50 (44.25)		
- Caregiver believes child status disclosure deteriorates child health	9 (32.14)	19 (67.87)	17.28	<0.00*
Agree	32 (44.44)	40 (55.56)		
Disagree	53 (71.62)	21 (28.38)		
Can't tell				
- Disclosure saves caregivers from frequent questioning from child	63 (53.0.85)	54 (46.15)	0.12	0.94
Agree	12 (50.00)	12 (50.00)		
Disagree	21 (53.85)	18 (46.15)		
Can't tell				
- Non-disclosure of child status maintains family trust			6.88	0.03*
Agree	47 (63.51)	27 (36.49)		
Disagree	24 (40.68)	35 (59.32)		
Can't tell	25 (53.19)	22 (46.81)		
- Caregiver believes disclosure benefits child by ensuring treatment	57 (58.16)	41 (41.84)	3.00	0.23
adherence	15 (41.67)	21 (58.33)		
Yes	24 (52.17)	22 (47.83)		
No				
Can't tell				
- Disclosure should begin when female child begins menstruation	49 (62.82)	29 (37.18)	5.81	0.06
Agree	29 (50.00)	29 (50.00)		
Disagree	18 (40.91)	26 (59.09)		
Can't tell				
- Disclosure is not beneficial to children < 15 years			2.73	0.10
Agree	43 (47.25)	48 (52.75)		
Disagree	53 (59.55)	36 (40.45)		
- Caregiver believe disclosure is beneficial to prevent children who may have sex (10–14 years) from further	55 (47.83)	60 (52.17)	6.17	0.05
transmission	11 (50.00)	11 (50.00)		
Agree	30 (69.77)	13 (130.23)		
Disagree				
Can't tell				
- Non-disclosure until adulthood is necessary to save caregiver from child blames and criticism	47 (51.09)	45 (48.91)	0.40	0.82
Agree	22 (56.41)	17 (43.59)		
Disagree	27 (55.10)	22 (44.90)		
Can't tell				
- Caregiver believes that disclosure should be done by only family members	48 (58.54)	34 (41.46)	9.10	0.01*
Yes	26 (39.39)	40 (60.61)		
No	22 (68.75)	10 (31.25)		
Can't tell				
- Caregiver believes disclosure will lead to child self-discrimination	28 (52.83)	25 (47.17)	0.01	0.93
Yes	68 (53.54)	59 (46.46)		
No				

3.5. Association between child disclosure status and caregiver's perceived barriers and benefit to paediatric disclosure

Table 5 presents a bivariate association between caregiver's perspective on the perceived benefits and barriers to disclosure and child disclosure status. Child asking questions frequently about reason for continuous medication intake ($p < 0.002$), caregiver perspective that disclosure should be done by only child family members ($p < 0.03$), caregiver perception of disclosure having the potential to make child socially isolated and distressed ($p < 0.01$) and caregiver not knowing how to go about the disclosure ($p < 0.003$) were significantly associated with disclosure.

Other caregiver perceived factors that had significant association with child disclosure were the perception that disclosure is a child's right issue and should be mandatory ($p < 0.03$) and caregiver belief that non-disclosure until adulthood is necessary to save caregiver from child blame and criticism($p < 0.03$). Higher child disclosure rates (36.5%, n = 23) was reported among children who frequently asked their caregivers questions on reasons for clinic visit compared to children who did not ask questions about the reasons for clinic visit (16.2%, n = 19).

The relationship between caregivers' knowledge on how to facilitate child HIV disclosure and the disclosure status of children was explored. The majority of children (33.85%, n=22) who had had their disclosed status known to them had their caregivers admitting not knowing how to go about the disclosure process compared to comparatively few children with disclosed status whose caregivers admitted knowing much about HIV disclosure (25.8%, n =16). It is also comparable to those whose caregivers expressed uncertainty about whether they considered themselves knowing or not knowing how to facilitate HIV disclosure to child (7.55%, n = 4)

3.6. Comparative caregiver perceived barriers and enablers to child HIV disclosure between Southern and Northern Ghana

The results as presented in Table 6 provides a comparism of caregiver perceived barriers and enablers to disclosure between the northern parts of Ghana and the Southern parts of Ghana. The two geographically northern regions (Upper East region and Northern region are classified as Northern Ghana whiles the Ashanti region is classified in this study as Southern Ghana. There statistically significant difference in caregiver perception on barriers and enablers to disclosure related to caregiver fear of accidental disclosure ($p < 0.03$), belief that child status disclosure deteriorates child health ($p < 0.01$) and perception that disclosure should be done only by family members.

Significantly, many caregivers living in Northern Ghana expressed less worry about accidental child status disclosure (32.0%,n= 8) compared to caregivers in Southern Ghana (68.0%, n = 17) out of the total caregivers of undisclosed children expressing fear of accidental disclosure to their wards (18.1%,n= 25). Other caregiver perceived barriers and enablers to disclosure that significantly differed between caregivers living in Northern and Southern Ghana were caregivers perception that non-disclosure of child status maintains family trust ($p < 0.03$). See Table 6.

3.7. Multivariate logistic regression on factors influencing disclosure to HIV-positive infected children/adolescents

The Table 7 presents a multiple logistic regression analysis of the study. Variables that showed significant association with child disclosure status were entered into the multivariate logistic regression model using the stepwise enter method. At the bivariate level, northern Ghana and southern Ghana were not significantly associated with disclosure of child status.

In the most northern part of Ghana (upper east region bordering Burkina Faso), the highest percentage of disclosure was recorded followed by the most southern part, the Ashanti region. The Northern

Table 7
Multivariate logistic regression on factors determining HIV disclosure to infected children.

Factor	Disclosed N = 42	Non-disclosed (N = 138)	cOR	95%CI	p-value	AOR*	95% CI	p-value
- Region								
Upper East(ref)	23 (33.33)	46 (66.67)	1					
Northern	2 (7.41)	25 (92.59)	0.2	0.03–0.74	0.02	0.1	0.00–4.61	0.24
Ashanti region	17 (20.24)	67 (79.76)	0.5	0.24–1.05	0.07	0.2	0.01–2.08	0.18
Child Age								
- 5 – 7 years (ref)	9 (11.39)	70(88.61)	1					
- 8 – 10 years	9 (24.32)	28 (75.68)	2.5	0.90–6.96	0.08	5.3	0.43–65.20	0.19
- 11 – 13 years	11 (25.00)	33 (75.00)	2.6	0.98–6.86	0.06	1.6	0.14–18.0	0.70
- 14 – 18 years	13 (65.00)	7 (35.00)	14.4	4.56–45.6	0.00	4.0	0.16–94.5	0.40
- Age child started ART								
5–7 years(ref)	25 (18.12)	113 (81.88)	1					
8 – 10 years	7 (30.43)	16 (69.57)	2.0	0.73–5.31	0.18	1	- 0.74–	-
11 – 13 years	7 (58.33)	5 (41.67)	6.3	1.86–21.5	0.03	11.0	181.0	0.08
14 – 18 years	3 (100)	0 (00.00)	-	-	-	1	-	-
Child often ask questions on reasons for frequent medication intake								
- No (ref)								
-Yes								
	19 (16.24)	98 (83.76)	1					
	23 (36.51)	40 (63.49)	3.0	1.46–6.03	0.03	19.0	2.02–177	0.01
Caregivers response on knowing or not knowing how to go about child disclosure								
- No (ref)								
- Don't know								
-Yes	16(25.81)	46(74.19)	1					
	22(33.85)	43(66.15)	0.65	1.98–2.1	0.50	–	–	–
	4(7.55)	49(92.45)	0.32	0.82–1.31	0.11	-	-	-
Caregivers perceives disclosure will result in child distress and social isolation								
- No (ref)								
- Don't know								
- Yes	21(37.50)	35(62.50)	1					0.40
	9(14.06)	55(85.94)	0.3	0.11–0.66	0.04	0.3	0.02–4.68	0.50
	12(20.00)	48(80.00)	0.4	0.18–0.96	0.04	0.5	0.03–6.74	
Whether caregiver shares the opinion that disclosure should be done by only family members								
- No (ref)								
- Don't know								
- Yes								
	15(22.73)	51(77.27)	1			-	-	-
	13(40.63)	19(59.38)	2.3	0.94–5.7	0.07	-	-	-
	14(17.07)	68(82.93)	0.7	0.31–1.57	0.39	-	-	-
Caregivers considers disclosure as child's right issue and should be mandatory								
No(ref)								
Don't know								
Yes	4(12.50)	28 (87.50)	1					
Delayed disclosure till adulthood saves caregiver from child	4 (12.50)	28 (87.50)	0.6	0.12–2.90	0.52			
blames and criticism	35 (31.82)	75 (68.18)	3.2	1.06–10.0	0.04	14.4	0.82–251.6	0.07
–No(ref)								
-Don't know								
-Yes								
	15(38.46)	24(61.54)	1					
	7(14.29)	42(85.71)	0.3	0.09–0.74	0.01	0.9	0.90–9.46	0.90
	7(14.29)	42(85.71)	0.4	0.19–1.00	0.05	2.0	0.21–17.96	0.50

cOR = Crude Odds Ratio, AOR = Adjusted Odds Ratio* Adjusted only for significant variables in the bivariate analysis.

region which geographically lies in the middle between upper east and Ashanti had the lowest disclosure rates., Children living in Northern region had a significantly reduced odds of being disclosed to about their HIV status (OR = 0.2, p = 0.02). Children living in Ashanti region similarly had reduced odds of knowing about their HIV status though this was not significant (OR = 0.5, p = 0.07).

In the multivariate regression adjusting for caregivers response on knowing or not knowing how to go about child disclosure and caregiver the opinion on whether disclosure should be done by only family members which were not significant at the bivariate analysis, children living in Northern region (AOR = 0.1, p = 0.24) and Ashanti region (AOR = 0.2, p = 0.18) had a much reduced odds of disclosure. Increasing age of the children shown an increased odd for disclosure for children within age bracket 14–18 years (OR = 14.4, p = 0.00) compared to lower age groups. However, older age group of 14–18 remained not significant in the adjusted model (AOR = 4.0. p = 0.40).

Children who start ART within 11 – 13 years group were sixth times higher than 5 – 7-year group to be informed about their HIV status (OR = 6.3, p = 0.03). This odd increased eleventh –fold but was not significant in the multivariate analysis (AOR = 11.0, p = 0.08). The child who ask questions about why he or she frequently took medication had three times odds to be informed about their HIV status than those do not (OR = 3, p = 0.003). A child who often asked questions on reasons for frequent medication intake was nineteen times more likely to be told his or her HIV status than one who rarely asked in the multivariate analysis (AOR = 19.0.0, p < 0.01).

Children living with caregivers who held the belief that disclosure will lead to child getting distressed and becoming socially isolated. In addition to children living with caregivers who remain unsure about the effect of disclosure on child's distress and social isolation situation had lower odds of knowing about their HIV status (OR = 0.4,p = 0.4; OR = 0.3, p = 0.04;). Table 7 presents the results.

4. Discussion

This study was cross-sectional in nature involving primary caregivers of HIV positive children from 12 ART clinics across rural and urban Upper East, Northern and Ashanti, regions of Ghana. The study sought to understand the factors facilitating or delaying HIV disclosure to infected children. In this study, only 23.3% of HIV infected children had been disclosed to about their HIV status. The median age at which children were disclosure to about their HIV status was 9.5 years. This was slightly lower than the median age of disclosure (10.39 years) reported in previous studies by Kallem and others (Kallem et al., 2011).

Disclosure of HIV status to infected children continue to remain a challenge for a caregiver given the potential benefits associated with it and the uneasiness that comes along with the process of disclosure (Vreeman et al., 2010; Arrivé et al., 2012). To the best of our knowledge, this is the first study that has examined HIV disclosure to infected children across Northern Ghana. Our study additionally emerges as the first study in Ghana to compare the HIV disclosure patterns across the two distinct geospatial zones in Ghana (Northern and Southern Ghana). This study established child age, ART start age and resident region of the care giver and child persistent questioning as major enablers of disclosure. The main barriers to disclosure were caregiver limited knowledge and caregiver presumption of protecting and seeking child best interest by not disclosing status to them.

Despite the study spanning across three different regions with different health system factors, distinct cultural and geographical context from the Northern and Southern Ghana , the proportion of disclosed children is consistent with the generally low disclosure prevalence of between 21% (in children aged 8–14 years (Kallem) and 52% in adolescents aged 15 to 24 years (Kenu) previously reported in single facility or one region studies in Ghana (Hayfron-Benjamin et al., 2018; Kallem et al., 2011; Kenu et al., 2014; Gyamfi et al., 2017). Comparing similar age groups, we observed a slight increase in disclosure rates among the subgroup of 8–14 year old children. Children above aged 14 had 65% disclosure rate, which was marginally higher than when compared to children of similar age as reported in Kenu's study. However, our study found that a third of children in a sexually active age had not been told their HIV status. Previous studies of children in Ghana with different mean ages have established different disclosure rates. The reported ages and means; 4–19 years (11 years), 6–17 years (10.4 years)), 13–22 years (16.9 years) have presented low child disclosure prevalence. Our finding reflect similar pattern reported by previous studies on child disclosure in Ghana despite the varying ages of children recruited and the difference in their mean and median ages (Hayfron-Benjamin et al., 2018; Kenu et al., 2014; Gyamfi et al., 2017).

A much recent study in Zimbabwe has reported high disclosure prevalence level of 67% (mean disclosure age of 11 years) among 372 children aged 9–15 years though equally higher prevalence of non-disclosure (64%) have been reported in recent studies in Malawi (Kalembo et al., 2019; Finnegan et al., 2019). Consistent with views expressed by Tadese *et al.* in Ethiopia and Vaz *et al.* in the Democratic Republic of the Congo, the varying and non-consistent disclosure rates in Ghana show how localized the issue of disclosure is necessitating context specific responses (Tadesse et al., 2015). This view is highly corroborated by the WHO (WHO, 2011). Our results of more than half of caregivers being HIV positive is consistent with the general pattern where majority of primary caregivers of infected children are themselves positive, though lower than results reported by Tadese *et al.* (72%) and Negese *et al.* (62%) (Tadesse et al., 2015; Negese et al., 2012).

The population of children with undisclosed status were generally younger compared to children with disclosed status. The median age at disclosure of 9.5 years is consistent with and falls within similar range of previously established findings in Ethiopia 9.9 years, Zambia–10.39 years and Ghana-10.9 (Biadgilign et al., 2011; Kallem et al., 2011; Lencha et al., 2018).

The study observed that as child aged, disclosure increased. This association was rather not statistically significant. The finding of non-significant association between increasing age and increasing child disclosure does not support recent findings by Finnegan et al. where child disclosure peaked around ages 13–15 years (Paintsil et al., 2015; Kallem et al., 2011; Finnegan et al., 2019; Brown et al., 2011 Sep 5). Contrary to several studies where child's age was associated with disclosure, child age was not significantly associated with disclosure in this study. Child's age did not independently influence child status disclosure (AOR = 11, p = 0.08; OR = 6.3, p = 0.03) (Biadgilign et al., 2011; Lencha et al., 2018). However child age was significantly associated with disclosure in the univariate analysis but was not independently associated with disclosure. This was possibly due to large within group variation of proportion of disclosed children for the age cohorts particularly age 14–18 compared to the lower ages

Though gender of child was found not to be significantly associated with child disclosure status in this study, a higher number of male children knew their HIV status compared to female children. The finding of non-significant association between disclosure status of child and child's gender contrast previous findings by Negese *et al.* in Ethiopia and Brown *et al.* in Nigeria, where disclosure and child gender were significantly associated (Negese et al., 2012; Brown et al., 2011 Sep 5). Our findings are rather consistent with those reported in Zambia and studied by Negese and others. These studies had found no association between gender and disclosure status (Tadesse et al., 2015; Tsuzuki et al., 2018). These corroborating and contrasting findings of the link between disclosure and child gender shows the non-uniformity of disclosure and its association with gender status of child.

The mean age at which caregivers intend disclosing the HIV status of undisclosed positive children was 16.28 (±2.96) years. This is a by far an advanced age for disclosing children status to them compared to Gyamfi *et al.* finding of 14.9 years and the previous results of our group's qualitative study where 10 years was a child preferred mean age of disclosure (Gyamfi et al., 2017; Appiah et al., 2019). Notwithstanding, nearly a half of caregivers did not have in mind a particular age of the child at which they were willing and able to disclose. It raises concern about caregiver's belief in the importance of early disclosure to the wellbeing of their children. This observation has a major setback implication for meeting the first 90% on the global goal of 90/90/90 and reiterates the need for more education on allaying caregiver's fears. This will enable caregivers appreciate the essence of child status disclosure and its effect on the quality of life of an HIV infected child.

The study findings suggest that, caregivers who have the skill and desire to disclose to their children are more likely to do so at an early stage compared to those who may not have the skill. This is corroborated by studies from Malawi where knowledge lack explained why 19% of caregivers had not disclosed their children's HIV status to them with a further 85% of health care workers considering skill know how as a principal barrier to disclosure(Kalembo et al., 2018; Kalembo et al., 2018). This prolongs the disclosure. Although caregivers who have reservations may have had adequate training similar to other caregivers or been exposed to similar barriers to disclosure, the majority remain unfazed about the need for early disclosure to their children. This is backed by the proportion of caregivers who did not have any intended year in mind to disclose to their children, and further supported by those who desire to disclose when children aged 16 years.

Our study did not identify caregiver's education level of influence on disclosure, unlike as reported by Kenu *et al.* and Paintsil *et al.*, though adequacy of knowledge on HIV illness and how to go about with disclosure may play a role in the disclosure patterns (Paintsil et al., 2015; Kenu et al., 2014). Low educational level of caregivers reflected in the limited HIV knowledge of caregivers could explain caregiver's ill-informed notion of acting in child's best interest by delaying disclosure. This could partly explain why many caregivers delayed disclosure. This shows the existence of a sharp contrast between caregiver ideal disclosure situation to child and practical disclosure engagement. This is critical particularly when it is grounded in the eclectic theoretical disclosure model. The delayed age at which caregivers of children with undisclosed status intend to disclose to their children does not appear in the children's' best interest. Neither does it demonstrate caregiver willingness to secure child disclosure support to initiate disclosure at a comparatively younger age of the child (Reynolds et al., 2015). This however demonstrates a shift of interest from the child to the caregivers.

Caregivers may thus be acting with limited knowledge of what defines child best interest. They may not consider this denial and prolonged age of disclosure as a violation of their child's right. The observation that caregivers may be violating their children's own right unnoticed have been strongly emphasized in the South African national guidelines on disclosure to children and adolescents with HIV and TB (National Department of Health SA, 2016). Denial of child right within non-disclosure context for which right violations and child right infringement occurs includes child right to non-discrimination, highest attainable medical care and enjoyment of the best attainable state of physical, mental and spiritual health. It additionally includes the child's right to have access to information on health promotion and right to the prevention and treatment of ill-health and diseases. Denial in disclosing child status to him or her at a comparatively old age amounts to the violations of several of the child human rights provisions espoused in international treaties and national laws (ACRWC, 1999; Nations Human Rights, 2014).

Although previous researchers have not considered the issue of prolonged non-disclosure as a child right violation, several child right provisions of the Convention on the Rights of the Child (CRC) and of the African Charter on the Rights and Welfare of the Child (ACRWC) are violated (ACRWC, 1999; Nations Human Rights, 2014). Caregiver prolonging of child disclosure may not necessarily be deliberate, but as a result of limited knowledge. In addition, caregivers contemplate between guilt, child possible emotional outburst and underestimate of child's evolving capacity necessitating disclosure (Appiah et al., 2019). The studies of Vaz *et al.* in Kinshasa in The Democratic Republic of the Congo and Brown *et al.* in South West Nigeria corroborates our finding and reiterates the observation about how most caregiver consider their children as being too young to disclose to.–Many caregivers have become overprotective of their children and potentially underrating their evolving capacity (Brown et al., 2011 Sep 5; Vaz et al., 2010). A transparent interpersonal communication strategy between caregivers and with their children anchored on trust and empathy is required (Vaz et al., 2010).

A greater number of children with disclosed status had their disclosure facilitated by the ART clinic nurses. However, among caregivers of undisclosed children, their preference of who to disclose HIV status to the HIV infected children in the years to come was themselves. The reasons for the difference in preference for who to initiate disclosure to the child between caregivers of disclosed children and caregivers of non-disclosed children remain unexplored. It is possible that caregivers of disclosed children might have shared unfavourable experiences encountered with caregivers of undisclosed children when they allowed clinic nurses to disclose to their children. This possible reason is corroborated by the significant association between child disclosure status and caregiver belief that disclosure should be done by only family members (Hayfron-Benjamin et al., 2018; John-Stewart et al., 2013).

In our present study, children with TB/HIV co-infection constituted a 12 percent of the entire number of children enrolled. The HIV/TB co-infection rate is lower compared to previous reported prevalence of 27% for children under age 15 in the Volta region of Ghana (Osei et al., 2017). Much more effort and attention is required to address the challenge of HIV/TB co-infection for children and adolescents as it increases their vulnerability and adds to the current disclosure challenge that this study seeks to address. This adds to the growing concern of the double burden that TB infection presents to children and adolescents living with HIV as compared to adults. The finding reflects a (Tarekegne et al., 2016; van der Werf et al., 2016).

Comparing the difference in caregiver beliefs and perceptions and their association with disclosure, significant difference existed. The difference existed caregiver's fear of accidental disclosure, disclosure deteriorating child health and belief that disclosure should be done only by child family members. Though it remains difficult in attributing what accounts for these variations as was observed by Vreeman *et al.* in Kenya, it must be understood that the Northern Ghana and Southern Ghana share significant difference in domains such as culture, language, religion, health access and health seeking behaviour (GSS, 2010; Vreeman et al., 2014).

Our study showed several child and caregiver factors that were associated with child status disclosure. Only children who repeatedly asked their caregivers the reason for the frequent (HIV) medication intake significantly and independently predicted child status disclosure in the multivariate analysis. A child living in Upper East, Northern or Ashanti region despite indicating significant association in the bivariate did not significantly and independently influence the disclosure of child HIV status in the multivariate analysis. Among the proportion of disclosed children, many children lived in Northern Ghana (59.5%) compared to Southern Ghana (40.48%).This explains and confirms the finding of one third of all disclosed children found to be living in Upper East region as compared to children who lived in the Northern region and Ashanti region.

Thus, the finding that a comparatively higher proportion of disclosed children lived in Upper East region is remarkable. This finding is remarkable comparing the uneven and disadvantaged health resource in the Upper East the Northern and Ashanti regions of Ghana. The Northern region is predominantly of Islamic faith adherents who rarely conduct premarital HIV test and counselling before marrying. The region has the lowest national HIV prevalence possibly due to the low testing rate for HIV. None of the study sites sampled from the Upper East region has had a history of being specialised dedicated clinic like the HIV/STI clinic at the Tamale Teaching hospital in the Northern region referral or specialized child and adolescent HIV clinics like Suntreso hospital in the Ashanti (Southern Ghana). More so the Upper East region is disadvantaged resource wise and have unfavourable health outcome such as under-five mortality of 128 per 1000 live births compared to 75 per 1000 births in Southern Ghana (Ghana Statistical Service, 2010).

It remains unclear what might be responsible for the higher disclosure rates in Upper East region over Northern region and Ashanti region, though it will not be far-fetched to consider possible clinic specific factors such as staff personal motivation, different cultural groupings of caregivers and health care providers who may share diverse opinions on disclosure and cost to clinic attendance (Vreeman et al., 2014).

Limitation of the study

Our study has a potential limitation in its design - facility based cross-sectional- in terms of establishing permanent causality. Clinic and staff motivation factors may affect disclosure patterns in the facilities. However, this was catered for in the design phase of the study via a careful selection of 12 study sites across the southern, northern, rural and urban parts of Ghana to offer much more representative and generalizable findings for paediatric/adolescent disclosure in Ghana. Despite attempts at accessing partial disclosure, we were unsuccessful as caregivers had difficulty differentiating between partial, prepared, complete, unprepared involuntary and accidental disclosure process. The study was designed to have a 100% response rate The relatively low response rate of 71% and the low recruited number from the Northern region remain a challenge to the study. It is also possible that caregiver may have given some inaccurate responses. The study might fall victim to social desirability biases though efforts were made to conveniently see caregivers outside the hospital wards. Our study did not explore the effect of disclosure on the mental and psychosocial outcomes.

A more longitudinal cohort mixed method study may be adequate in exploring these domains of child disclosure. Another limitation of our study, is that, despite the random sampling approach adopted, the sampled population (child-caregiver dyads) were more skewed towards children of younger ages. However, the median age of the children studied did not differ significantly from similar studies conducted on positive children within Ghana and the Sub region. Our study is limited by its inability to verify the content of the disclosure message. We could not authenticate whether children had been partially or fully told they were HIV positive.

5. Conclusions

This study to the best of our knowledge is the largest and cohort of caregiver/children dyads across 3 different regions in Ghana suggests low prevalence of HIV disclosure to infected children. The study and established the unique association between child disclosure and the region of residence. In our study, children recruited from the region with comparatively less resourced health facilities and ART clinics had the highest disclosure rates. This finding is significant as it has implication for improving health care delivery and re-echoing the need to extend health strengthening approaches beyond health facility level and personnel issues and to integrate client oriented and community-based factors. This should be complemented with the design of a child friendly HIV disclosure guideline that incorporates all the factors enabling disclosure while taking into account the barriers to child HIV disclosure. Factors such as age of child, age child started ART medication and caregiver willingness to disclose but with limited "know-how" were associated with disclosure though child frequent query about medication intake was the only independent significant predictor of disclosure. While single facility and region-bound studies on disclosure may present findings with in−country geographical limitation, our study shed light on the need to find out the factors accounting for the extremely low disclosure rates in the Northern region (comparatively health resourced region) and Ashanti region-a comparatively health resourced region than the Upper East region (less health resourced region).

Author contributions

SCYA conceived the study and designed the experiments, administered the questionnaires, analysed the data and wrote the first draft manuscript. JMD supervised the study and contributed to the writing of the manuscript. Study supervision and manuscript review were done by OI, MH and IK. All authors agreed to the publication.

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Data availability

Data may be available upon request.

Declaration of Competing Interest

There is no conflict of interest for this paper. The authors take responsibility for the content in this paper. Travel support received from the Church of Pentecost International and the CIH ^{LMU} Center for International Health, Munich, Germany did not in any way influence the findings in this paper.

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References

UNICEF. Paediatric care and treatment - UNICEF DATA [Internet]. 2018 [cited 2019 Feb 5]. Available from: https://data.unicef.org/topic/hivaids/paediatric-treatment-and-care/.

Joint United Nations Programme on Hiv/Aids. Global HIV & AIDS statistics 2018— 2018 fact sheet | UNAIDS [Internet]. 2018 [cited 2019 Feb 5]. Available from: http://www.unaids.org/en/resources/fact-sheet.

UNAIDS. UNAIDS. Global HIV & AIDS statistics—2020 fact sheet. https://www.unaids.org/en/resources/fact-sheet [Internet]. 2020 [cited 2020 Nov 16]. Available from: http://www.unaids.org/en/resources/documents/2018/UNAIDS_FactSheet.

Mutanga, J. N., Mutembo, S., Ezeamama, A. E., Song, X., Fubisha, R. C., Mutesu-Kapembwa, K., et al. (2019). Long-term survival outcomes of HIV infected children receiving antiretroviral therapy: An observational study from Zambia (2003–2015). *BMC Public Health, 19*(1), 115.

WHO. Global update on HIV treatment 2013: results, impact and opportunities. 2013 [cited 2019 Feb 5]; Available from: http://apps.who.int/iris/bitstream/handle/10665/85326/978?sequence=1.

UNAIDS. Criminalisation of HIV Non-Disclosure, Exposure and Transmission: Background and Current Landscape. 2012 (February).

Vaz, L.M.E., Maman, S., Eng, E., Barbarin, O.A., Tshikandu, T., Behets, F. (2011). Patterns of Disclosure of HIV-Status to Infected Children in a Sub-Saharan African Setting. Journal of Developmental and Behavioral Pediatrics 32(August 2008)307–315.

Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., … & Bunnell R. (2019). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. AIDS Behavior [Internet]. 2006 [cited 2019 Feb 6];1(10):85. Available from: https://link.springer.com/article/10.1007/s10461-006-9141-3.

Appiah, S. C. Y., Badu, E., Dapaah, J. M., Harriet, T., & Abubakar, M. (2015). Youth friendliness of sexual and reproductive health service delivery and reproductive health service utilization in Ghana. *International Journal of Innovation and Applied Studies, 10*(2), 716–725.

Rosen, S., Sanne, I., Collier, A., Simon, J.L. (2005). Rationing Antiretroviral Therapy for HIV/AIDS in Africa: Choices and Consequences. PLoS Medicine [Internet]. 2005 Sep 20 [cited 2019 May 24];2(11) e303. Available from: https://dx.plos.org/10.1371/journal.pmed.0020303.

Biadgilign, S., Deribew, A., Amberbir, A., Escudero, H.R., Deribe, K. (2011). Factors Associated with HIV/AIDS Diagnostic Disclosure to HIV Infected Children Receiving HAART: A Multi-Center Study in Addis Ababa, Ethiopia. Ho J, editor. PLoS One [Internet]. 2011 Mar 21 [cited 2019 Mar 11] 6(3) e17572. Available from: https://dx.plos.org/10.1371/journal.pone.0017572.

Madiba, S. (2012). Patterns of HIV diagnosis disclosure to infected children and family members: Data from a paediatric antiretroviral program in South Africa. *World Journal AIDS, 2*(03), 212.

Mengesha, M.M., Dessie, Y., Roba, A.A. (2018). Perinatally acquired HIV-positive status disclosure and associated factors in Dire Dawa and Harar, Eastern Ethiopia: a health facility-based cross-sectional study. BMJ Open [Internet]. 2018 Aug 30 [cited 2019 Mar 11];8(8) e019554. Available from: http://www.ncbi.nlm.nih.gov/pubmed/30166287.

Buor, D. (2004). Determinants of utilisation of health services by women in rural and urban areas in Ghana. GeoJournal [Internet]. 2004 Sep 1 [cited 2019 Mar 11] 61(1) 89–102. Available from: http://link.springer.com/10.1007/s10708-005-1929-6.

Britto, C., Mehta, K., Thomas, R., Shet, A. (2016). Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review. Journal of Developmental and Behavioral Pediatrics [Internet]. 2016 [cited 2019 Mar 11] 37(6) 496–505. Available from: http://www.ncbi.nlm.nih.gov/pubmed/27262128.

National AIDS Control Programme. 2017 HIV sentinel survey report. Accra: Paper presented at theNational HIV and AIDS Research Conference, Accra International ConferenceCentre; 20[Internet]. Accra: Ghana Health Service; 20Available from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ah=UKEwj4xYex_jsAhVLQMAKHSJXDd8QFjAAegQIARAC&url=http%3A%2F%2Fwww.ccmghana.net%2Findex.php%2Fpolicies-guidelines%3Fdownload%3D199%3Aart-guidelines-revised-2017&usg=AOvVaw2nCEcqw4yLr1KfKP1.

Ghana AIDS Commission. Ghana's HIV Fact Sheet 2019 [Internet]. Accra; 20Available from: https://www.ghanaids.gov.gh/mcadmin/Uploads/2019 FACT SHEET 22 06 2020 revised(1).pdf.

Dako-Gyeke, P., Dornoo, B., Addo, S. A., Atuahene, M., Addo, N. A., & Yawson, A. E. (2016). Towards elimination of mother-to-child transmission of HIV in Ghana: An analysis of national programme data. *International Journal for Equity in Health, 15*(1), 5.

Ghana AIDS Commision. Summary of the 2016 HIV Sentinel Survey Report [Internet]. 2016 [cited 2019 Feb 5]. Available from: http://ghanaids.gov.gh/gac1/aids_info.php.

Unicef, National Aids Control Programe GHS. National Paediatric Acceleration Plan for HIV 2016-2020. Accra; 2016.

Norman, I., Awiah, B., … FN-A in A, 2016 undefined. Homosexuality in Ghana. file.scirp.org [Internet]. [cited 2019 Mar 11]; Available from: https://file.scirp.org/pdf/AASoci_2016012014100379.pdf.

Hayfron-Benjamin, A., Obiri-Yeboah, D., Ayisi-Addo, S., Siakwa, P. M., & Mupepi, S. (2018). HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central Region of Ghana. Dec 22 [cited 2019 Mar 11];18(1): 365. Available from: *BMC Pediatrics [Internet]*.

Paintsil, E., Renner, L., Antwi, S., Dame, J., Enimil, A., Ofori-Atta, A., et al. (2015). HIV knowledge, stigma, and illness beliefs among pediatric caregivers in Ghana who have not disclosed their child's HIV status. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV*.

Dapaah, J. M. (2016). Attitudes and behaviours of health workers and the use of HIV/AIDS health care services. *Nursing Research and Practice, 2016*.

Ofori-Atta, A., Reynolds, N. R., Antwi, S., Renner, L., Nichols, J. S., Lartey, M., et al. (2019). Prevalence and correlates of depression among caregivers of children living with HIV in Ghana: Findings from the Sankofa pediatric disclosure study. *AIDS Care, 31*(3), 283–292.

Kallem, S., Renner, L., Ghebremichael, M., & Paintsil, E. (2011). Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS Behavior, 15*(6), 1121–1127.

Kenu, E., Obo-Akwa, A., Nuamah, G. B., Brefo, A., Sam, M., & Lartey, M. (2014). Knowledge and disclosure of HIV status among adolescents and young adults attending an adolescent HIV clinic in Accra, Ghana. *BMC Research Notes, 7*(1), 844.

GSS. 2010 population and housing census: summary report of final results. Ghana Statistical Service Accra; 2012.

Reynolds, N.R., Ofori-Atta, A., Lartey, M., Renner, L., Antwi, S., Enimil, A., et al. SANKOFA. AIDS [Internet]. 2015 Jun [cited 2019 Mar 11] 29 S35–45. Available from: http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00002030-201506001-00004.

Serovich, Julianne M. (2001). A test of two HIV disclosure theories. *AIDS education and prevention, 14*(4), 355–364.

Vreeman, R. C., Nyandiko, W. M., Ayaya, S. O., Walumbe, E. G., Marrero, D. G., & Inui, T. S. (2010). The Perceived Impact of Disclosure of Pediatric HIV Status on Pediatric Antiretroviral Therapy Adherence, Child Well-Being, and Social Relationships in a Resource-Limited Setting. *AIDS Patient Care STDS*.

Madiba, S., Mahloko, J., Mokwena, K. (2013). Prevalence And Factors Associated With Disclosure Of HIV Diagnosis To Infected Children Receiving Antiretroviral Treatment In Public Health Care Facilities In Gauteng, South Africa. Kramer K, (Eds.), Journal of Clinical Research In HIV AIDS And Prevention [Internet]. 2013 Jun 20;1(2): 13–23. Available from: http://openaccesspub.org/jcrhap/article/42.

Arrivé, E., Dicko, F., Amghar, H., Aka, A. E., Dior, H., Bouah, B., et al. (2012). HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. *PLoS One*.

Kalembo, F. W., Kendall, G. E., Ali, M., & Chimwaza, A. F. (2019). Socio-demographic, clinical, and psychosocial factors associated with primary caregivers' decisions regarding HIV disclosure to their child aged between 6 and 12 years living with HIV in Malawi. *PLoS One, 14*(1), Article e0210781.

Kalembo, F. W., Kendall, G. E., Ali, M., Chimwaza, A. F., & Tallon, M. M. (2018). Primary caregivers, healthcare workers, teachers and community leaders' perceptions and experiences of their involvement, practice and challenges of disclosure of HIV status to children living with HIV in Malawi: A qualitative study. *BMC Public Health, 18*(1), 884.

Gyamfi, E., Okyere, P., Enoch, A., & Appiah-Brempong, E. (2017). Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC International Health Hum Rights, 17*(1), 8.

Radcliffe, C., Sam, A., Matos, Q., Antwi, S., Amissah, K., Alhassan, A., et al. (2020). Sankofa pediatric HIV disclosure intervention did not worsen depression scores in children living with HIV and their caregivers in Ghana. *BMC Public Health, 20*(1), 1–10.

Appiah, S., Kroidl, I., Hoelscher, M., Ivanova, O., & Dapaah, J. (2019). A Phenomenological Account of HIV Disclosure Experiences of Children and Adolescents from Northern and Southern Ghana. *International Journal of Environmental Research and Public Health, 16*(4), 595.

Lachin, J. M., Matts, J. P., & Wei, L. J. (1988). Randomization in clinical trials: Conclusions and recommendations. *Control Clinical Trials, 9*(4), 365–374.

Weir, C. J., & Lees, K. R. (2003). Comparison of stratification and adaptive methods for treatment allocation in an acute stroke clinical trial. *Statistics in Medicine, 22*(5), 705–726.

Vreeman, R. C., Scanlon, M. L., Mwangi, A., Turissini, M., Ayaya, S. O., Tenge, C., et al. (2014). A cross-sectional study of disclosure of HIV status to children and adolescents in Western Kenya. *PLoS One*.

Finnegan, A., Langhaug, L., Schenk, K., Puffer, E. S., Rusakaniko, S., Choi, Y., et al. (2019). The prevalence and process of pediatric HIV disclosure: A population-based prospective cohort study in Zimbabwe. *PLoS One, 14*(5), Article e0215659.

Tadesse, B.T., Foster, B.A., Berhan, Y., Tang, J.W. (2015). Cross sectional characterization of factors associated with pediatric HIV status disclosure in southern Ethiopia. PLoS One [Internet]. 10(7) 1–9. Available from: http://dx.doi.org/10.1371/journal.pone.0132691.

WHO. Guideline on HIV disclosure counselling for children up to 12 years of age. - Google Search [Internet]. WHO Geneva. 2011 [cited 2019 Feb 18]. Available from: https://www.google.com/search?client=firefox-b-d&q=Guideline+on+HIV+disclosure+counselling+for+children+up+to+12+years+of+age+. . +

Negese, D., Addis, K., Awoke, A., Birhanu, Z., Muluye, D., Yifru, S., et al. (2012). HIV-Positive Status Disclosure and Associated Factors among Children in North Gondar, Northwest Ethiopia. Int Sch Res Netw ISRN. *AIDS, 485720*(7).

Lencha, B., Ameya, G., Minda, Z., Lamessa, F., & Darega, J. (2018). Human immunodeficiency virus infection disclosure status to infected school aged children and associated factors in bale zone, Southeast Ethiopia: Cross sectional study. Dec 15 [cited 2019 Apr 3];18(1):356. Available from: *BMC Pediatrics [Internet]*.

Brown, B. J., Oladokun, R. E., Osinusi, K., Ochigbo, S., Adewole, I. F., & Kanki, P. (2011 Sep 5). Disclosure of HIV status to infected children in a Nigerian HIV Care Programme. Available from *AIDS Care [Internet], 23*(9), 1053–1058 https://www.tandfonline.com/doi/full/10.1080/09540121.2011.554523.

Tsuzuki, S., Ishikawa, N., Miyamoto, H., Dube, C., Kayama, N., Watala, J., et al. (2018). Disclosure to HIV-seropositive children in rural Zambia. Dec 18 [cited 2019 Apr 4]; 18(1):272. Available from: *BMC Pediatrics [Internet]*.

Appiah, S., Kroidl, I., Hoelscher, M., … OI-… environmental research, 2019 undefined. A Phenomenological Account of HIV Disclosure EXperiences of Children and Adolescents from Northern and Southern Ghana. mdpi.com [Internet]. [cited 2019 Mar 12]; Available from: https://www.mdpi.com/1660-4601/16/4/595.

Kalembo, F. W., Kendall, G. E., Ali, M., & Chimwaza, A. F. (2018). Healthcare workers' perspectives and practices regarding the disclosure of HIV status to children in Malawi: A cross-sectional study. *BMC Health Services Research, 18*(1), 540.

National Department of Health SA. Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases [Internet]. Johanesburg: National Department of Health; 2016. p. 1–82. Available from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=2ahUKEwjn4_uFpMnhAhWzTBUIHbRXDyMQFjAAegQIAxAC&url=http%3A%2F%2Fwww.health.gov.za%2Findex.php%2Fhiv-aids-tb-and-maternal-and-child-health%3Fdownload%3D1696%3Ahiv-disclosure-.

African Charter on the Rights & Welfare of the Child (ACRWC). ACERWC: African Committee of EXperts on the Rights and Welfare of the Child. (1999). The African Charter on the Rights and Welfare of the Child [Internet]. 1999. Available from: http://acerwc.org/wp-content/uploads/2011/04/ ACRWC-EN.pdf.

Nations Human Rights: Office of the High Commissioner for Human Rights. (2014). Convention on the rights of the child. Available from: http://www.ohchr.org/en/professionalinterest/pages/crc.aspx, retrieved on the 04 march 20199.

Appiah, S., Kroidl, I., Hoelscher, M., Ivanova, O., Dapaah, J. (2019). A Phenomenological Account of HIV Disclosure EXperiences of Children and Adolescents from Northern and Southern Ghana. mdpi.com [Internet]. 2019 [cited 2019 Apr 12] 16(4) 595. Available from: https://www.mdpi.com/1660-4601/16/4/595.

Vaz, L. M. E., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling Children They Have HIV: Lessons Learned from Findings of a Qualitative Study in Sub-Saharan Africa. Available from *AIDS Patient Care STDS [Internet], 24*(4), 247–256 http://www.liebertonline.com/doi/abs/10.1089/apc.2009.0217.

John-Stewart, G.C., Wariua, G., Beima-Sofie, K.M., Richardson, B.A., Farquhar, C., Maleche-Obimbo, E., et al. (2013). Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. AIDS Care [Internet]. [cited 2019 Apr 4] 25(9) 1067–1076. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23256520.

Osei, E., Der, J., Owusu, R., Kofie, P., & Axame, W. K. (2017). The burden of HIV on Tuberculosis patients in the Volta region of Ghana from 2012 to 2015: Implication for Tuberculosis control [cited 2019 Apr 7];17(1):504. Available from: *BMC Infectious Diseases [Internet]*.

Tarekegne, D., Jemal, M., Atanaw, T., Ebabu, A., Endris, M., Moges, F., et al. (2016). Prevalence of human immunodeficiency virus infection in a cohort of tuberculosis patients at Metema Hospital, Northwest Ethiopia: A 3 years retrospective study. Dec 29 [cited 2019 Apr 7];9(1):192. Available from: *BMC Research Notes [Internet]*.

van der Werf, M.J., Ködmön, C., Zucs, P., Hollo, V., Amato-Gauci, A.J., Pharris, A. (2016). Tuberculosis and HIV coinfection in Europe. AIDS [Internet]. 2016 Nov 28 [cited 2019 Apr 7] 30(18) 2845–2853. Available from: http://www.ncbi.nlm.nih.gov/pubmed/27755106.

Vreeman, R. C., Scanlon, M. L., Mwangi, A., Turissini, M., Ayaya, S. O., Tenge, C., et al. (2014). A cross-sectional study of disclosure of HIV status to children and adolescents in Western Kenya. *PLoS One, 9*(1), 1–10.

Ghana Statistical Service. 2010 Population and Housing Census, National Analytical Report. 2013, 1–117.

9. Statement of pre-release and contribution

I was responsible for the day-to-day management of all the research activities till its completion. My responsibility to this work had to do with the conceptualisation of the study, design of study protocols, submissions to Ethical Committees for approval and the study itself. I took responsibility for the on the field data collection, data input and data analysis.

I am responsible for the collection of both - qualitative and quantitative data. My research assistant who used to work with the Bongo District Hospital, Maxwell Antwi supported me in the collection of the quantitative data from the Upper East region after I had trained him in the data collection. Other ART centre data managers also supported me by making arrangements for my meeting with caregivers

I took responsibility for the analysis of both the quantitative and qualitative data under the guidance of PD Dr. med Inge Kroidl, Olena Ivanova (MD, MPH), Dr Jonathan Mensah Dapaah and Prof. Dr. med Michael Hoelscher. After completing the initial draft of the manuscript, all my supervisors made critical inputs in them before the papers were submitted for pre-review and publication. I took the responsibility of lead and corresponding author and responded to reviewer comment under the guidance of my supervisors.

10. List of Publication

1. **Appiah, S.C.Y.**, Ivanova, O., Hoelscher, M., Kroidl, I., & Dapaah, J. M. (2020). Disclosure of HIV/AIDS status to infected children in Ghana-a north-south comparison of barriers and enablers. *Children and Youth Services Review*, 105753.
2. **Appiah, SCY**.; Kroidl, I.; Hoelscher, M.; Ivanova, O.; Dapaah, J.M. A Phenomenological Account of HIV Disclosure Experiences of Children and Adolescents from Northern and Southern Ghana. *Int. J. Environ. Res. Public Health* **2019**, *16*, 595.
3. Agyei-Baffour, P., Ansong, D., Osei, F. A., **Appiah, SCY**., Kwarteng, S. O., Nyanor, I., ... & Mensah, N. (2020). Social constructs, late recognition and decision making for managing fast breathing in children. *Children and Youth Services Review*, 105416.doi: https://doi.org/10.1016/j.childyouth
4. Haagsma JA, James SL, Castle CD, Dingels ZV, Fox JT, Hamilton EB, Liu Z, Lucchesi LR, Roberts NLS, Sylte DO, Adebayo OM, Ahmadi A, Ahmed MB, Aichour MTE, Alahdab F, Alghnam SA, Aljunid SM, Al-Raddadi RM, Alsharif U, Altirkawi K, Anjomshoa M, Antonio CAT, **Appiah SCY,** Aremu O, Arora A, Asayesh H, Assadi R, Awasthi A, Quintanilla BPA et al (2020) Burden of injury along the development spectrum: associations between the Socio-demographic Index and disability-adjusted life year estimates from the Global Burden of Disease Study 2017. *Injury Prevention*. 8 January 2020; 0:1-15. doi:10.1136/injuryprev-2019-043296
5. Murray, C. J., Callender, C. S., Kulikoff, X. R., Srinivasan, V., Abate, D., Abate, K. H. **Appiah SCY**,... & Abdelalim, A. (2018). Population and fertility by age and sex for 195 countries and territories, 1950-2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, *392*(10159), 1995-2051.
6. Dicker, D., Nguyen, G., Abate, D., Abate, K. H., Abay, S. M., **Appiah SCY**; Abbafati, C., ... & Abdelalim, A. (2018). Global, regional, and national age-sex-specific mortality and life expectancy, 1950-2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, *392*(10159), 1684-1735.

7. Barnie, AJ.,Nyarko, AS, Dapaah, JM. **Appiah, SCY**& Awuviry-Newton, K (2017) Understanding Youth Violence in Kumasi: Does Community Socialization Matter? A Cross-Sectional Study, Urban Studies Research, Volume 2017 , Article ID 1565602, 10 pages https://doi.org/10.1155/2017/1565602
8. Badu, E., Opoku, M. P., & **Appiah, S. C.Y** (2016). Attitudes of health service providers: the perspective of people with disabilities in the Kumasi Metropolis of Ghana: original research. *African Journal of Disability*, *5*(1), 1-8.
9. Dapaah, J.M., **Appiah, SCY**., Amankwaa, A. and Ohene, L.R. (2016) Knowledge about Sexual and Reproductive Health Services and Practice of What Is Known among Ghanaian Youth, a Mixed Method Approach. *Advances in Sexual Medicine*, **6**, 1-13.
10. **Appiah, SCY**, Dapaah, JM & Awuviry-Newton, K (2016) Reflections on Research Communication, Dissemination and Uptake to impact Outreach, British Journal of Education, Society & Behavioural Science, 18(3), 1-9
11. Dapaah, J.M., **Appiah, SCY**, Badu, E., Obeng, B. Ampiah V (2015) ‘Does facility based sexual and reproductive health services meet the needs of young persons? Views from cross section of Ghanaian Youth’, *Advances in Sexual Medicine,2(5)*
12. Badu, E., Peprah, O.M., **Appiah, SCY**., Agyei-Okyere, E (2015) Financial access to healthcare among Persons with Disabilities in the Kumasi Metropolis of Ghana’. *Disability, CBR & Inclusive Development, 26*(2), 47-64.ttp://dx.doi.org/10.5463/dcid.v26i2.402
13. **Appiah, SCY**, Badu, E., Dapaah, J.M., Harriet T., Abubakar, M. (2015) ‘Youth friendliness of sexual and reproductive health service delivery and reproductive health service utilization in Ghana*’, International Journal of Innovation and Applied Studies,10 (2),716-725*
14. **Appiah, SCY** (2015 Perceptions of Care, Socio-Demographic Characteristics and Health Care Utilization among Health Insurance users in Ghana. *Journal of Social Sciences*, 11(2) DOI: 10.3844/jsssp.2015

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I hereby declare, that the submitted thesis entitled

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