

# A cross-sectional study on caregivers' perspective of the quality of life and adherence of paediatric HIV patients to highly active antiretroviral therapy

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## Research article

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# Abstract

**Background** Non-compliance to highly active antiretroviral therapy (HAART) can lead to sub-therapeutic drug concentrations in children leading to emergence of drug resistance and poor quality of life in children with HIV/AIDS. This study assess the response of caregivers for determination of the percentage adherence, child and caregivers' demographics and related characters to the four domains of quality of life in children (aged 14 years and under) on HAART. **Methods** A cross-sectional survey was done for 188 paediatric patients accompanied by their caregivers' attending Ola During Children's Hospital and Makeni Government Hospital between September and November 2016 in Sierra Leone with ethical approval obtained from the Sierra Leone Ethics and Scientific Review Committee; Directorate of Policy and Planning, Ministry of Health and Sanitation. Adherence to HAART was measured as no indication of a missed dose in the past week or month using three adherence questions on dose in the past week or month. Quality of life was assessed using the four domains of the Quality of life summary questionnaire (WHOQOL-BREF) as the dependent variable and the demographic characteristics of caregiver and child as the independent variable. Inferential test was used to determine the association between variables and the regression model to determine association of significant variables to the four domains of the WHOQOL BREF. **Results** The study showed 5.9% adherence among 188 paediatric HIV/AIDs patients. Caregiver HIV status and caregiver type were also found to be associated with quality of life domains with high mean values for HIV positive caregivers and caregiver type that included a member of the nuclear family (father, mother or siblings). **Conclusion** This study showed strong association for involvement of caregiver that includes the nuclear family, caregiver's knowledge of their HIV status and adherence to HAART. Therefore, these factors can improve the quality of life of paediatric HIV/AIDS patients on highly active antiretroviral therapy.

## Background

Children and adolescents make up 33.3% of the world's population and a major part of the world's future [1]. On a global scale in 2014, 33.3% of the two million six hundred children aged 0 to 15 years are currently on treatment for Human Immunodeficiency Virus (HIV) infection in a world in which HIV/AIDS is the second most significant cause of death amongst adolescents and a leading cause of death in Africa amongst teenagers most of whom acquire HIV as babies [2]. A Joint United Nations Program on HIV/AIDS (UNAIDS) 2016 estimates showed that 28% of children aged less than 14 years are living with HIV in Western and Central Africa with 40% of these children dying from AIDS related illness.

A systematic review of over fifty studies revealed the use of varying methods for assessment of antiretroviral adherence in which 8 of these studies that evaluated HAART interventions showed that non-adherence was associated with worse quality of life [3]. However, a study in south-south Nigeria showed improvement in health-related quality of life when appropriate short-term HIV care was provided to an infected person. [4]. Similarly, studies using clinical and immunological markers have shown that early introduction of highly active antiretroviral therapy on Children with HIV/AIDS can have positive influence on the quality of life of children living with HIV (CLHIV) [5]. Good clinical outcomes have been observed

as a direct effect of adherence to HAART with known reduction in morbidity and mortality in children infected with HIV in Kenya [6]. In several African countries as compared with America and China [7] a systemic review indicates that African states do share similar drivers of non-adherence with western nations.

Non-adherence is defined as the discontinuation of part or all of the treatment regimen that includes missing dose, under-dose, over-dose and drug holidays [8]. The International Association of Physicians in AIDS Care recommends routine monitoring of adherence to prevent drug resistance and evaluate adherence interventions. Studies have also shown that there is no specific recommendation for monitoring quality of life in paediatric HIV patients [7] and achieving good quality of life requires high level of adherence of over 95% for paediatric patients on HAART for whom there is also no specific recommendation for monitoring adherence [7]. In addition, caregiver reports for ART adherence in children is usually consistently higher than adherence by other measures like pharmacy refill and other new technologies, suggesting that caregivers likely overestimate their child's adherence. Outside funded research settings, new technologies for Medication Event Monitoring Systems are usually too expensive than caregiver estimates for routine use [9]. Despite the limitations associated with caregiver estimates of adherence, it remains the most widely used method of adherence in most Low and middle-income countries.

A study of seventy five caregivers with HIV-positive children on antiretroviral therapy reported that non-adherence was due to stress from caregiver, old aged children, poor quality of life of caregiver and child's stress. The study also observed that caregiver related factors was the most strongly related to non-adherence in children [10].

In Sierra Leone, HIV prevalence is 1.5% overall national and a 5.8% prevalence amongst children [11]. Currently, the country has an overall 37.7% antiretroviral therapy coverage amongst all age groups with an estimated 383 children receiving antiretroviral therapy (ART) and 1,810 children in need of antiretroviral treatment [12].

The Ebola epidemic in 2014, reduced access to HIV/AIDS care because most parents were afraid of the Ebola stigma attached to visiting hospitals or afraid of becoming infected with the virus and mistrust for healthcare workers [13]. Post Ebola interventions such as identification of loss to follow-up (non-adherent to medication) and public sensitization have been implemented with the goal of improving hospital utilization among people living with HIV (PLHIV) [12]. Most studies on HIV/AIDS in Sierra Leone are focused on knowledge, attitudes and behavior of high risk group like sex workers and youths [14] [15] [16]. Currently, there is no research evidence on the level of adherence and the quality of life of children living with HIV/AIDS (CLHIV) in Sierra Leone.

## **Methods**

### **Study design, Setting and Population**

We conducted cross sectional study of caregivers accompanying HIV-infected children aged 14 years and under between 1<sup>st</sup> September and 30<sup>th</sup> November 2016. A caregiver was defined in our study as a parent or guardian accompanying HIV-infected children aged 14 years and under.

We conducted our study at the HIV/AIDS clinics of the Ola During Children's Hospital (ODCH) and Makeni Government Hospital located in the Western and Northern regions of Sierra Leone respectively. These hospitals are the main referral hospitals in two of the four regions of Sierra Leone. A convenient sampling method was used to recruit caregivers accompanying HIV-infected children in our study. 200 caregivers accompanying HIV-infected children who attended clinic between 1st September and 30th November 2016 were invited to take part in the study.

### **Ethical approval**

Ethical approval was obtained to conduct this study from the Sierra Leone Ethics and Scientific Review Committee (SLESRC); Directorate of Policy and Planning, Ministry of Health and Sanitation (MoHS) (approved on 1<sup>st</sup> September 2016 by SLESRC). The study nurses were trained to use the questionnaire and to behave in an ethical manner that allows for appropriate conduct of the study. The nurses informed the caregivers/guardians about the purpose of the survey and informed all caregivers that they had the right to participate or refuse participation in the study and that appropriate treatment would be offered in each situation. Each caregiver was asked to sign to indicate their acceptance for participation in the study. All data collected were also coded to prevent disclosure to any third party.

### **Outcome Measures and Data collection**

A validated WHO quality of life questionnaire (Quality of life summary questionnaire) was used [17], [18]. The questionnaire consisted of three parts that includes caregiver details, adherence questions and quality of life questions. All the information on the questionnaire was filled in by the nurse during a one-on-one session between the caregiver and the nurse in the HIV/AIDS clinic. A five point likert scale of "Not at all or very dissatisfied or very poor, A little or dissatisfied or poor, moderately or neither satisfied nor dissatisfied or neither poor nor good, Mostly or satisfied or good and completely or very satisfied or very good" was used to measure the quality of life of each participant. For the instrument to be adapted and utilized for the pediatric age group in Sierra Leone, sex life question under social relationship was not used as part of this questionnaire.

The dependent variables in this study were the four domains (Physical Health, Psychological Health, Environmental Health and Social Health) of the WHOQOL-BREF questionnaire for quality of life assessment [17] [18].

The independent variables were the demographic variables adapted from a previous study that measures adherence in pediatric patients [19]. Adherence was assessed using self-reporting measures for adherence to highly active antiretroviral therapy (HAART) by caregiver. Non-adherence was measured as "any indication of missed dose in the past week/month, or a dose more than an hour late". Adherence

was measured as “no indication of a missed dose”. This measure of adherence is still widely used in resource limited countries [20] although other studies showed that caregiver reports can overestimate the level of adherence in pediatric HIV/AIDS patients [19] [21].

Four trained data collectors (two nurses working in each of the two HIV/AIDS clinics at Ola During Children’s hospital and Makeni Government hospital) collected the data through interviewer-administered format.

## **Statistical analysis**

Statistical package (SPSS version 16.0) was employed during data analysis. Reliability and validity of the instrument were done by determining Cronbach’s alpha value for which alpha values greater than or equals to 0.7 was deemed acceptable [22] and [23] while correlations above 0.4 were considered acceptable [23]. Descriptive statistics was used to analyse categorical and continuous variables. The Pearson’s correlation was used to determine the level of agreement between the two overall Quality of life questions and the four domains of the WHOQOL-BREF. Chi square and Fischer’s exact tests were used to assess association between the independent variables and the level of adherence of paediatric patient to HAART. An independent t-test and analysis of variance tests were used to determine the association between participants’ characteristics and the average quality of life scores (transformed scores of four domains) and post-Hoc analysis was further conducted for domains that showed significant difference with caregiver or patient characteristics. Associated factors were also examined by backward multivariate linear regression to investigate the relationship between quality of life and patient characteristic with *P*-value less than 0.05 considered statistically significant. For stepwise multivariate linear regression analysis, Caregiver HIV status (Positive, negative and Don’t Know) was grouped into a binary data as Positive and non-positive. The non-positive data includes the data for patient with negative HIV status and patient with no knowledge of their HIV status. This help in determining the influence of sensitization programs on improving the quality of life of children with HIV/AIDS. Caregiver relation (1-mother/Father/Sibling, 2-cousin/Aunties/uncles, 3-Neighbours/Relatives outside home) was analyzed as Nuclear family (1) and Extended family (2, 3) to determine the influence of close relatives against other family members on quality of life of children with HIV/AIDS.

## **Results**

### **Demographic and other related characteristics**

Out of the 200 caregivers that was approached and invited, 188 consented to participate and their data were included in our final analysis. Table 1 shows that 74.5% of caregivers were aged 30 years or older, 76.6% of caregivers were female, 43.6 % were HIV positive and 33% caregivers do not know their HIV status, while 60.6% of caregivers are members of the nuclear family. 62.8% of the caregivers had problem with keeping to timing of medication with 35.1% of this occurring in the morning and 15.4 % of problems occurring in the evening. 56.9% of caregivers also agreed that they had difficulty in getting child to take their medication. 61.7% of children in the study were less than five years, 54.3% of the children were male,

and 76.1 % of the children were involved in an institutional nutritional program. Only 5.9% paediatric age group were adherent to Highly Active Antiretroviral Therapy (HAART) while 94.1% were non-adherent.

### **Factors affecting non-adherence**

The study showed that three factors that influence Paediatric HIV patient adherence to HAART includes child related factors, caregiver related factors and Institutional factors. Formulation problem (72.3%) and bitter medication (52.7%) were top on the list for child related factors. Top on the list for caregiver related factors are “did not want others to see” (61.7%), “was away from home” (60.6%) and “don’t know how to use the medication” (11.2%). For related institutional factors, 56.9% of the caregivers stated that they did not have money to take child to the hospital while 2.7% stated that “medicine was not available in the clinic”. (Table 2).

### **Factors affecting adherence**

No Statistical significant association was seen between independent variables and adherence to HAART (Table 3).

### **Assessment of quality of life in paediatric HIV/AIDs patient on HAART**

The average transformed scores of the four different domains with the highest average score of 63.1(SD 17.7) in the Psychological domain, while the lowest mean score was 44.1(SD 18.2) in the social relationship domain. (Table 4).

### **Association of independent variables and quality of life domains**

The mean scores of the study demography and characteristics among the four domains of quality of life showed significant difference for physical health, psychological Health and social health. There was significant difference in caregiver HIV status for physical health and psychological health domain and significant difference for caregiver relation for physical health, psychological health and environmental health. The study also showed significant difference for adherence in the physical health domain. The response from caregivers for children less than five years showed significant difference in social health. Female children also recorded mean scores higher than average for physical health and psychological health and Environmental health (Table 5).

Multivariate backward linear regression model after adjusting for other covariates revealed significant association between HIV status of caregiver. Our study also revealed a significant association between caregiver type to psychological health. A significant association is also seen for caregiver type to the environmental health domain (Table 6).

### **Validity and reliability of questionnaire**

Pearson’s Correlation was found to be significant for the four domains (Table 7) and Cronbach’s alpha was found to be 0.769.

## Discussion

This study provides an empirical evidence on the level of adherence and quality of life as well as their associated determinants among children living with HIV/AIDS in Sierra Leone.

### **Factors Affecting Non-adherence.**

The results of this study indicate that non-adherence among HIV positive paediatric patients was rife. Most of the caregivers had problems administering medication to their children in the morning than at any other time of the day. Such difficulty may be due to caregivers leaving home in the early hours of the morning for work/trade when the child is still sleeping or decided to skip dose due to the absence of food. [24]. The key reasons for the high prevalence of non-adherence in our study were formulation related factors such as taste of medication. Caregiver related factors were fear of discrimination from others, lack of support and or fear of disclosure. Institutional factors were absence of money to take child to hospital, inadequate knowledge on the use of medication and shortage of HIV/AIDS drugs in the clinic. Previous studies have identified these factors affecting adherence [25] [26]. Non-adherence among children with HIV/AIDS means not achieving the high level of adherence of 95% or more. This might result in sub-therapeutic blood concentrations, treatment failure, and emergence of drug resistance with resulting burden on the health system due to lengthy hospital stay and increased healthcare cost.

Therefore, it is important that the health care team is involved in medication counselling for the pediatric age group. This will possibly require a separate counselling session that is focused on assessing adherence of paediatric patient/caregiver, providing information on use of medication and reasons for medication use, HAART side effects and contraindication with the aim of improving the factors affecting patient adherence to their medication.

There is also the need for development of health policies or guidelines in all hospitals that take these factors (patient, institutional, caregiver) into consideration. Also, family support and community sensitization and awareness are crucial in preventing the stigma that may be associated with HIV/AIDS in the society.

Further assessment of demographic characteristic in our study that involvement of caregiver relationship with active involvement of nuclear family member (Father/Mother/Sibling) presented a 5.3 times more chance of being adherent than an extended family member. Although this was not statistically significant, studies have shown that involvement of a member of the nuclear family especially the father [19] can improve adherence to HAART and that caregiver report can correlate very well with viral load and clinical outcomes [27]. HIV/AIDS programs and community sensitization should encourage nuclear family members (if they are alive and well) towards active involvement in caring for their paediatric HIV/AIDS patients. Studies in tropical regions have shown that HIV/AIDS disclosure can improve adherence in children with HIV/AIDS on HAART [28, 29] and other studies have confirmed that disclosure of HIV status is a major issue for caregivers of paediatric HIV/AIDS patient on HAART [30] [31].

## **Assessment of quality of life in paediatric HIV/AIDS patient on HAART**

Quality of life was assessed using descriptive data that collects information on means data variability inferential statistics of quality of life domains. The highest mean score was obtained in the psychological domain reflecting caregivers' assessment of child's happiness, acceptance of child's bodily appearance and child's negative feelings. The lowest score was seen in the social domain reflecting caregivers' expressed dissatisfaction from friends and lack of support from other people with high variability in psychological and social domain compared to physical health and environmental health domain. The lowest mean score in the social domain of this study is similar to a study conducted in South India [31], Thailand [32] and China [33]. This shows the need for continued general public sensitization, caregiver education of the positive effect of treatment compliance and the need for paediatric treatment prioritization.

## **Association of Independent variables and quality of life domains**

A Post-Hoc analysis of HIV status (Positive, Negative and Don't Know) of the quality of life domains revealed that the difference was more significant between the Positive and Don't Know for Physical Health and Psychological Health and between the Positive and Negative for Environmental Health domain. Higher mean scores were observed and therefore quality of life among children accompanied by HIV positive caregivers' compared to children accompanied by caregivers that don't know their status. Higher mean scores were also observed for children that were accompanied by HIV positive caregivers' in the environmental health domain than children accompanied by HIV negative caregivers. Probably HIV positive caregivers were actively involved in sensitization and counselling sessions organized by HIV program, seek information to improve their health status, are possibly on antiretroviral treatment themselves and so they can appreciate the need for use of HAART in the suppression of viral load of the virus to enhance immunity [34].

Post-Hoc Analyses for caregiver type involved in paediatric HIV/AIDS care revealed significant differences between the participation of nuclear family and extended family in the psychological and environmental domains. Significant difference was observed between the nuclear family and the other family type with higher mean for nuclear family involvement than involvement of extended family and other family type. This can be translated to better health outcomes when a member of the nuclear family is actively involved in caring for the child. The child's physical health, psychological health and environmental health improved when an extended family member was involved in caring for the child than when other family type other than the nuclear family was involved. This provides an option for better child health in the absence (or death) of the nuclear family member. A study in Kenya also reported improved adherence when the mother or father was involved as caregiver [19].

In this study, a backward multiple linear regression model was used after adjusting for other covariates to assess the independent variables that showed significant association with the dependent variables, revealing the associations below.

The significant association between HIV status and physical health shows that a child accompanied by a caregiver without knowledge of HIV status had poorer Physical health than those accompanying caregivers with knowledge of their HIV status (positive/negative). Similarly, the results also showed that non-adherence was strongly correlated with poor physical health. The results of this study are further emphasized by UNAIDS best practices [34] and other studies on adherence which indicate positive relationship between awareness and good health [28]. Other study also indicated a negative relationship between children's awareness to HIV medication in which awareness was found to have poor adherence outcome [4]. Counselling sessions must focus the use of HIV medication and its benefits to improving quality of life of the paediatric age group. They must be informed about the high level of adherence required for achievement of better physical health and therefore quality of life of paediatric HIV/AIDS patients.

The results of this study revealed that a child's poorer psychological health is more associated with whether the caregiver is from the extended family as seen in a study in Kenya [35]. A study on paediatric HIV disclosure did not find statistically significant differences between pre-disclosure and post-disclosure quality of life [36]; therefore, disclosure should be encouraged at an appropriate time. Another study in Kenya revealed low prevalence of disclosure of HIV status to children with highlights of how disclosure may be related to key outcomes such as medication adherence, experiences of stigma and symptoms of depression. [37]

The study also showed that poor social health is more associated with children age group greater than or equal to 5years. This may be because of commencement of schooling amongst this age group. A research in South-South Nigeria showed that schooling could also account for the factors contributing to poor adherence amongst children [38].

The regression model did not show any association between social health and the independent variables. The results of this study revealed that children had poor environmental health when the caregiver was a member of the extended family compared to when a nuclear family was involved.

### **Assessment of bias**

The method of caregiver report to assess adherence is widely used in adherence studies in low resource settings despite its possibility of overestimating adherence measures [39]. Other methods that can possibly be used to assess the level of adherence are pill count, biological markers, medication event monitoring tool and other measures like pharmacy refill. There is need for further studies with use of other measures of adherence rather than self-reporting by caregivers in order to provide a more reliable evidence of measures of adherence among paediatric HIV/AIDS patient on HAART in these hospitals.

### **Strengths and limitations of study**

The study demonstrates good internal consistency for the WHOQOL-BREF. Cronbach's alpha value for assessing the reliability was 0.769 for the four quality of life domain scores. The validity was assessed using Pearson's Correlation Coefficient with statistically significant correlations found among two overall quality of life questions and the four domains, and most correlations greater than 0.4. Similar findings were reported in other studies with low social domain correlation values though significant [22] [18] [23] and in paediatric age group using the GHAC questionnaire that also uses the quality of life domains as in the WHOQOL-BREF [32]. The demographic data and adherence questionnaire have also been used in several other studies that measure the adherence and quality of life of paediatric HIV/AIDS patients [19] [32].

To date, no study has been conducted in Sierra Leone to determine the quality of life of pediatric HIV/AIDS patients on Highly Active Antiretroviral Therapy and its association to therapeutic adherence. The study is a cross sectional study of caregivers that fulfilled the inclusion criteria during the study period in the two hospitals, with a good sample size of 188 relative to the available data of 383 children [12] that are receiving antiretroviral therapy in Sierra Leone.

The result of this study is conservative and may not be used to generalize whole population because of the small sample size. These limitations should be considered when interpreting the results of this study. The study was able to detect statistically significant association with other variables, which suggests that it had enough power to be able to detect their association with adherence and/or quality of life.

## **Conclusion**

The study revealed a high level of non-adherence amongst paediatric HIV/AIDS patients on Highly Active Antiretroviral Therapy. The study showed that knowledge of HIV status, involvement of nuclear family and adherence is key for improvement of physical health, whilst involvement of nuclear family as caregiver was is key in improvement of psychological and environmental health. Therefore, involvement of a member of the nuclear family in the treatment of children with HIV/AIDS and caregivers' knowledge of their own HIV status can improve adherence to treatment and improve quality of life of children living with HIV/AIDS.

## **Declarations**

### **Ethics approval and consent to participate**

Approval was granted by the Sierra Leone Ethics and Scientific Review Committee. The nurses informed the caregiver/guardian about the purpose of the survey and assured them that appropriate treatment would be administered if they decide not to participate or participate in the study. Each Caregiver/guardian was also asked to confirm consent to the study by signing the consent form or thumb-print (illiterate respondent) after provision of study information by the nurses.

### **Availability of data and material**

The datasets used and/or analysed during the study are available from the corresponding author on reasonable request

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## **Authors' contributions**

ML and NNW developed the concept and proposal of the study. ML and PBJ provided guidance on research methods, sampling and analysis of the survey. ML and AJB prepared documents and framework for ethical approval and consent for the study. PBJ, NNW, HRW, SC and MHS provided expert review. ML trained the study nurses for data collection and prepared the write-up. ML and PBJ finalized the review of the study.

## **Declaration**

The authors declare no competing interests whatsoever.

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## **References**

- [1] UNAIDS, "Children AIDS Statistical Update," 2015.
- 
- [2] UNAIDS/UNICEF/WHO , "Global AIDS Response Progress Reporting and UNAIDS," 2014.
- 
- [3] Simoni JM, Montgomery A, Martin E, New M, Demas PA and Rana S, "Adherence to Antiretroviral Therapy for Pediatric HIV Infection: A Qualitative Systematic Review With Recommendations for Research and Clinical Management," *Pediatrics*, vol. 119, no. 6, 2007.
- 
- [4] Motilewa OO, Ekanem US, Onayade A and Sule SS, "A comparative Health Related-Quality of Life Among HIV Patients on Pre-HAART and HAART in Uyo South-South Nigeria," *Journal of Antivirals and Antiretrovirals*, vol. 7, no. 2, pp. 60-68, 24 April 2015.
- 
- [5] Choudhary GSNM, "Clinico-immunological profile and outcome of antiretroviral therapy in HIV positive Children," *Public Health Nutrition*, vol. 15, pp. 1442-1445, 2012.
- 
- [6] Scanlon ML and Vreeman RC, "Current strategies for improving access and adherence to antiretroviral therapies in resource-limited settings," *HIV/AIDS- Research and Palliative Care*, vol. 5, pp. 1-17, 2013.
- 
- [7] Thompson MA, Mugavero MJ, Amico KR, Cargill VA, Chang LW and Robert Gross EA, "Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from International Association of Physicians in Aids Care panel," *Annals Internal Medicine*, vol. 156, no. 11, pp. 817-833, 2012.
- 
- [8] Maduka O and Tobin-West CI, "Barriers to HIV treatment Adherence: findings from a treatment center in South-South, Nigeria," *International Journal of Tropical and Health*, vol. 4, no. 12, pp. 1233-1244, 2014.
- 
- [9] Muller AD, Jaspan HB, Myer L, Harling G and Bekker LG, "Standard measures are inadequate to monitor patient adherence in resource limited setting," *AIDS Behaviour*, vol. 15, no. 2, pp. 422-431, 2011.
- 
- [10] Mellins CA, Brackis-Cott E, Dolezal C and Abrams EJ, "The Role of Psychosocial and Family Factors in Adherence to Antiretroviral Treatment in Human Immunodeficiency Virus-Infected Children," *Paediatric Infectious Disease Journal*, vol. 23, no. 11, pp. 1035-1041, 2004.
- 
- [11] UNAIDS, "Fact sheet for children, state of the world Children country statistical tables," UNAIDS, 2015.
- 
- [12] National AIDs Secretariat, "Sierra Leone National AIDS response progress Report 2015," June 2015.
- 
- [13] UNDP, "Assessing the Socio-economic impacts of Ebola virus Disease in Guinea, Liberia and Sierra Leone- The Road to Recovery," Camilo J. Salomon, 2014.
- 
- [14] Larsen MM, Casey SE, Sartie MT, Tommy J, Musa T and Saldinger M, "Changes in HIV/AIDS/STI knowledge, Attitudes and Practices among Commercial Sex workers and military forces in PortLoko, Sierra Leone," *Disasters*, vol. 28, pp. 239-254, 2004.
- 
- [15] Casey SE, Larsen MM, McGinn T, Sartie M, Dauda M and Lahai P, "Changes in HIV/AIDS/STI knowledge, attitudes and behaviours among the youths in Portloko Sierra Leone," *Global Public Health*, vol. 1, no. 3, pp. 249-63, Oct 2006.
- 
- [16] Richter DL, Harris MJ, Coker AL and Fraser J, "Limiting the spread of HIV/AIDS in Sierra Leone: Opportunities for intervention," *Journal of Association of Nurses in AIDS care*, vol. 12, no. 5, pp. 48-54, 31 Oct 2001 .
- 
- [17] Hasanah CI, Naing L and Rahman ARA, "World Health Organisation Quality of Life Assessment: Brif Version in Bahasa Malaysia," *Med Journal Malaysia*, vol. 58, no. 1, pp. 79-88,

- 
- [18] Nedjat S , Holakouie Naieni K, Mohamed K , Majdzadeh R and Montazeri A, "Quality of life among an Iranian general Population sample using the World Health Organisation's quality of life instrument(WHOQOL-BREF)," *International Journal of Public Health*, vol. 56, no. 1, pp. 55-61, 2011.
- 
- [19] Vreeman RC, Nyandiko WM, Liu H, Tu W, Scanlon ML, Slaven JE, Ayaya SO and Inui TS, "Measuring adherence to antiretroviral therapy in children and," *Journal of the International AIDS Society*, vol. 17, no. 19227, pp. 1-10, 2014.
- 
- [20] Vreeman RC, Nyandiko WM, Liu H, Tu W, Scanlon ML, Slaven JE, Ayaya SO and Inui TS, "Comprehensive measure of caregiver-reported Antiretroviral Therapy Adherence for HIV-infected Children," *AIDS Behaviour*, vol. 19, no. 4, pp. 626- 634, 2016.
- 
- [21] Simon JM, Montgomery A , Martin E, New M, Dumas PA and Rana S, "Adherence to antiretroviral therapy for pediatric HIV infection: a qualitative systematic review with recommendations for research and Clinical Management," *Paediatrics*, vol. 119, no. 6, pp. 1371-83, 2007.
- 
- [22] Ha NT, Duy HT, Le NH, Khanal V and Moorin R, "Quality of life among people living with hypertension in a rural Vietnam community," *BMC Public Health*, vol. 833, no. 14, pp. 1-9, 2014.
- 
- [23] Gholami A, Jahromi LM, Zarei E and Dehghan A, "Application of WHOQOL-BREF in measuring quality of life in health-care staff," *Int J Prev Med*, vol. 4, no. 7, pp. 809-817, 2013.
- 
- [24] Fetzer BC, Mupenda B, Lusiyama J, Kitetele F, Golin C and Behets F, "Barriers to and facilitators of Adherence to Pediatric Antiretroviral Therapy in a sub-saharan Setting. Insights from Qualitative study," *AIDS Patient Care And STDS*, vol. 25, no. 10, pp. 611-621, Oct 2011.
- 
- [25] Shah CA, "Adherence to High Activity Antiretroviral therapy(HAART) in paediatric Patients infected with HIV/AIDs: Issues and Interventions," *Indian Journal of Paediatrics*, vol. 74, pp. 55-60, 2007.
- 
- [26] Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, "Guidelines for the Use of Antiretroviral Agents in paediatric HIV infection," 2016. [Online]. Available: <http://aidsinfo.nih.gov/guidelines> . [Accessed 30 October 2016].
- 
- [27] Nieuwkerk PT, Oort FJ and Nieuwkerk PT, "Self-reported adherence to antiretroviral therapy for HIV-1 infection and virologic treatment response: a meta-analysis.," *Journal of Acquired Immune Deficiency Syndromes.*, vol. 38, no. 4, pp. 445-448, 2005.
- 
- [28] Domek GJ, "Debunking common barriers to paediatric HIV Disclosure," *Journal of Tropical Paediatrics*, vol. 56, no. 6, pp. 440-442, 2010.
- 
- [29] Kallem S, Renner L, Ghebremichael M and Paintsil E, "Prevalence and Pattern of Disclosure of HIV Status in HIV-Infected Children in Ghana," *AIDs and Behaviour*, pp. 1-7, 2010.
- 
- [30] Alemu A , Berhanu B and Emishaw S, "Challenges of Caregivers to Disclose their Children's HIV Positive receiving Highly Active Antiretroviral Therapy at paediatric antiretroviral therapy clinics in Bahir Dar, North West Ethiopia," *Journal of AIDs and Clinical Research*, vol. 4, no. 11, pp. 1-7, 2013.
- 
- [31] Bharathi, Pai MS and Nayak BS, "Quality of life and Social Support among Children Living with HIV (CLHIV) in South India," *Journal of Nursing and Health Science*, vol. 3, no. 6, pp. 55-58, 2014.
- 
- [32] Oberdorfer P, Louthrenoo O, T. Puthanakit T, Sirisanathana V and Sirisanatha T, "Quality of life among HIV-infected Children in Thailand," *Journal of the International Association of*

- 
- [33] Xu T, "Quality of life of children living in HIV/AIDS-affected families in rural areas in Yunnan, China.," *Journal of AIDS Care*, pp. 390-396, 2010.
- 
- [34] UNAIDS point of view, "Paediatric HIV Infection and AIDs," UNAIDS Best Practice Collection, Geneva, 2002.
- 
- [35] Vreeman RC, Wiehe SE, Pearce EC and Nyandiko WM, "A systemic review of paediatric adherence to antiretroviral therapy in low and middle-income countries," *Paediatric Infectious disease Journal*, vol. 27, no. 8, pp. 686-691, 2008.
- 
- [36] Butler AM, Williams PL, Howland CL, Storm D, Hutton Nand Seage GR, "Impact of disclosure of HIV infection on Health-Related Quality of Life Among Children and Adolescents with HIV infection," *Paediatrics*, vol. 123, no. 3, pp. 935-943, 2009.
- 
- [37] Vreeman RC, Scanlon ML, Mwangi A, Turissini M, Ayaya SO, Tenge C and Nyandiko WM, "A cross-sectional study of disclosure of HIV Status to Children and Adolescents in Western Kenya," *Plos One*, 27th January 2014.
- 
- [38] Ugwu R and Eneh A, "Factors influencing adherence to paediatric antiretroviral therapy in Portharcourt, South- South Nigeria," vol. 16, no. 30, pp. 1-8, 29 September 2013.
- 
- [39] Stirratt MJ, Dunbar-Jacob J, Crane HM, Simoni JM, CZajkowski S, Hilliard ME, Aikens JE, Hunter CM, Velligan DI, Huntley K, Ogedegbe G, Rand CS, Schron E and Nilsen WJ, "Self-Report measures of medication adherence behaviour: recommendations on optimal use," *Transl Behav Med*, vol. 5, no. 4, pp. 470-482, 2015.
- 
- [40] Mukherjee A, Shah N, Singh R, Vajpayee M, Kabra SK and Lodha R, "Outcome of highly active antiretroviral therapy in HIV-infected Indian children,," *BMC Infectious Diseases*, vol. 14, p. 704, 2014.

## Tables

Due to technical limitations, tables 1-7 are only available as a download in the supplemental files section.

## Supplementary Files

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