

## Human Immunodeficiency Virus Infected Children and Attendant Social Issues Seen At a Nigerian Paediatric Anti-Retroviral Clinic

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### ABSTRACT

**Background:** HIV infected individuals have other challenging social issues apart from stigmatization. There is a need to fill the gap in knowledge on other attendant social issues associated with paediatric HIV disease and how they impact on care.

**Aim:** To document the social issues identified among children attending the paediatric anti-retroviral clinic of Nigerian tertiary hospital, with a view to discovering how this affects the care of the patients.

**Methodology:** Consecutive consenting HIV infected children and their care givers attending Ladoke Akintola University of Technology Teaching Hospital, Osogbo, South West Nigeria, were studied. Information on their socio-demographic details and perceived social challenges and how they affect care was obtained. Data obtained was analysed using SPSS version 16.

**Results:** Of the 55 children studied 43(78.2%) had social issues. Some children had more than 1 social issue. The ages of the children studied ranged from 3 months to 13years, with a mean of  $5.7 \pm 3.2$  and the 55 consisted of 28 boys and 27 girls giving a male to female ratio of 1.0: 1.0. The range and mean of the ages of the fathers was 20-71 years and  $43.2 \pm 10.3$  years respectively, while it was 20-54 years and  $34.7 \pm 5.8$  years respectively for the mothers. The social issues identified were non-disclosure of HIV status to the HIV infected children, fear of stigmatization of children and accompanying caregiver or parents, sero-discordant HIV status of the parents, death of one or both parents (single or double Orphans), single parent, divorced or separated parents, parental polygamy. Other social issues are low socioeconomic status, poor parental education; neglect of the HIV infected child and residence

in remote rural settings. All of the social issues listed impacted negatively in one way or the other on the care of the HIV infected children.

**Conclusion:** Social issues are common among HIV infected children. Effective strategies to mitigate against the effect of these social issues need to be identified and instituted in order to improve on care.

**Keywords:** Paediatrics, HIV, care, community

### INTRODUCTION

Studies on social issues in HIV infected individuals are many and common. [1-4] However, many of them are in adults and centre mostly around the issues of stigmatization and HIV status disclosure. In addition, available studies in paediatric HIV do not sufficiently reflect the social issues encountered in the day to day contemporary paediatric practice, in Africa, [1-6] and especially South West Nigeria.

Furthermore, many of the previous studies were conducted outside West Africa, [1-5] and at dates close to a decade. The present study was conducted to address these defects as well as to generate data on neglected or under researched social issues in our own and similar practice areas.

### METHODOLOGY

The study was carried out at the paediatric anti-retroviral clinic of Ladoke Akintola University of Technology Teaching Hospital, (LAUTECH) Osogbo, South West, Nigeria. Consecutive, consenting HIV infected children and their accompanying care givers seen at the paediatric Anti-retroviral clinic between

February 2013 and October 2015 were studied

Information was obtained from the participants using a proforma. Details of the information include the socio-demographic details of the HIV infected children and their care givers. Other details contained in the proforma include the reason for preference for care at LAUTECH paediatric anti-retroviral clinic and if there was any other Paediatric Anti-retroviral unit closer or more accessible to the family apart from our hospital. Information on disclosure of HIV status to the child by the care givers or others and further enquiries as to why HIV status disclosure was still pending and at what age the care givers/ parents would like to disclose the status to the infected children. Also, the HIV status of the parents of the child studied was also obtained. Additional information recorded in the proforma include the challenges encountered in obtaining care at the paediatric anti-retroviral clinic and enquiries as to how supportive the spouse of the caregiver/ parent had been concerning the care of the HIV infected child, is. Information concerning the educational attainments and occupation of the parents was also obtained.

Families were regarded as functional if both the father and mother were both alive and living and raising up their children together either in a nuclear family or in the context of an extended family. A family was regarded as dysfunctional in a situation where any of the above stated conditions could not be met. Social classes were computed for the families based on Oyedejis classification.<sup>[7]</sup> Separate scores were awarded to both parents for their educational attainments and their occupational rankings. The means of these scores was computed as the social class.<sup>[7]</sup>

Data was analysed with SPSS version 16.<sup>[8]</sup> Numerical variables were analysed as ranges, means and standard deviation, while categorical variables were analysed as percentages. Associations were tested using the chi square and P value less

than 0.05 was taken as statistically significant.

## RESULTS

### General characteristics

A total of 55 children and accompanying care givers were studied. The care givers were either the parents or close relations. These mothers in 43(78.2%), fathers in 8(14.5%), grandmother in 2(3.6%) and aunt in 2(3.6%) cases each

### Prevalence and pattern of social issues

Forth three (78.2%) of the 55 children studied had social issues and 12(21.8%) did not. Some of the 43 children had more than 1 social issue. The social issues identified were non-disclosure of HIV status to the HIV infected children, fear of stigmatization of children and accompanying caregiver or parents, sero-discordant HIV status of the parents, death of one or both parents (single or double Orphans), single parent, divorced or separated parents, parental polygamy, Additional social issues identified include residence in a remote rural location, neglect by father arising from extra-marital affairs and other undisclosed reasons, low parental education and socioeconomic status. Most of these social issues were said to adversely affect parental support for care of the HIV infected children in some cases.

### Age and sex distribution of the children studied

The ages of the children studied ranged from 3 months to 13years. The mean $\pm$  SD age of the children studied was  $5.7 \pm 3.2$ . Twenty seven (49.1%) of the 55 children were aged between 3months and 5years, 22(40.0%) aged between 6-10 years and 6(10.9%) aged between 11-15 years. Of the 55 children studied 28 were boys and 27 girls giving a male to female ratio of 1.0: 1.0

### Age distribution of the parents

The ages of the fathers ranged from 20-71 years with a mean of  $43.2 \pm 10.3$  years, while the range was 20-54 years with a mean of  $34.7 \pm 5.8$  years for the mothers.

### **Family settings**

Thirty seven (67.3%) of the 55 children were in monogamous family settings, while 17(30.9%) were in polygamous family settings and the remaining 1(1.8%) raised by a single parent (mother). Of the 55 children studied 31(56.4%) were living in functional families while the remaining 34(43.6%) were from dysfunctional families. Of the 34 from dysfunctional homes, 10(18.2%) were single orphans, 4(7.3%) were from polygamous homes where the father was not responsible for the care of the children, 3(5.5%) were from families in which the parents were separated for issues not disclosed, 2(3.6%) were complete orphans and another 2(3.6%) had non-supportive fathers because of sero-discordant HIV status with their mothers, 1(1.8%) child each was from a family in which the parents were either divorced, or father was both non-committed to care of his child and was having extra-marital affairs. The remaining one dysfunctional family was that of a single mother in a case where the father was alive and not legally separated from the mother, but had no commitment to the care of the child or the mother.

### **Orphans**

There were two (3.6%) children who had lost both parents (complete orphans) and 10(18.2%) single orphans that had lost either their father or mother. Of the 10 children that had lost either parent, 5 had lost their fathers and 5 lost their mothers

### **Mode of infection of the children studied**

The mode of transmission of HIV to the HIV infected children was horizontal in 3(5.5%) and vertical in 52(94.5%)

### **Parental educational attainments**

Two (3.6%) of the fathers had no formal education, 14(25.5%) had only primary school and equivalent education, 12(21.8%) had secondary school and equivalent education, while the remaining 27(49.1%) had tertiary education. Concerning the mothers 5(9.1%) had no formal education, 15(27.3%) received

primary school and equivalent education, 16(29.1%) had secondary school education and the remaining 19(34.6%) had tertiary education.

### **Social classes of the children studied**

Of the 132 children studied 4(7.3%) were from social Class I, 15(27.3%) from social class II, 16(29.1%) from social class III, 19(34.5%) from Social Class IV and 1(1.8%) from social class V. Thus 19(34.5%) children were from the upper social classes, 16(29.1%) from the middle classes and 20(38.4%) from the lower social classes. Of the 19 children in upper social class 15(78.9%) had social issues, while 11(68.8%) of the 16 children in the middle social class had social issues and 17(85.0%) of the remaining 20 in the lower social classes had social issues. ( $P = 1.39$ ,  $\chi^2 = 0.50$ ). Thus, the distribution of social issues was not influenced by social classes.

### **Disclosure and issues associated with disclosure.**

Of the 55 children studied only 2 children, aged 9 and 10 years, knew their HIV status. Two of the children to whom the parents did not disclose their HIV status had previously questioned their caregivers for there as ones they were on routine medications. These two children were aged 6 and 7 years.

### **Reasons for non-disclosure of HIV status to the children**

The reason for non-disclosure Of HIV status to the infected children by 31(56.4%) care givers, was that the child would not understand in, while 10(18.2%) wanted to keep the information confidential and not known to anyone else, 2(3.6%) did not know how to communicate the information, while another 2(3.6%) care givers felt it was not necessary as they felt the child will be healed and one person gave no reason. Some of the parents gave multiple reasons. The question was not applicable in the two caregivers that had disclosed to their children and in many of the children aged under 5, because some of these children had not started talking yet, also ability of the children to comprehend

the information was doubtful in most children aged under 5 year, thus informing the need to exempt them from this question.

#### **Age at which care giver would want disclosure of HIV status**

Of the 55 mothers studied 5(9.1%) felt this question was not applicable, 2(3.6%) suggested disclosure at the age of 7 years, 2(3.6%) at 8 years, 11(20.0%) at 10 years, 1(1.8%) at 11 years, 11(20.0%) at 12 years, 2(3.6%) at 13 years, 8(14.5%) at 15 years, 1(1.8%) at 16 years, 1(1.8%) at 20 years and 11 did not suggest any age at which they would like to disclose to their children, their HIV status. Of the 55 caregivers studied, 37(67.3%) wanted the doctors to disclose to the children, and 15(27.3%) did not.

#### **HIV status of parents and discordance**

Of the 55 fathers, the HIV status of the fathers was negative in 22(40.0%), positive in 18(32.7%) and unknown in 15(27.3%), while amongst the mothers the HIV status was positive in 46(83.6%) and negative in 9(16.4%).

Sixteen (29.1%) of the fathers had the same HIV status with their spouses, while 24(43.6%) were discordant while the status of the parents/ couple could not be classified in 15(27.3) because HIV status of one of either of the spouse was unknown.

#### **Number of sibling of the children studied**

The range of the number of siblings of the HIV infected children ranged from 0 – 5 with a mean  $\pm$  SD of  $1.5 \pm 1.3$ .

#### **Domiciles**

The majority 29(52.7%) of the children studied domiciled within Osogbo township, while the remaining 26(47.3%) lived outside of Osogbo. Some of the parents resided in locations as far as 200km from our hospital. Specifically 5 children with their care givers came from cities or towns where there were other paediatric ART clinics, but still came to our facility, because of the fear of being identified to have HIV in their constituency which might put them at risk of stigmatization. Domiciliary location was remote and rural in 8(16%) of the total 55 children studied.

Furthermore, these 8 children lived at least 120km away from our health facility and had no other nearer health facility with paediatric anti-retroviral clinic to access care. Additional challenges associated with rural remote domicile include difficulty in securing transport services to our Paediatric ART facility.

#### **Stigmatization**

Fear of stigmatization was the most common reason why care givers residing in settings where there were other nearer alternative health care settings but still attended our health facility. Five (9.1%) of the total 55 caregivers living further than 150kilometres from our hospital, attended our clinics because of a fear of been identified and linked with HIV by those familiar to them in their respective residential constituencies.

#### **Parental support for child**

Fourteen (25.5%) of the 55 fathers were not involved in the upkeep or care of their children. Death was responsible for 10 out of these cases, while the remaining 4 truly neglected their children for various reasons. Concerning the mothers, 8(14.5%) of the total 55 mothers studied were not involved in the care of their children. All the eight mothers had died.

#### **Association between family setting and functionality**

Of the 38 children from monogamous family setting 26(68.4%) had a functional family setting while of the 17 children from polygamous family setting 5(41.5%) had a functional family setting. ( $X^2 = 7.26, P = < 0.01$ )

#### **School Absenteeism and Missed work days**

Twenty (36.4%) children and their care givers raised the concerns that their attendance of the Paediatric anti-retroviral clinic has been responsible for missed school for the child and work days for the parent or caregiver. Furthermore, mothers who were the caregivers and who were HIV infected had to spend additional time in the health facility to attend to their personal

health needs or their own clinic appointments.

## DISCUSSION

The present study shows that the main social issues surrounding HIV infected children are similar to those documented in previous studies. [1,2,9,10,11] Those studies suggest that stigmatization is probably the most common and feared social issue associated with HIV disease infection. [1,2]

The present report shows that stigmatization is a major issue with parents as evidenced from their unwillingness to disclose the HIV status to their children, who they fear would probably divulge such information to others. The parents may consider that the children, especially at the younger ages may have neither an adequate understanding of the implication of the diagnosis nor the fear of the likely stigmatisation. Thus, most care givers withhold information on the HIV status of the children till the ages that they believe the children would have acquired enough maturity and discretion to handle the situation. Other reasons for non-disclosure in the present study were based on the caregivers' assumption that the children were still too young to understand and or the parents unable to satisfactorily communicate and explain the results. Our findings on disclosure in the present study are similar to those of previous researchers. [12,13]

The age at which to disclose has however been and remains a controversy and associated with disparities as also found in the present study. The current Nigerian National guidelines also, do not address this issue. [14] However this issue needs to be addressed because of the need for adherence to HAART and also the right of the child. However a review supported partial disclosure in early adolescence in order to avoid stigmatization. [13]

Another social issue that needs to be addressed is child abuse. This probably was the real issue lying covert around the cases of parental lack of care and support or even presented as neglect in the present study.

Reasons for this behaviour on the part of the fathers could be due to their search for alternatives sexual partners either through polygamy or extra spousal affairs which, is a socially deviant behaviour that may have several adverse impacts on the HIV infected child, being raised alone by a mother. Of course it can predispose to emotional and other forms of abuse by the mother who may be overwhelmed with care of herself and other children. Other people in the close society can also take advantage of the vulnerabilities to perpetrate other forms of abuse. The rights of children irrespective of their status need to be upheld and the care of the children needs to be safe guarded. Nawakesti et al also reported a few cases of paediatric HIV associated neglect in Uganda and other social needs highlighting the need for social support. [15] Even polygamy as a fall out of the discordant HIV status has many ill effects on the growth and health of children including morbid jealousy, suspicion and strife in the family.

Absenteeism of the children and their caregivers from school and work respectively was a concern arising from attendance of clinic appointments either for treatment of sickness or regular follow up on the part of the child and or their caregivers respectively. Previous studies have reported similar findings. [16-18] Both the child and HIV infected care givers may be attending busy clinics, the events which may extend to or even beyond five hours, considering clinic routines of, registration, health talk, consultation with the doctor, laboratory investigation, etc apart from the travelling time. A day may be lost by the caregiver and patient pair.

The predominant mode of transmission of HIV was vertical and the pyramidal structured age distribution, widest in the 3month to 5years group and narrowest in the above 10year age group implies that more children are still been infected vertically and that lots of effective interventions need to be undertaken to correct the anomalous demographic age pyramid associated with HIV infected

children. This unacceptably high rates of vertical transmission of HIV and the need to scale up prevention and treatment of HIV has been severally documented by previous studies. [14,19, 20]

The results of our study further show that a lot of issues in the care of HIV infected children and their care givers need to be handled sensitively. Indiscreet disclosure of HIV status in the hospital setting has been reported to lead to stigmatization. [21] Disclosure of HIV status of the child thus, needs to be handled wisely as it may affect family harmony and lead to non-commitment by a spouse and parents to separation or divorce. Thus, there is a need to train and re-train health workers managing HIV infected children along these lines with emphasis on confidentiality and the need to exhibit medical ethics and professionalism in the disclosure of results.

A considerable proportion of children studied were also orphans. Previous studies have shown that this is a common problem with children from the developing world. [20,22,23] There is a need to empower institutionalized care of orphans and vulnerable children in the hospital. The social workers should visit the community to support care when required.

Both children of the well-educated and illiterate parents were affected by social issues, in the present study, thus indicating that social issues in HIV infected children has no predilection for parental educational attainments. Similarly, all social classes had a fair representation of social issues, although the lower socioeconomic classes had the highest rates of social issues in our study. Our finding is consistent with previous reports from South Eastern and Western Nigeria, [22,23] However the study conducted by Onivre et al in the South Eastern parts of Nigeria, recorded a statistically significant difference of the proportion with attendant social issues in the lower socioeconomic classes.

The residential location of the studied children showed that more than half of the children attending our health facility

were from the study setting township. The ease of accessibility to our health facility is the most plausible reason for their greater majority of children and care givers patronizing this health facility. However, some other children with their families had to travel more than 100km to patronize our health facility, just because there were no other easily accessible alternatives. Previous studies have also indicated that the ease of accessibility of a health facility affects its patronage. [24, 25] Caregivers and children attending clinics from residential locations close to or about 100km without alternative health facilities represent a population that the government needs to cater for, in terms of provision of accessible health facilities.

However it must be noted that the care givers deliberately chose to patronise far away health facilities in the hope to avoid coming across people who might recognize and stigmatize them. It has been stated that the fear of stigmatization may discourage HIV infected children and their care givers from accessing the much needed care, thus leading to delay in presentation and non-disclosure of HIV status. [26,27]

The social determinants of health and related inequalities prevailing in a geographic setting have been shown to impact significantly on the overall health status of the residents in the setting. [28] The social issue identified in the present study viz; stigmatization, poor support of a spouse, for the care of HIV infected child, death of one or both parents (orphans), polygamy, etc are all forms of social disadvantage and they impact adversely on the health of the infected children. [29] Although, the present paper did not examine the details of the health effects on the issues, it is obvious that the HIV infected children are still worse off. For one, their mothers who are also socially disadvantaged have been shown to be worse care givers and the health of their children is worse. [30]

In conclusion social issues associated with HIV infected children are common and many. Issues such as stigmatization and residential location affect

how the children and their care givers access care. Disclosure of HIV status in the child or parents however, can have negative consequences on the family harmony and care of the child, if it is not handled discreetly. HIV disease can lead to other social issues such as missed school or work days in child or caregivers and neglect of the child. Thus there is a need to further study these attendant issues with a view of proffering effective strategies that will mitigate the effect of these social issues.

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