Research

Factors associated with HIV-status disclosure to HIV-infected children receiving care at Kilimanjaro Christian Medical Centre in Moshi, Tanzania.

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Abstract

Introduction: With the introduction of antiretroviral drugs HIV-infected children live longer. Disclosure of HIV diagnosis is increasingly an important and inevitable issue. Both healthcare providers and caregivers face challenges of disclosure to children. The objective of the study was to explore factors associated with HIV-status disclosure to HIV-infected children receiving care at Kilimanjaro Christian Medical Centre (KCMC).

Methods: A cross-sectional hospital-based study was conducted from October 2011 to April 2012. Study population included HIV-infected children aged 5 to 14 years, their caregivers and healthcare providers. Structured questionnaires were used to collect information. Children were asked the reason for hospital visits. Outcome of interest was HIV disclosure status. Data was processed and analysed using SPSS version 16.0. Multivariate logistic regression at 5% margin error was used to account for confounders. Results: A total of 211 children were enrolled with mean age of 9.7 (SD = 2.6; range 5-14) years. Only 47 (22.3%) children knew their HIV-status. The mean age of disclosure was 10.6 years. Most of disclosed children were aged above 10 years (p). Conclusion: Most of children were not disclosed. Ages, self medication, getting other support and parents/caregivers prior discussion were strong predictors of disclosure status.

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Introduction

Worldwide about 2.5 million children younger than 15 years of age are infected with HIV and 90% (2.3 million) of them live in Sub-Saharan Africa. Although the rate of new HIV infections has decreased, the total number of people living with HIV continues to rise because of increased life expectancy of those infected relative to the pre Antiretroviral Therapy (ART) era [1].

By 2009, in Tanzania it was estimated that 1.4 million people (5.7%), including adults and children, were living with HIV and children below 18 years accounted for 10% [1]. Globally, HIV-related deaths among adults have declined by 33% while that of adolescents aged 15 to 19 years have increased by 50% [2].

The increase of HIV services in low-resource settings and introduction of HIV counselling, testing and treatment coupled with ART during pregnancy has resulted in a dramatic drop in the rate of vertical transmission as well as significantly lowered HIV-related morbidity and mortality rate [2, 3]. As a result of the increased maternal survival coupled with introduction of long-term therapy of antiretroviral therapy, many children with HIV experience a less symptomatic early course of the disease and survive to older ages [4].

Consequently, the disclosure of HIV infection diagnosis to a child is becoming inevitable and an increasingly important issue as caregivers and healthcare providers face challenges of disclosure to children. Furthermore children have right to know their HIV-status and thus prevent transmission to others [5, 6].

In disclosing HIV infection to children, the American Academy of Pediatrics recommended that counselling to the caregiver be provided by healthcare providers, be individualized putting into consideration the child’s cognitive ability and developmental stage, and that disclosure is an on-going process. It also insisted that adolescents should know their HIV status and be fully informed in order to appreciate the consequences of their health including sexual behaviour and issues around their treatment [7].

The levels of disclosure vary widely in developing and developed countries from as low as 9% to high as 95% but with an average of 29%. Disclosure also seems to vary with age of the children; with older children above 10 years being more likely to be told their HIV status as compared to children who are less than 10 years. Many (82.6%) school-age children have not been disclosed [8-12].

The aim of the study was to explore factors associated with HIV-status disclosure to HIV-infected children receiving care at Kilimanjaro Christian Medical Centre (KCMC), with the expectation that the findings of this study will facilitate the formulation of relevant counselling strategies to parents/caregivers of HIV-infected children.

Results

Of 211 children involved in the study mean age was 9.7 (SD ± 2.6; range 5-14) years. Of these 100 (47.4%) were female.

Disclosure status

Based on parents/caregivers’ report, majority of children (n=112; 53.1%) had their serostatus undisclosed to them while nearly a quarter (n=52; 24.6%) had partial disclosure and only 47 (22.3%) had complete disclosure. Among 47 HIV-infected children who had their serostatus disclosed, the mean age was of 10.6 years (SD ± 1.7; range 6-14), about three quarters of them (74.5%) in the range of 10-14 years.

Children’s demographic characteristics by their disclosure status (Table 1)

Adolescents were more likely to have their serostatus disclosed than pre-adolescent (OR 0.04; 95% CI 0.01-0.10; p

Children’s clinical characteristics in the disclosed and non-disclosed group (Table 2)
At the time of enrolment into care and treatment, 113 (53.6%) of the children had advanced disease as defined by WHO clinical stage III and IV, but there was no statistically significant difference to those in WHO stage I and II in terms of disclosure status (p=0.955). Though it was at borderline statistically significant (p=0.051), children with CD4 counts of 350 cells/µL or less were twice more likely to have been told their HIV infection compared to those with CD4 counts of more than 350 cells/µL. Children who were taking medication self-supervised were significantly more likely to have been told about their HIV-status compared to those supervised by parents/caregivers or anyone else (OR 33.1; 95% CI 13.9-78.9; p

Disclosure of HIV status by parents/caregivers (Table 3)

Of 211 parents/caregivers of HIV-infected children, 173 (82.0%) were female. Age ranged from 20 to 81 years with a median (IQR) age of 39 (33-46) years. Majority (n=130; 61.7%) were parents of the infected child. Parents/caregivers whose age was above 35 years, were 1.9 times significantly more likely to disclose the child’s HIV-status than those aged between 20 - 35 years (OR 1.9; 95% CI 1.0-3.3; p=0.032). Parents/caregivers who had discussed HIV status disclosure with healthcare providers were more likely to disclose the child's HIV status (OR 4.4; 95% CI 2.2-8.7; p

Reasons for partial disclosure and non-disclosure

The 164 parents/caregivers who had partially disclosed or not disclosed the HIV-status to their children gave the following reasons for not doing so: 71 (43.3%) said children were too young to understand, 50 (30.5%) disclosure may cause negative emotional consequences like discrimination, 28 (17.1%) said the child may not be able to keep it secret and 15 (9.1%) did not know what and how to deliver the disclosure message.

Reasons for HIV-status disclosure

Common reasons for disclosure by the 47 disclosing parents/caregivers included: the child was becoming suspicious due to regular clinic attendances (n=17; 36.2%), child inquiring about illness (n=15; 31.9%), need for the child to understand his/her problem (n=11; 23.4%), child’s right to know his/her problem (n=8; 17.0%), child was very sick (n=5; 10.6%), death of parents (n=4; 8.5%) and 2 (4.3%) were compelled to disclose because the child had to start ART.

Predictors of HIV-status disclosure (Table 4)

Out of seven variables with p values less than 0.05, only four variables had statistical significance after multivariate logistic regression test. Child’s age, person supervising medication uptake to the child, support given to the child and discussion of child’s disclosure with healthcare providers were the major predictors of HIV-status disclosure to children.

 Responsible person to initiate disclosure to the child

Majority of parents/caregivers (n=138; 65.4%) indicated that the parent or caregiver alone should disclose about the illness to the child while 60 (28.4%) preferred healthcare providers to disclose the HIV-status to the child. Only 8 (3.8%) preferred both parents/caregivers and healthcare providers to initiate disclosure to the child and 5 (2.4%) caregivers indicated that anyone can do it.

Age at which the illness should be disclosed to the child

Forty one parents/caregivers (19.4%) preferred disclosure to happen between 6-9 years, while 170 (80.6%) preferred disclosure to happen between 10-16 years. The median age preferred for disclosure was 11 years (IQR = 6-16).

Healthcare provider’s perception on disclosure

Of the 25 interviewed healthcare providers, majority (n=13; 52%) were doctors, who had working experience with HIV-infected children of 3 to 5 years. Others were nurses (n=2; 8%), counsellors (n=3; 12%), pharmacists (n=3; 12%), social worker (n=1; 4%), medical record workers (n=2; 8%) and lab technician (n=1; 4%). Seventeen (68%) believed that the optimal age for general discussion about child’s disease is 5 to 9 years; and most of the healthcare providers (n=22; 88%) choose that age for the reason that children develop cognitive maturation. The majority of healthcare providers (n=15; 60%) believed that the age between 10 to 12 years is more appropriate to have specific discussion on HIV and 13 (52%) believed that caregivers should lead disclosure discussion with the help of healthcare providers.

Discussion

Our finding that 22% of children know their HIV-sero status is consistent with studies in Ghana (21%) [11] and Ethiopia (17.4%) [12], is higher than the findings reported in South Africa (9%) [10], but lower than the findings reported in Thailand (30.1%) [13], and in California (USA) (43.1%) [14]. The reasons for these variations could be that in South Africa the study population included children of younger age (5 months - 11 years), as opposed to that of our study participants (5 to 14 years), which is considered to be the time of cognitive maturation and hence the right time for disclosure. The different findings in level of disclosure in our study and Thailand is because in our study we confirmed with the caregivers that they really told the child that they have HIV/AIDS as opposed to Thailand where some caregivers told the children that they had the same infection as their mother. The high level of disclosure in United States may be due socio-cultural differences showing higher levels of expressiveness within the family and more intensive child-parent interactions [14], which is not the case in most African countries, including Tanzania.

Mean age of disclosure was 10.6 years which was different from 9.2 years, reported in Thailand [13] and 8.7 years found in Nigeria [15]. The reason for this age in disclosure in our set up may be because of lack of disclosure protocol in our setting and parents/caregivers reluctance to initiate disclosure.

Regarding reasons for not disclosing HIV-status to children, caregivers reported that disclosure did not happen because children were too young or not emotionally mature enough to be conveyed the message on HIV, not being able to keep a secret and it may cause negative emotional consequences like being stigmatized, discriminated, and become psychologically affected. These reasons are consistent with previous findings from Thailand and Nigeria [13, 15].

The large sample size in our study gave us a good picture of what is prevailing in our setting regarding HIV-status disclosure in children. Though we did stepwise multivariate logistic regression to account for confounders we still acknowledge the possibility of close proximity of ‘self-medication and age’ and this result should be interpreted with cautions.
Most of parents/caregivers in our study preferred disclosure to take place when the child is entering adolescence, i.e. at a median age of 11 years and above. These findings are consistent with those reported in South Africa [10], where caregivers perceived that a median age of 11 years is the best time to have general discussion regarding child’s illness and 12 years to tell the child specifically about HIV. Similar findings of an average age of 10.8 years were also reported in England [16]. However our findings differ from those in India and Ethiopia [17,12], which showed that majority of the caregivers wanted disclosure to take place during the mid-teen age (14-18 years). Caregivers who proposed mid-teen age believed that it is the age at which children become emotionally mature enough to cope with chronic disease and need sex education to prevent spread of infection. However, their argument may be risky because by mid teen age they may actually already involve in sexual activities and without knowing their status, risk transmission, and thus the need disclosure to take place before that age.

We found that 65% of parents/caregivers wanted themselves to be responsible for disclosure initiation and process of HIV-status to their children, consistent with findings reported in Thailand and Nigeria [13,15], where 57% and 63.5% of caregivers respectively believed that it was caregiver’s responsibility to disclose the child’s HIV-status.

Parents/caregivers who had discussed disclosure with healthcare providers were more likely to disclose HIV-status to their children, similar to findings reported in South Africa [10], where also caregivers who had discussion with healthcare providers on disclosure to their children were more likely to disclose. This may be due to the fact that parents/caregivers who had the opportunity to discuss disclosure with healthcare providers have more skills on handling disclosure to their children.

Children, who knew their HIV status, were more likely to take the pills themselves as compared to those who were not disclosed. Similar findings were reported in Ghana [11]. Disclosed children have been told the reason of taking the medicines and being responsible for taking their medication without caregiver supervision.

Children getting outside household support e.g. for transport costs and school fees, were twice more likely to know their HIV-status than those who do not get such support. Similar findings have been reported in the United States [6]. Most of HIV-infected children were orphans who needed help from other people. In the course of looking for help, the caregiver sees the need to reveal HIV status to the child.

We believe that disclosure is an ongoing process, commensurate with the child’s age and maturity. It starts with partial disclosure and becomes in due course complete disclosure. We would like to encourage further studies geared on assessing the psychological aspects, knowledge and long-term sequelae of children in both the disclosed and non-disclosed groups.

Conclusion

There was a low level of HIV-status disclosure in children. Efforts should be made to develop a disclosure protocol for healthcare providers, and parents/caregivers should be involved in disclosure protocol development. Healthcare providers should be encouraged to have formal discussion and also to provide health education and community sensitization to alleviate stigma and discrimination.

Parents/caregivers should be empowered on disclosure process techniques.

Competing interests

The authors have declared that no competing interests exist.

Authors’ contributions

LPM was involved in this study from the design to the writing of the manuscript. BH was involved in critical review. RNP contributed in study design. GK contributed in data analysis and interpretation. LM supervised all steps of this study.

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Table 1: Demographic characteristics of children by their disclosure status (n=211)

| Variable                      | Total | Disclosure status | p-value | OR (95% CI) |
|-------------------------------|-------|-------------------|---------|-------------|
|                               |       | Disclosed         | Not disclosed |       |             |
|                               |       | n=47             | n=164   |             |             |
|                               |       | No. (%)           | No. (%) |             |             |
| Sex                           | 211   | 47               | 164     |             |             |
| Male                          | 111   | 23 (20.7)        | 88 (79.3)| 0.568      | 0.8 (0.4-1.6)|
| Female                        | 100   | 24 (24.0)        | 76 (76.0)|             |             |
| Age (years)                   |       |                  |         |             |             |
| Pre-adolescent (5 – 10)       | 123   | 4 (3.25)         | 119 (96.75)|          |             |
| Adolescent (11 – 14)          | 88    | 43 (48.9)        | 45 (51.1)| <.001      | 0.04 (0.01-0.10)|
| Educational status            |       |                  |         |             |             |
| Pre-school                    | 29    | 0 (0.0)          | 29 (100.0)|          |             |
| In school                     | 182   | 47 (25.8)        | 135 (74.2)| 0.001      | Undefined   |
| Father alive                  |       |                  |         |             |             |
| Yes                           | 144   | 25 (17.4)        | 119 (82.6)|          |             |
| No                            | 67    | 22 (32.8)        | 45 (67.2)| 0.012      | 0.4 (0.2-0.8)|
| Mother alive                  |       |                  |         |             |             |
| Yes                           | 138   | 31 (22.5)        | 107 (77.5)|          |             |
| No                            | 73    | 16 (21.9)        | 57 (78.1)| 0.928      | 1.0 (0.5-2.0)|
| Orphanage status of child     |       |                  |         |             |             |
| Orphan                        | 33    | 8 (24.2)         | 25 (75.8)|           |             |
| Not orphan                    | 178   | 39 (21.9)        | 139 (78.1)| 0.767      | 1.1 (0.5-2.7)|
| Child getting any support     |       |                  |         |             |             |
| Yes                           | 39    | 14 (35.9)        | 25 (64.1)| 0.024      | 2.4 (1.1-5.0)|
| No                            | 172   | 33 (19.2)        | 139 (80.8)|           |             |
| Variable                                      | Total | Disclosure status | p-value | OR (95% CI) |
|----------------------------------------------|-------|------------------|---------|-------------|
|                                              |       | Disclosed        |         |             |
|                                              |       | No. (%)          |         |             |
| WHO clinical stage                           |       |                  |         |             |
| Stage I + II                                 | 98    | 22 (22.4)        |         |             |
| Stage III + IV                               | 113   | 25 (22.1)        |         |             |
|                                              |       | 76 (77.6)        |         |             |
|                                              |       | 88 (77.9)        |         |             |
|                                              |       | 0.955            |         | 1.0 (0.5-2.0) |
| Child’s CD4 categories (cells/μ)             |       |                  |         |             |
| 350 or less                                  | 38    | 13 (34.2)        |         |             |
|                                              |       | 25 (65.8)        |         |             |
| Above 350                                    | 173   | 34 (19.7)        |         |             |
|                                              |       | 139 (80.3)       |         |             |
|                                              |       | 0.051            |         | 2.1 (1.0-4.6) |
| Duration of clinic attendance (months)       |       |                  |         |             |
| Less than 12                                 | 17    | 5 (29.4)         |         |             |
|                                              |       | 12 (70.6)        |         |             |
| 12 and above                                 | 194   | 42 (21.7)        |         |             |
|                                              |       | 152 (78.4)       |         |             |
|                                              |       | 0.462            |         | 1.5 (0.5-4.5) |
| ART regimen                                  |       |                  |         |             |
| On ARV                                       | 182   | 40 (22.0)        |         |             |
|                                              |       | 142 (78.0)       |         |             |
| Not on ARV                                   | 29    | 7 (24.1)         |         |             |
|                                              |       | 22 (75.9)        |         |             |
|                                              |       | 0.795            |         | 0.9 (0.4-2.2) |
| Duration of treatment (months)               |       |                  |         |             |
| Less than 12                                 | 27    | 5 (18.5)         |         |             |
|                                              |       | 22 (81.5)        |         |             |
| 12 and above                                 | 184   | 42 (22.8)        |         |             |
|                                              |       | 142 (77.2)       |         |             |
|                                              |       | 0.616            |         | 0.8 (0.3-2.2) |
| Who supervises medication                    |       |                  |         |             |
| Child                                        | 46    | 34 (73.9)        |         |             |
|                                              |       | 12 (26.1)        |         |             |
| Others                                       | 165   | 13 (7.9)         |         |             |
|                                              |       | 152 (92.1)       |         |             |
|                                              |       | <0.001           |         | 33.1 (13.9-78.9) |
### Table 3: Disclosure status to children by parents/caregivers characteristics (n=211)

| Variable                        | Total | Disclosure status | p-value | OR (95% CI) |
|---------------------------------|-------|-------------------|---------|-------------|
|                                 |       | Disclosed         | Not disclosed |
|                                 | n=47  | n=164             |          |             |
|                                 | No. (%) | No. (%)          |         |             |
| Sex                             |       |                   |          |             |
| Male                            | 38    | 6 (15.8)          | 32 (84.2)| 0.289       |
| Female                          | 173   | 41 (23.7)         | 132 (76.3)| 0.6 (0.2-1.5)|
| Age (years)                     |       |                   |          |             |
| 20 – 35                         | 80    | 12 (15.0)         | 68 (85.0)|             |
| Older than 35                   | 131   | 35 (26.7)         | 96 (73.3)| 0.048       |
|                                 |       |                   |          | 0.5 (0.2-1.0)|
| Education level                 |       |                   |          |             |
| Up to primary                   | 131   | 28 (21.4)         | 103 (78.6)|             |
| Post primary                    | 80    | 19 (23.8)         | 61 (76.3)| 0.688       |
|                                 |       |                   |          | 0.9 (0.4-1.7)|
| Occupation                      |       |                   |          |             |
| Unemployed                      | 37    | 6 (16.2)          | 31 (83.8)|             |
| Employed                        | 174   | 41 (23.6)         | 133 (76.4)| 0.330       |
|                                 |       |                   |          | 0.6 (0.2-1.6)|
| Relationship to the child       |       |                   |          |             |
| Parent                          | 130   | 26 (20.0)         | 104 (80.0)|             |
| Caregiver                       | 81    | 21 (25.9)         | 60 (74.1)| 0.314       |
|                                 |       |                   |          | 0.7 (0.4-1.4)|
| Monthly income (Tsh)            |       |                   |          |             |
| Up to 100,000                   | 134   | 30 (22.4)         | 104 (77.6)|             |
| More than 100,000               | 77    | 17 (22.1)         | 60 (77.9)| 0.958       |
|                                 |       |                   |          | 1.0 (0.5-2.0)|
| Results of HIV test (n=198)     |       |                   |          |             |
| HIV infected                    | 132   | 30 (22.7)         | 102 (77.3)|             |
| Not HIV infected                | 66    | 17 (25.8)         | 49 (74.2)| 0.637       |
|                                 |       |                   |          | 0.8 (0.4-1.7)|
| Discussed disclosure with healthcare provider | Yes | 73 | 29 (39.7) | 44 (60.3) | <0.001 | 4.4 (2.2-8.7) |
| No                              | 138   | 18 (13.0)         | 120 (87.0)|             |

### Table 4: Predictors of HIV disclosure status (final table after stepwise multivariate logistic regression test)

| Variables                                      | p value | 95.0% CI for EXP(B) |
|------------------------------------------------|---------|---------------------|
|                                                |         |                   |
| Child age                                      | 0.015   | 0.047 0.721        |
| Who supervises medication                      | 0.000   | 11.366 220.536     |
| Support to child                               | 0.009   | 1.641 33.713       |
| Discussed disclosure with healthcare provider  | 0.001   | 2.563 34.958       |