



Prevalence and Factors Associated with Disclosure of HIV Diagnosis to Infected Children Receiving Antiretroviral Treatment in Public Health Care Facilities in Gauteng ,South Africa.

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Abstract :

HIV infected children who started antiretroviral therapy (ART) in public health facilities in South Africa have survived to older age and disclosure has become an essential part of their care. Available data on HIV disclosure to children were collected much earlier in the provision of ART in South Africa. The aim of the study was to (a) determine the characteristics of caregivers of pediatric HIV patients in Gauteng, South Africa, (b) estimate the prevalence and timing of HIV disclosure among these patients, and (c) assess the factors associated with disclosure status. A cross-sectional study was conducted among 286 caregivers of paediatric ART children aged 4–17 in two centres in Gauteng, South Africa. Bivariate and multivariate logistic regression analyses were carried out. The highest proportion of care givers were biological mothers (n=140, 49.3%). The mean age of the children was 8.5 years, (range 4-17 years). More than a third (n=99, 34%) were disclosed their HIV status, and the mean age at disclosure was 9.3 years, (SD = 2.7). Child's age older than 10 years (OR =1.63; 95% CI: 1.44–1.85), having a nonbiological caregiver (OR=1.75; 95% CI: 1.06-2.89), caregiver educational level (OR =0.64; 95% CI: 0.47–0.87), and caregiver's age older than 60 years (OR=1.02; 95% CI: 1.01-1.04), were significantly associated with HIV disclosure to infected children. The relatively higher prevalence of disclosure is attributed to increasing access to paediatric ART. Training healthcare providers to support caregivers in disclosure will increase the rate of disclosure to HIV infected children receiving ART in public health facilities.

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Introduction

In the past six years, South Africa has established the largest paediatric antiretroviral programme in the world, with an estimated coverage of 81% of children in need of antiretroviral therapy (ART) by the end of 2009 [1]. The increased access to ART in South Africa resulted in an increase in the survival time of adults and children living with HIV [2]. With increased access to ART, HIV infected children are surviving to older ages, and disclosure has become an essential part of their comprehensive medical care [3]. However, data from studies conducted in developing countries show that many HIV infected children on ART do not know their HIV diagnosis [4-9]. Furthermore, available data on HIV disclosure to infected children from studies conducted in developed and developing countries do not explain the low disclosure rates [10-12]. Literature further shows that, most studies on the prevalence and effects of HIV disclosure to children are mainly from developed countries [13, 14].

Disclosure has been shown to have positive effects on the clinical course of the disease, an important implication for the success of ART [7, 10, 12, 15, 16]. However, despite the growing evidence of the benefits of disclosure from developed countries [17], disclosure to HIV infected children in developing countries continues to be delayed until older childhood [9, 18, 19]. Due to the increasing access to ART, most HIV infected children who started ART in public health facilities in South Africa, have survived to older age. As a consequence, health care providers are currently faced with the challenge of providing HIV care to an increasing population of children who have not been informed of their HIV diagnosis. There are limited data on what influences caregivers' disclosure of HIV diagnosis to their infected children in South Africa. Available data on HIV disclosure to children were collected much earlier in the provision of ART in South Africa [11]. This study sought to (a) determine the characteristics of the caregivers of pediatric HIV patients in Gauteng, South Africa, (b) estimate the prevalence and timing of HIV disclosure among these patients, and (c) assess the factors associated with disclosure status.

Materials and Methods

Setting

A cross sectional study was conducted using structured interviews with caregivers of children receiving ART. Data were collected between November 2009 and December 2010 as part of a multicentre study on HIV disclosure to children. A total of 286 caregivers were recruited from two paediatric HIV clinics in Gauteng Province, South Africa. The paediatric HIV clinic at the Dr George Mukhari academic hospital started providing paediatric ART in 2004 and serves children from urban, peri-urban and informal settlements. At the time of data collection, the registration records indicated that about 1000 children aged between birth and 17 years were receiving ART in this centre. The Odi district hospital started with adult ART in 2006 and paediatric ART during the course of 2010. The centre provides services to children from surrounding rural villages and informal settlements. Most of the children who were receiving ART from this clinic were referred from a tertiary hospital in the district.

Caregivers of paediatric ART children aged 4–17 years were recruited to participate as they waited for consultation and medication during the routine monthly visits for their children. For the purpose of this study, we defined a caregiver as the biological mother, biological father, grandmother, grandfather, foster parent, or other relatives who perform primary caregiving functions for the child routinely or on a daily basis.

Data Collection

Data were collected by the second author and two trained research assistants. Structured interviews were conducted using a questionnaire developed with inputs from literature on disclosure of HIV to children [20, 21]. The questionnaire was first developed in English and then translated into Setswana, the local language of the caregivers in the study area. To ensure quality of the data, the questionnaire was pre-tested at the Dr George Mukhari Hospital and revised prior to the start of data collection. The questionnaire captured caregiver socio-demographic information regarding their age, gender, employment status, level of education, marital status,

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and relation to the child as well as their HIV status. Caregivers also provided clinical information for the children under their care including age, diagnosis age, duration on ART, disclosure status, as well as age at disclosure.

Ethics

The Medunsa Research Ethics Committee of the University of Limpopo granted ethical approval for the study. The hospital management of each setting gave permission to conduct the study. After the purpose of the study was explained, a written informed consent was obtained from caregivers before data collection. Caregivers were informed that participating in the study was voluntary and that refusal to participate would not compromise the medical care their children received from the hospital. The right to withdraw from the study at any time was also assured. The interviews were conducted in a private room in the health centre to ensure privacy. No personal identifiers were collected from the participants to ensure participants confidentiality.

Analysis

Data were entered into a Microsoft Excel 2003 spreadsheet and imported to the Stata version 10.0 [22]. First, descriptive statistics were carried out to explore the socio-demographic characteristics of caregivers and children. The results for numerical variables were summarised as means and standard deviations. T-tests and Chi-square tests were used to compare continuous and categorical variables between children who knew their HIV diagnosis and children who did not know. To determine which factors were associated with HIV status disclosure to infected children multiple logistic regression were employed.

Variables associated with disclosure in bivariate analyses were included in the logistic models.

Results

Caregivers' Demographics

A total of 286 caregivers provided information on the children under their care. Almost all the caregivers (n=264, 92.6%) were female, with a mean age of 40.8 years, (SD =14.0 year). The highest proportion of care

givers were biological mothers (n=140, 49.3%), followed by grandmothers (n=61, 21.5%). A third of the caregivers (n=83, 29.3%) had completed 12th grade, while (n=121, 42.8%) completed secondary school. The majority of the caregivers 176 (62%) were unemployed, almost half (n=139, 48.9%) were single and only about a third (n=80, 28.2%) were married (Table 1).

Children's Demographics

There were nearly equal numbers of girls (n=144, 50.3%) and boys (n=142, 49.6%) in the sample. The mean age of the children was 8.5 years, (SD = 3.0 years). More than half of the children (n=159, 55.6%) were between 6-10 years while one quarter (n=74, 25.9%) was between 11-17 years. Almost all the caregivers (n=283, 98.9%) provided information on the diagnosis age of the children and the majority (n=170, 60.0%) were diagnosed between 1-5 years, almost a third (n=81, 28.6%) were diagnosed between 6-10 years, and a tenth (n=32, 10%) were diagnosed between 11-17 years. The mean age at diagnosis was 5.1 years (SD= 4.7). All the children were on ART, and the mean time when children started ART was 3.0 years (SD = 1.79). The majority of the children 257 (90.8%) were attending school (Table 2).

The data was further analysed per clinic and is presented in table 3. The samples were comparable in terms of the mean age (11yrs vs. 10.6yrs), mean diagnosis age (6.02 yrs vs. 7.8 yrs) and the mean disclosed age of the children (9.4 yrs vs. 9.3yrs) as well as the mean age of the caregiver (42.4 yrs vs. 38.9yrs) and caregiver relation to child.

Prevalence of HIV Disclosure

Based on caregiver reports, 99 (34%) of the children knew about their HIV diagnosis. Nearly equal numbers of girls (n=51, 51.5%) and boys (n=48, 48.5%) were reportedly informed of their HIV diagnosis. The mean age at disclosure was 9.3 years, (SD 2.7 years). Of the 99 children who were disclosed (n=39, 39.4%) were reportedly told their HIV diagnosis by biological mothers, a quarter (n=26, 26.3%) was reportedly told by

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Table 1: Caregiver demographic characteristics by disclosure status of children

Variable	All N=286 %	No N=187 %	Yes N=99 %	Crude OR (95%CI)	P-value
Age					0.001
19-30yrs	77 (27.3)	54 (29.7)	23 (23.7)	1.00	
31-40yrs	95 (33.7)	58 (31.9)	36 (37.1)	1.45 (0.76-2.77)	
41-50yrs	40 (14.2)	28 (15.4)	12 (12.4)	1.00 (0.43-2.32)	
51-60yrs	39 (13.8)	26 (14.3)	13 (13.4)	1.17 (0.51-2.69)	
61-70yrs	23 (8.1)	14 (7.7)	9 (9.3)	1.50 (0.56-4.01)	
71-80yrs	8 (2.8)	3 (1.6)	3 (3.1)	1.76 (0.35-8.62)	
82 year	1 (0.36)	1 (0.5)	1 (1.0)	0	
Sex of the caregiver					0.934
Female	264 (92.9)	174 (93.0)	90 (92.8)	1.00	
Male	20 (7.1)	13 (7.0)	7 (7.2)	1.05 (0.40-2.73)	
Employment status					0.075
Employed	64 (22.5)	47 (25.1)	17 (17.5)	1.00	
Unemployed	176 (62.0)	116 (62.0)	60 (61.9)	1.43 (0.75-2.70)	
Pensioner	25 (8.8)	13 (7.0)	12 (12.4)	2.55 (0.95-6.85)	
Schooling					
Part time employ	15 (5.3)	8 (4.3)	7 (7.2)	2.41 (0.74-7.88)	
Marital status					0.106
Single	139 (48.9)	100 (53.5)	39 (40.2)	1.00	
Married	80 (28.1)	48 (25.7)	32 (33.0)	1.70 (0.95-3.07)	
Live with partner	25(8.8)	15 (8.0)	10 (10.3)	1.70 (0.70-4.15)	
Divorced	11(3.8)	7 (3.7)	4 (4.1)	1.46 (0.40-5.31)	
Widowed	29 (10.2)	17 (9.1)	12 (12.4)	1.80 (0.78-4.16)	
Level of education					0.009
Primary	62 (21.9)	34 (18.2)	28 (28.9)	1.00	
Secondary	121 (42.8)	76 (40.6)	45 (46.4)	0.71(0.38-1.34)	
Grade 12	83 (29.3)	64 (34.2)	19 (19.6)	0.36 (0.17- 0.75)	
Tertiary	17 (6.0)	12 (6.4)	5 (5.2)	0.50 (0.15-1.63)	
Relation to child					0.026
Biological parent	152 (53.5)	109 (58.3)	43 (44.3)	1.00	
Non biological parent	132 (46.5)	78 (41.7)	54 (55.7)	1.75 (1.06-2.89)	

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Table 2: Characteristics of children on ART by disclosure status

Variable	All N=286 %	Not disclosed N=187 %	Disclosed N=99 %	Crude OR (95% CI)	P-value
Gender					0.774
Boy	142 (49.7)	94 (50.3)	48 (48.5)	1.00	
Girl	144 (50.3)	93 (49.7)	51 (51.5)	0.93 (0.57-1.51)	
Age of the child					0.000
4-5yrs	53 (18.5)	49 (26.3)	3 (3.0)	1.00	
6-10yrs	159 (55.6)	115 (61.8)	44 (44.4)	6.37 (1.82-22.3)	
11-17yrs	74 (25.9)	22 (11.8)	52 (52.5)	39.3 (7.48-207.4)	
Mean age	8.5 years	7.3 year	10.7 years		
Diagnosis age					0.000
1-5yrs	170 (60.1)	128 (69.2)	42 (42.9)	1.00	
6-10yrs	81 (28.6)	50 (27.0)	31 (31.6)	1.88 (1.06-3.35)	
11-17yrs	32 (11.3)	7 (3.8)	25 (25.5)	10.4 (3.84-28.3)	
Mean age	5.1 years	4.2 years	6.9 years		
Schooling					0.009
Yes	257 (90.8)	161 (87.5)	96 (97.0)	1.00	
No	26 (9.2)	23 (12.5)	3 (3.0)	0.21 (0.06-0.76)	

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Table 3: Disclosure status of children on ART by demographic characteristics and clinic

Variable	Disclosure status n %			
	Non-disclosed groups	Disclosed groups		
	Clinic A (Odi)	Clinic B(DGM)	Clinic A (Odi)	Clinic B(DGM)
Disclosed	90 (60.4)	97 (70.8)	59 (39.6)	40 (29.2)
Sex of the child				
Girl	54 (60.0)	57 (58.8)	32 (54.2)	21 (52.5)
Boy	36 (40.0)	40 (41.2)	27 (45.8)	19 (47.5)
Age of the child				
4 yrs	31 (34.4)	19 (19.6)	3 (5.1)	0
6-10 yrs	54 (60.0)	61 (62.9)	26 (44.1)	18 (45.0)
11-17 yrs	5 (5.6)	17 (17.5)	30 (50.8)	22 (55.0)
Mean age	6.7yrs	8 yrs	10.6yrs	11yrs
95% Conf. Inter	CI: 6.26-7.15	CI: 7.50-8.49	CI: 9.82-11.4	CI:10.2-11.7
Diagnosis age of the child				
1 -5 yrs	67 (74.4)	63 (64.9)	23 (39.0)	20 (50.0)
6-10 yrs	23 (25.6)	27 (27.8)	18 (30.5)	13(32.5)
11-17 yrs	0	7 (7.2)	18 (30.5)	7 (17.5)
Mean age	4.5yrs	4.36 yrs	7.8 yrs	6.02 yrs
95% Conf. Inter	CI:4.02-5.09	CI: 3.68-5.04	CI: 6.76-8.84	CI: 4.75-7.29
Disclosed age of the child				
4-5 yrs			3 (5.0)	0
6-10 yrs			26 (44.0)	18 (45.0)
11 -17 yrs			30 (50.8)	22 (55.0)
Mean age			9.3yrs	9.4 yrs
95% Conf. Inter			CI:8.55-10.0	CI:8.57-10.3
Schooling				
Not at school	19 (21.1)	25 (25.8)	2 (3.4)	2 (5.0)
Attending school	71 (78.9)	72 (74.2)	57 (96.6)	38 (95.0)

** DGMH (Dr George Mukhari Hospital), data collected between November-March 2010, (n=137).

*Odi Hospital, data collected between December-January 2011, (n=149).

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Table 4: Characteristics of people who disclosed the HIV diagnosis to children (n=99)

	Frequency	Percentage
Biological mother	39	39.4
Father	2	2.0
Grand parents	26	26.3
Aunt	7	7.1
Health provider	23	23.3
Other	2	2.0

grandparents, and slightly less than a quarter (n=23, 23.4%) were reportedly told by health care providers.

Health care providers were comprised of doctors, nurses, and social workers (Table 4).

Factors associated with HIV disclosure to infected children

We found that caregiver level of education was statistically significant associated with HIV disclosure (OR =0.64; 95% CI: 0.47–0.87). Caregivers who completed the 12th grade were 64% less likely to disclose the HIV diagnosis to the child (OR=0.36; 95% CI: 0.17- 0.75), in comparison with caregivers with a secondary education (OR=0.71; 95% CI: 0.38-1.34). Caregiver relation to child was one other factor that was statistically significant associated with HIV disclosure to children. Nonbiological caregivers (OR=1.75; 95% CI: 1.06-2.89) were 1.7 times more likely to disclose to infected children as compared to biological parents. The other factor associated with HIV disclosure was the age of the caregiver, caregivers older than 50 years (OR=1.02; 95% CI: 1.01-1.04) were 1.2 times more likely to disclose HIV to children as compared to younger caregivers. When we compared caregivers in the 51-60 years age group (OR=1.17; 95% CI: 0.51-2.69) and caregivers in the 61-70 years age group (OR=1.50; 95% CI: 0.56-4.01), caregivers in the 71-80 years age group (OR=1.76; 95% CI: 0.35-8.62) were 1.7 times more likely to disclose as compared to the two groups. Caregiver gender, marital status, relation to child, and employment status, were not statistical significantly associated with HIV disclosure (Table 1).

The age of the child was also significantly associated with HIV disclosure, children older than 10 years of age

(OR =1.63; 95% CI: 1.44–1.85) were 1.6 times more likely to be disclosed as compared to younger children. When we compared children in the 6–10 years age group to children in the 11–17 years age group (OR=39.3; 95% CI: 7.48 -207.4), we found that the last group is 39.3 times more likely to be informed of their HIV status than the age group 6-10 years (OR=6.37: 95% CI: 1.82- 22.3). The rates of disclosure increased significantly with the age of the child. Age at diagnosis was significantly associated with disclosure of HIV-positive status (OR =1.24; 95% CI: 1.15–1.34). Children diagnosed when they were between 11-17 years were 10.4 times more likely to be disclosed to (OR=10.4; 95% CI: 3.84-28.3) compared to children in the age group 6-10 years (OR=1.88; 95% CI: 1.06-3.35). The mean diagnosis age of the children who were disclosed to was 6.9 vs. 4.2 years for children not disclosed to (Table 2).

Discussion

The study determined the prevalence and factors associated with disclosure among children aged between 4–17 years enrolled in the ART programme of two HIV clinics in Gauteng province, South Africa. The prevalence of disclosure in our sample was 34%, much higher than the 9% previously reported with children on ART in a similar setting in Cape Town, South Africa [11]. This study collected data six years after the roll out of ART whereas the study conducted by Moodley and colleagues collected data within the first year of the roll out of ART to children. Previously, Thorne and colleagues attributed higher prevalence of disclosure to HIV infected children to the increasing use of ART in developed countries [23]. The current data presented here are from two paediatric HIV clinics and were collected a year apart. When calculated individually, there was a significant difference between the prevalence of the two samples. The prevalence increased from 29.9% to 39.9% in one year. The samples were comparable in terms of the mean age of the children as well as the mean age of the caregiver and caregiver relation to child.

Our findings are comparable with prevalence of HIV disclosure from some studies conducted in developing countries. Oberdorfer and colleagues reported

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prevalence of 30.1% in Thailand [12], and Bikaako-Kajura and colleagues reported a prevalence of 29% in Uganda [6]. Meanwhile, our estimated prevalence of HIV disclosure was higher than that reported in other studies conducted with caregivers of HIV infected children. Kallem and colleagues reported prevalence of 21% in Ghana [7], while Biadgilign and colleagues reported prevalence of 17.4% in Ethiopia [5]. Published prevalence of HIV disclosure in children from the United States, Canada, and Europe show that between 18–77% of HIV infected children had been told their HIV diagnosis [17].

Factors that were statistically significant associated with disclosure were the age of the child, diagnosis age of the child, caregiver relation to child, caregiver age, and caregiver level of education. Older child age was identified as a determining factor for disclosure, children older than 10 years were more likely to be disclosed than those younger than 10 years. The association between HIV disclosure and older age of the child has been documented in studies conducted in developing countries [7, 11, 12], and in well developed countries [17]. Our findings are consistent with previous studies showing that children younger than 6 years were least likely to be told their HIV diagnosis [9]. In our study only nine out of 99 children were younger than 6 years when they were told their diagnosis. Caregivers delay disclosure till older age because they believe that at early age, the child does not have the maturity needed to understand the disease [10, 24, 25].

The mean age of disclosure in this study was 9.35 years and is comparable to other studies in developing countries [7, 11], but much lower than the mean age of 13.6 and 15 years reported in Thailand and Congo respectively [8, 12]. Nevertheless, the mean age of disclosure in our study falls within the range of 5 to 14 years reported in several studies in developed countries [18, 20, 26, 27]. Children were also more likely to be disclosed if they were older than 10 years when they were diagnosed with HIV as compared to children diagnosed earlier than 10 years.

However, almost a third (29.7%) of 11-17 years-olds did not know their HIV diagnosis, implying that a number of children in this setting enter adolescence without important information regarding their illness as well as

their HIV diagnosis. Age at disclosure in studies conducted in developing countries varies between 11-16 years, and most caregivers delay disclosure to 14 years and above [28-31]. The older age of children who are not informed of their HIV diagnosis, suggests that despite increased access to ART, there are still significant barriers to discussing HIV with infected children in these settings

The highest proportion of care givers in this study were biological mothers who made up half of the caregivers. The increased representation of biological mothers is attributed to the increased access to PMTCT and increased survival time of adults on ART [2]. Although biological mothers were in the majority, nonbiological caregivers were more likely to disclose the child's HIV status than biological caregivers. This finding is in line with previous studies highlighting that nonbiological caregivers tend to disclose soon after learning about the HIV diagnosis of the child [16, 23, 26, 32, 33]. Studies show that disclosure is particularly difficult for HIV infected biological parents who may be responsible for the infection of the child [23, 26, 32].

In this study older caregivers were more likely to disclose the child's HIV status than younger caregivers. In South Africa, the impact of HIV and AIDS has led to older people becoming primary caregivers of children infected or affected by HIV and AIDS. About a quarter (26.3%) of children in this study were informed about their HIV diagnosis by grandparents. We also found that the level of education of the caregiver was statistically significant to HIV status disclosure. In this study caregivers with a higher educational level were less likely to disclose HIV to infected children than caregivers with primary education. The association between HIV disclosure educational status of the caregiver were documented in a study conducted in Ethiopia [4].

The study had some limitations; caregiver reports of HIV status disclosure might have been affected by social desirability, and they might have said they disclosed when they hadn't truly disclosed. Secondly, our findings outcome measurement is assessed based on self-reports by the caregivers and may have resulted in recall bias,

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caregivers might not remember the child's age at disclosure or age at diagnosis. The study was cross-sectional and could not establish the process and circumstances leading to disclosure, we recommend more studies be conducted to answer these questions. Further studies are needed to determine whether our findings are representative of the situation in Gauteng province in South Africa.

Conclusion

The prevalence of disclosure among our study population was 34%. Children older than 10 years of age, the level of education of the caregiver, age of the caregiver, nonbiological relation to child were significantly associated with disclosure of HIV-positive status to HIV infected children. In addition, a relatively high proportion of children were entering adolescence without knowing their HIV diagnosis. These findings have implications for health care providers working in paediatric HIV services. It is important that health care providers are cognisant of the factors to develop interventions to facilitate HIV disclosure to infected children. Informing children about their HIV diagnosis is an essential step in preventing secondary HIV transmission.

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