PROFILE AND HIV DIAGNOSIS DISCLOSURE STATUS OF CHILDREN ENROLLED IN A PEDIATRIC ANTIRETROVIRAL PROGRAM IN GAUTENG PROVINCE, SOUTH AFRICA

Sphiwe Madiba[1] and Kebogile Mokwena[2]

[1]Department of Environmental and Occupational Health, [2]Department of Social and Behavioral Sciences, School of Public Health, Faculty of Health Sciences, University of Limpopo, Medunsa Campus, South Africa

Abstract. A cross sectional survey was conducted with 121 caregivers of HIV-infected children aged 6-13 years enrolled in an antiretroviral treatment (ART) program at a tertiary hospital to determine the profile and HIV disclosure status of children on ART, as well as the socio-demographic profile of their caregivers. The majority of caregivers (*n*=104, 87.4%) were females, with a mean age of 39.6 years (range 21-76 years). Eighty-four (70.6%) caregivers had secondary education, 61 (51.3%) were single, 83 (69.8%) were unemployed, 73 (61.9%) depended on childcare grants, and 51 (42.9%) were biological mothers. The mean age of children was 9.4 years (range 1-13 years), 109 (90.8%) were schooling, and the mean diagnosis age was 5.2 years. Prevalence of disclosure was 40 (33.3 %), mean disclosure age was 9.4 years (range 3-13 years), and mean diagnosis age was 5.2 years. Fifteen (37.5%) of the children were told their HIV diagnosis by biological mothers, 10 (25%) by healthcare providers, 7 (17.5%) by grandmothers, and 8 (20%) were told by other relatives and foster parents. The prevalence of diagnosis disclosure to HIV infected children was higher than previously reported rates in South Africa and could be attributed to the older mean age of diagnosis. Although biological mothers were the main caregivers, they disclosed the HIV diagnosis to only one-third of the children. There is a need for more research to profile HIV infected children accessing ART in public health facilities to inform interventions to manage this growing population of children.

Keywords: antiretroviral therapy, caregivers, children, disclosure, prevalence, profile, South Africa

INTRODUCTION

South Africa has made considerable progress in providing antiretroviral treatment (ART) to children. According to the United Nations General Assembly 26th Special Session (UNGASS), the country has the largest pediatric ART program in the world, and 81% of children in need of ART were enrolled on ART at the end of 2009 (UNAIDS, 2010). Similar to what has been observed in well-resourced settings, the increased access to ART has resulted in an increasing population of children

Correspondence: Sphiwe Madiba, School of Public Health, University of Limpopo, Medunsa Campus Box 215, Medunsa 0204, Pretoria, South Africa.
Tel: +27125213093
E-mail: sphiwe_madiba@embanet.com

and families living with HIV as a chronic illness in poor resourced settings (Ledlie, 1999; Lee and Johann-Liang, 1999; Lester *et al* 2002a; Wiener *et al*, 2007; Butler *et al*, 2009).

Studies conducted in well-resourced and poorly resourced settings have reported that, as the population of children living with HIV matures, the issue of HIV diagnosis disclosure to children becomes more significant and becomes part of their comprehensive clinical care (Lee and Johann-Liang, 1999; Myer *et al*, 2006; Oberdorfer *et al*, 2006; Rujumba *et al*, 2010).

Despite the growing evidence of the benefits of disclosure from well-resourced settings, disclosure of HIV diagnosis to children infected through mother-to-child transmission (MTCT) remains a difficult and controversial issue for families and health care providers in resource-limited settings (Lesch *et al*, 2007; Wiener *et al*, 2007). For the majority of children on ART in these settings, HIV diagnosis disclosure continues to be delayed until older childhood and beyond (Wiener *et al*, 2007). It has been 6 years since the roll out of ART to children in South Africa, and little has been empirically gathered and documented on the age profile and HIV disclosure status of children on ART. This survey sought to determine the socio-demographic profile and HIV disclosure status of children enrolled in the ART program of an academic hospital in South Africa, and to describe the socio-demographic profile of their caregivers.

MATERIALS AND METHODS

This study was carried out between December 2009 and January 2010. A descriptive survey was conducted for the purpose of recruiting caregivers of HIV infected children receiving ART to participate in a series of scheduled focus group (FG) interviews. The unit of analysis was the caregiver who provided information on the disclosure status and demographic profile of children under their care. The survey was the main strategy used to recruit potential caregivers for the FG interviews that used a qualitative grounded theory approach to explore caregiver disclosure of HIV to infected children. A pediatric HIV clinic of an academic hospital in Pretoria, South Africa was the primary site for recruitment of caregivers who participated in a demographic survey.

The pediatric HIV clinic started its operation with pediatric ART in 2004 and provides care to children from birth to 16 years of age. The clinic receives children referred from primary care services in the surrounding areas and patients from pediatric wards at the hospital. The hospital is in an urban area but provides services to children from a vast area of urban, peri-urban, and informal settlements. When this study was conducted, the registration records indicated that about 1,000 children were enrolled in the ART program in this clinic.

At the time of data collection, more than 60% of the children enrolled in the ART program were between the ages of 1 to 5 years old. The inclusion criteria for the study were caregivers of children who were between the ages of 6 to 13 years old. The study used a convenience sample, and caregivers who met the inclusion criteria and were present, and who were willing to participate in the study during the six weeks of data collection were recruited.

Caregivers were recruited as they accompanied children for routine follow-up for HIV care. A 'caregiver' was defined as a biological mother, biological father, grandmother, grandfather, foster parents, aunts, or siblings who performed routine care giving for the child. 'Disclosure' meant formally telling the child that the name of their disease is HIV or AIDS.

Data collection

The researcher and two trained research assistants conducted the fieldwork. The research team was guided and assisted by the health providers from the clinic who also provided a private space for data collection. A tool was developed in English by the researcher based on inputs from the literature on disclosure of HIV to children (Ledlie, 1998; Dematteo *et al*, 2002). The tool was pretested and translated to Setswana, which was the first language of most participants in the study setting.

Structured interviews were conducted to accommodate caregivers who could not read and write. Caregivers provided demographic information regarding their age, gender, employment status, level of education, marital status, and relationship to child, as well as demographic information for the children under their care, including age, gender, school grade, diagnose age, length of time on ART, whether the child was told about the diagnosis, and the age when the child was told about the diagnosis.

Data analysis

Data were entered into Microsoft Excel 2003® (version 11; Microsoft Corp, Redmond, WA) and the data were analyzed using STATA for Windows® (version 10, StataCorp LP; College Station, TX).

For the purpose of analysis, children's ages were rounded off to whole completed years; for example, 15 months would be documented as 1 year. Descriptive statistics were carried out to explore the socio-demographic characteristics of caregivers and children. The Student's *t*-test was used to compare means between children who knew their HIV status and those who did not know.

Ethical considerations

The Medunsa Research Ethics Committee of the University of Limpopo granted ethical approval for this study (MREC/PH/170/2009: PG; 2009 Nov 26). The hospital management also gave permission to conduct the study, and written informed consent was obtained from caregivers before data collection.

RESULTS

Caregiver socio-demographics

The survey participants consisted of caregivers of children on ART who were recruited from an HIV pediatric clinic of a tertiary hospital. One hundred and twenty-one caregivers were recruited to participate in the survey. The caregivers resided in urban, peri-urban, and informal settlements within the catchment areas of the hospital. Table 1 summarizes the socio-demographic characteristics of caregiver participants. The majority of caregivers (*n*=104, 87.4%) were females. The mean age of caregivers was 39.6 years [range 21-76 years, standard deviation (SD) =12.7 years].

The main caregivers were biological mothers (*n*=51, 42.9%), other relatives (*n*=27, 22.7%), and grandmothers (*n*=17, 14.3%). Therefore, biological mothers cared for just less than half of the children (42.9%), while people other than their biological parents cared for approximately 60% (*n*=68, 57.1%).

Half of the caregivers (*n*=61, 51.3%) were single, and more than one-third (*n*=43, 36.1%) were married. The highest level of education of the majority of caregivers was a secondary education (*n*=84, 70.6%), with 42 (35.3%) of those having attained grade 12.

Table1
Demographic characteristics of caregivers of children on ART (*N*=121).

Variable	No.	%
Age (years)		
21-30	34	29.0
31-40	40	34.2
41-50	19	16.2
51-60	16	13.6
61-76	8	6.8
Mean age	39.6	
Gender		
Male	15	12.6
Female	104	87.4
Marital status		
Single	61	51.3
Married	43	36.1
Widowed	4	3.4
Live with partner	7	5.9
Divorced	4	3.4
Employment status		
Employed	20	16.8
Part time employed	8	6.7
Self employed	5	4.2
Unemployed	83	69.8
Pensioner	3	2.5
Level of education		
Primary	25	21.0
Grade 8-11	42	35.3
Grade 12	42	35.3
Tertiary	10	8.4
Relationship to child		
Mother	51	42.9
Father	9	7.6
Grandmother	17	14.3
Grandfather	3	2.5
Foster parent	12	10.1
Other relatives	27	22.7
Receiving childcare grant		
No	45	38.1
Yes	73	61.9

More than two-thirds of caregivers (*n*=83, 69.8%) were unemployed, and only 20 (16.8%) were employed; two-thirds of caregivers (*n*=73, 61.9%) in this study received the child-care grant.

Table 2
Profile of children on antiretroviral therapy (*N*=121).

Variable	No.	%
Age (yrs)		
6-9	62	51.2
10-13	59	48.8
Mean age	9.4 yrs (SD=2.2 yrs)	
Gender		
Boy	66	54.6
Girl	55	45.5
Age at diagnosis (yrs)		
Birth-5	67	55.4
6-10	40	33.1
11-13	14	11.6
Mean diagnosis age	5.2 yrs (SD=3.7 yrs)	
Disclosed		
No	81	66.9
Yes	40	33.1
Age at disclosure (yrs)		
3-5	3	8.3
6-10	18	50.0
11-13	15	41.7
Mean disclose age	9.4 yrs (SD=2.6 yrs)	
Duration on HAART (yrs)		
1	7	5.8
2	114	94.2
Mean duration on ART	1.9 yrs (SD=0.3 yrs)	
Schooling		
No	11	9.2
Yes	109	90.8
Grade		
No schooling	10	8.6
Grade 1-5	82	70.1
Grade 6-7	17	14.5
Grade 8-10	8	6.8
Mean grade	3.7 yrs (SD+2.3 yrs)	

Profiles of children

One hundred and twenty-one caregivers provided information on the children under their care. Table 2 summarizes the profile of children on ART. The gender distribution of the children in the sample shows that there were a few more boys

Table 3
Child characteristics in disclosed and non-disclosed group.

Variables	Disclosed HIV diagnosis, *n* (%)	
	N (*n*=81)	Yes (*n*=40)
Age (years)		
6-10	64 (79.1)	18 (45)
11-13	17 (20.9)	22 (55)
Mean age	8.7	10.8
Gender		
Boy	45 (55.6)	21 (52.5)
Girl	36 (44.4)	19 (47.5)
Diagnosis age (years)		
1-5	47 (58.0)	20 (50.0)
6-10	27 (33.3)	13 (32.5)
11-13	7 (8.6)	7 (17.5)
Mean diagnosis age	4.8	6.0
Schooling		
No	9 (11.3)	2 (5.0)
Yes	71 (88.8)	38 (95.0)
School grade		
No schooling	10 (12.5)	0
Grade 1-5	58 (72.5)	24 (64.9)
Grade 6-7	10 (12.5)	7 (18.9)
Grade 8-10	2 (2.5)	6 (16.2)
Mean grade	3.1	5.0
Duration on ART (years)		
1	6 (7.4)	1 (2.5)
2	75 (92.6)	39 (97.5)
Mean ART duration	1.9	1.9

(*n*=66, 54.6%) than girls (*n*=55, 45.5%).

The caregivers provided information about the age at which children were diagnosed with HIV, and more than half of the children (*n*=67, 55.4%) were diagnosed between birth and 5 years, 40 (33.1%) were between 6-10 years, and 14 (11.6%) were between11-13 years. The mean age of the children was 9.4 years (range 6-13, SD= 2.2 years); the mean time on ART was 1.9 years (range 0-2, SD=0.27 years).

The majority of the children (*n*=109, 90.8%) were schooling; only one-tenth (*n*=11, 9.2%) were pre-school children. The grades of children who were in school ranged from Grades 1 to 10. The mean age at which children were diagnosed with HIV was 5.2 years (range 6-13, SD=3.7 years), with the majority of children (*n*=67, 55.4%) diagnosed between birth and 5 years old, 40 (33.1%) between 6-10 years, and 14 (11.6%) between 11-13 years.

Profiles of HIV status disclosure to children (Table 3)

The caregivers reported that 40 (33%) of the children had been told their HIV diagnosis, and slightly more boys (*n*=21, 52.5%) than girls (*n*=19, 47.5%) knew their

Table 4
Persons who told the children about their HIV diagnosis (*n*=40).

Person who disclose	Freq	Percent
Biological mother	15	37.5
Biological father	1	2.5
Grandmother	7	17.5
Grandfather	2	5
Foster parent	2	5
Other relatives	3	7.5
Health worker	10	25
Total	40	100

HIV diagnosis. The mean age when children were told their HIV diagnosis was 9.4 years (range 3-13, SD = 2.6 years). Almost all children who had their HIV status disclosed (*n*=40, 33%) were schooling, with a mean school grade of 5.02 (SD=2.08), as compared to mean school grade of 3.0 (SD = 2.26) for children who had not had disclosure.

The mean age of children disclosed to was 10.8 years (SD=1.9 years), as compared to 8.7 years (SD=1.9 years) for children who did not know their HIV diagnosis.

The mean age when children were informed of their HIV status was 6.0 years (SD = 3.9 years), as compared to 4.7 years (SD = 3.5 years), the mean diagnosis age of children not disclosed to.

Characteristics of persons who disclose to the child

Table 4 shows that more than one-third (*n*=15, 37.5%) of the children who knew their HIV diagnosis were told by their biological mothers, one-quarter (*n*=10, 25%) were told by health care providers (nurses, doctors and social workers), and grandmothers told about 7 (17.5%) of the children. The remaining percentages of children were told their HIV diagnosis by a combination of grandfathers, biological fathers, foster parents, and other relatives. Overall, nearly two-thirds of children (*n*=26, 60.0%) were told of their HIV diagnosis by people other than their biological parents.

Demographic characteristics of caregivers who disclosed

The characteristics of caregiver for disclosed and non-disclosed children are shown in Table 5. Forty caregivers reported that the children under their care were informed of their HIV diagnosis. The majority (*n*=33, 86.8%) of the caregivers who disclosed HIV to the children were female, only (*n*=5, 13.2%) were males. The mean age of caregivers who disclosed was 43.9 years (SD=12.9 years) as compared to 37.6 years (SD=12.1 years) for caregivers who have not disclosed.

DISCUSSION

This survey described the profile and HIV diagnosis disclosure status of children enrolled in ART at a tertiary hospital, as well as the socio-demographic profile of their caregivers. We found that the caregiving responsibility for HIV infected children is a shared responsibility among a variety of caregivers comprised of biological parents, grandparents, foster parents, and other relatives (aunts, uncles and siblings).

In this study, the majority of caregivers were females (87.4%), and this gender distribution of caregivers is an indication of the role played by women in caring for HIV-infected children in poor resource settings (Shisana *et al*, 2009). Indeed, unemployment among the caregivers in this setting was very high, with 69.8% of the caregivers reporting to be unemployed, and two-thirds (61.9%) depending on the child care grant as a source of income.

Table 5
Characteristics of caregivers for disclosed and non-disclosed children.

	Disclosed HIV diagnosis n (%)		
Variables	No (n=81)	Yes (n=40)	p-value[a]
Age			
Mean age	37.6 yrs	43.9 yrs	0.005
21-30 yrs	29 (36.3)	5 (13.5)	
31-40 yrs	27 (33.8)	13 (35.1)	
41-50 yrs	12 (15.0)	7 (18.9)	
51-60 yrs	7 (8.8)	9 (24.3)	
61-71 yrs	5 (6.3)	3 (8.1)	
Gender			1.000
Male	10 (12.4)	5 (13.2)	
Female	71 (87.7)	33 (86.8)	
Marital status			0.319
Single	43 (53.1)	18 (47.4)	
Married	25 (30.9)	17 (44.7)	
Live with partner	4 (4.9)	0	
Divorced	4 (4.9)	3 (7.9)	
Widowed	5 (4.9)	0	
Employment status			0.574
Unemployed	55 (67.9)	27 (71.1)	
Employed	16 (19.8)	4 (10.5)	
Self employed	4 (4.9)	4 (10.5)	
Part time	3 (3.7)	2 (5.3)	
Pensioner	3 (3.7)	1 (2.6)	
Level of education			0.201
Primary	13 (16.3)	11 (29.0)	
Grade 8-11	27 (33.8)	15 (39.5)	
Grade 12	33 (41.3)	9 (23.7)	
Tertiary	7 (8.8)	3 (7.9)	
Relationship to child			0.624
Biological mother	37 (45.7)	14 (36.8)	
Biological father	7 (8.6)	2 (5.3)	
Grandmother	10 (12.4)	7 (18.4)	
Grandfather	2 (2.5)	1 (2.6)	
Foster parents	6 (7.4)	6 (15.8)	
Other relatives	19 (23.5)	8 (21.1)	

[a]Fisher's exact test.

The high unemployment rates exist among caregivers in this sample despite a high proportion (35.3%) of caregivers having completed grade 12 and a few having a tertiary education (8.4%). The mean age of caregivers was 39.6 years (range 21 -76), about one-third of the caregivers fall within the lower age range of 20-30 years. This younger category of caregivers of HIV-infected children could possibly be attributed to the increased enrollment of pregnant women in prevention of mother-to-child transmission (PMTCT) of HIV programs in the country and the initiation of ART to children infected through MTCT soon after diagnosis (Orie *et al*, 2009). A small percentage of caregivers falls within the age category of 50-80 years and is comprised mostly of non-biological mothers including grandmothers.

The main caregivers in this sample were biological mothers who made up almost half of the caregivers. The increased representation of biological mothers could be attributed to the increased access to ART and increased survival time of adults living with HIV (Shisana *et al*, 2009). It should be noted that although biological mothers were the main caregivers, non-biological caregivers cared for half of the children. This survey did not collect information on the orphan status of children cared for by non-biological caregivers.

In resource-limited settings, the impact of the disease on society has placed the care of HIV-infected children with other non-biological caregivers as well as grandmothers. Findings from other studies have indicated that grandmothers are often the major caregivers of children infected with HIV (Chazan, 2008; Boon *et al*, 2010). However, our findings suggested that other relatives comprised the second main caregivers of children, followed by grandmothers. Other relatives comprised of older siblings, aunts, and cousins who often played the role of informal foster parent (a phenomenon where the child is cared for by the next available adult in the family without following formalized foster-care processes). This finding is in line with the relatively younger population of caregivers.

The age profile of children in this study shows that the majority of children were 10-years-old, with a mean age of 9.4 years (range of 3-13 years). The increased availability of ART, the increased enrollment of pregnant women in PMTCT programs, as well as the initiation of ART to children immediately after diagnosis are changing the age profile of children on ART. This is also evident in the mean diagnosis age of 5.2 years, where 55.4% of children were diagnosed between 0-5 years. While it was also noted that more than one-third of these children were diagnosed between 6 -13 years, denoting a high-age profile of children surviving without ART.

The prevalence of disclosure of HIV diagnosis to children in this sample was 33.3%, similar to the prevalence of 30.1% and of 29% reported in Thailand and Uganda among HIV infected children aged between 5 and 17 years (Bikaako-Kajura *et al*, 2006; Oberdorfer *et al*, 2006; Kallem *et al*, 2010). However, this was much higher than a prevalence of 9% reported in a previous study conducted with caregivers of children aged between 5 and 11 years in Cape Town, South Africa (Moodley *et al*, 2006). The high prevalence in this study is in contrast with reports from several studies showing that disclosure of HIV diagnosis to children in poor resource countries remains very low (Instone, 2000; Mialky *et al*, 2001; Lester *et al*, 2002b; Mellins *et al*, 2002; Moodley *et al*, 2006; Oberdorfer *et al*, 2006; Vaz *et al*, 2008; Kallem *et al*, 2010; Vaz *et al*, 2010). According to Moodley *et al* (2006), the low disclosure rates in poorly resourced settings are suggestive of significant barriers to discussing HIV status with children in these settings. Although reasons for non-disclosure of HIV diagnosis to children were not investigated in this sample, although several studies conducted in well-resourced and in resource-limited settings have shown that age is a factor in disclosing HIV diagnosis to children (Wiener *et al*, 1996).

The literature suggests that the best age to disclose to a child is 6 years, as the child is able to understand disease and illness (Lester *et al*, 2002b; Wiener *et al*, 2007; De Baets *et al*, 2008; Kallem *et al*, 2010). In the current study, the mean age of disclosure was 9.4 years, suggesting that disclosure in this setting is still delayed much longer than the mean age of 6 years documented in the literature. Reports from several studies have suggested that caregivers consider children less than 5 years of age as too young to understand their illness and its implication.

Moreover, Mellins *et al* (2002) argue that evidence from the literature shows that very few children less than 7 years of age know of their HIV status. We found a significant difference between the mean age of children who were informed about their HIV diagnosis (10.8 years) and those who were not informed (8.7 years). These findings support previous studies showing that children disclosed to tended to be older than children who have not been disclosed to (Moodley *et al*, 2006; Wiener *et al*, 2007).

More than one-third of children (37.5%) were informed about their HIV diagnosis by caregivers other than their biological mothers, and about one-quarter (25%) were informed about their HIV diagnosis by healthcare providers. Healthcare providers played an active role in the disclosure of HIV diagnosis in this setting. Our data confirms recent findings of health care providers' direct involvement in initiating disclosure with HIV infected children in Congo (Vaz *et al*, 2010). Previous studies conducted in the country reported low levels of direct involvement of health care providers in disclosure of HIV to infected children (Kouyoumdjian *et al*, 2005; Moodley *et al*, 2006; Myer *et al*, 2006).

The high disclosure of HIV diagnosis by caregivers other than the biological mother is in line with previous reports that caregivers who disclose early tend to be primary caregivers who are not the biological parents of the infected children (Ledlie, 1999; Lee and Johann-Liang, 1999; Mellins *et al*, 2002; Thorne *et al*, 2002; Lesch *et al*, 2007). According to Wiener *et al* (1998), disclosure of HIV diagnosis is an emotional process, and most biological parents find it painful and difficult to inform children of the HIV diagnosis.

One of the limitations of this study was selection bias; we therefore cannot generalize our findings to other settings. Selecting a range of caregivers, including biological mothers, grandmothers, foster parents, aunts, and siblings representing caregivers caring for HIV infected children in parts of the country similar to the study setting, minimized selection bias.

Another potential limitation of the study was recall bias, as caregivers might not recall some of the events in the child's life, such as the age when the child started with ART and the age when the child was diagnosed with HIV. The other limitation was that the scope of the survey did not include the collection of data on reasons for disclosure and non-disclosure that are important in understanding disclosure of HIV diagnosis to children. Nevertheless the findings provide important preliminary information on the profile of caregivers and children on ART program in the study setting.

In conclusion, the prevalence of disclosure to HIV infected children was higher than previously reported rates in South Africa and could be attributed to the older mean age of diagnosis. The study also found a high-age profile of children surviving without ART. Biological mothers were the main caregivers, although mothers disclosed to only one-third of children who knew their HIV diagnosis. There is a need for more qualitative and quantitative research to profile HIV infected children accessing ART in public health facilities to inform interventions to manage this growing population of children.

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