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Parental disclosure of HIV positive status to HIV-uninfected children and their reactions to disclosure in Ekurhuleni district, Gauteng Province, South Africa

S. MADIBA

*Department of Environmental and Occupational Health, School of Public Health, Sefako Makgatho Health Sciences University, Ga-Rankuwa, South Africa.
E-mail: sphiwe_madiba@embanet.com*

Abstract

The largest populations of HIV-infected patients live in Africa and care for many un-infected children, this has heightened the need for disclosure of parental HIV status to un-infected children. However, existing literature in sub-Saharan shows low parental disclosure rates. The study sought to determine reasons for parental disclosure and non-disclosure of HIV status to un-infected children and examine the reactions of children to disclosure. A cross sectional survey was conducted among HIV-infected parents of children aged 6-18 years attending a primary health care clinic at Ekurhuleni district, Gauteng province. The sample consisted of 340 HIV-infected adult patients. There were more females 235 (69%) than males 105 (31%). Over half (n=197, 57.9%) had known about their HIV status for 1-5 years, 210 (63%) tested because they were sick, 215 (72.9%) were receiving ART for 1-5 years, 105 (31%) disclosed to children and 26 (26.4%) disclosed immediately after testing. Based on parents reports, the majority (n=74, 68%) of children were sad, worried, angry, confused, shocked, tearful, scared, and distressed after parental disclosure. Non-disclosed parents believed that the child was too young to understand, 217 (94.8%) planned to disclose in the future, and 129 (57.1%) said 21-25 years was the ideal age for disclosure. Non-disclosed parents were not totally against disclosure but were fearful of the perceived negative consequences of disclosure. Health care-workers can play a crucial role in supporting parents to disclose but also offer specific counselling and support to children before and after parental disclosure.

Keywords: HIV, un-infected children, parental disclosure, reaction to disclosure, antiretroviral treatment.

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Introduction

Improvements in HIV-treatment and prevention have resulted in higher proportions of HIV-infected parents surviving to care for their HIV-infected and uninfected children (Ndirangu et al., 2012). Most of the children born to HIV-infected pregnant women in Sub-Saharan Africa, will be HIV-uninfected as a result of the effectiveness of the prevention of mother-to-child transmission (PMTCT) of HIV programs (Mkwanzazi et al., 2012). The positive health gains from ART and PMTCT have heightened the need for disclosure of parental HIV

status to un-infected children in sub Saharan Africa. However, existing literature shows low parental disclosure rates in both developed and developing countries, with most studies reporting rates between 30–45% (Mkwanazi et al., 2012; Qiao et al., 2013). The parental disclosure rates are low despite the many documented benefits of parental disclosure of HIV status for both the parents and children (Nam et al., 2009; Palin et al., 2009; Rwemisisi et al., 2008). The World Health Organization (WHO) published guidelines on HIV disclosure for children up to 12 years of age, recommending that they should be told about their own or their parents' HIV status at primary school age (WHO, 2011). The recommended age of disclosure is supported by literature showing that younger children have no long-term adjustment problems as a result of HIV disclosure (Jones et al., 2007; Qiao et al., 2013). Yet in practice, HIV-infected parents generally disclosed to older children (De Baets et al., 2008; Rwemisisi et al., 2008; Thomas et al., 2009).

For many HIV-infected mothers in particular, the challenge is that they do not know how to initiate or approach disclosure to children and address questions that may include issues relating to death or sexual relationships (Corona et al., 2006; Madiba, 2013; Nam et al., 2009; Rwemisisi et al., 2008; Xu et al., 2007). The lack of skills to disclose is a consequence of lack of support from health care providers, most parents never received any disclosure counselling for parental disclosure to children (Rujumba et al., 2010). The perceived negative consequences of parental disclosure are another reason why parents decide not to disclose to their children. They delay disclosure to protect the children from stigma, emotional pain, as well as worrying that their parents' might die. Some parents believe that children deserve a carefree childhood (Avornyo & Amoah, 2014; Corona et al., 2006; Delaney et al., 2008; Madiba, 2013; Nam et al., 2009; Palin et al., 2009; Rwemisisi et al., 2008; Thomas et al., 2009; Tompkins, 2007). Parents are also often uncertain about the appropriate age to disclose parental HIV status to children (Rwemisisi et al., 2008). As a result, they delay disclosure when they believe that the child is too young to understand HIV. Parents also believe that when children are too young to understand HIV related stigma, they might carelessly tell other children and thus experience stigmatization (Madiba, 2013; Nam et al., 2009; Palin et al., 2009; Thomas et al., 2009; Tompkins, 2007; Xu et al., 2007). Stigma and discrimination was identified in a review of literature as one of main barriers for HIV-infected parents' disclosure of HIV status to their children (Qiao et al., 2013).

As already mentioned, parents decide not to disclose because of perceived negative consequences of parental disclosure to children. Yet generally, children react negatively and positively to disclosure of parental status. The most cited negative reactions to disclosure include: sadness, crying, shock, worry, fear of maternal death, worry about stigma, and rejection of the HIV positive results of

the parents (Kennedy et al., 2010; Murphy et al., 2006; Palin et al., 2009). There are also reports of positive reactions to disclosure where children comforted mothers and provided emotional support to their mothers after disclosure (Delaney et al., 2008; Kennedy et al., 2010).

Parental disclosure is influenced by considerations of the rights and benefits of the children as well as the needs of parents (Qiao et al., 2013). Disclosure considerations for children include that; they have the right to know, disclosure is the right thing to do, parents want children to hear about the HIV diagnosis from them, they want to be honest with their children, and they want to reassure the children and allay their fears (Delaney et al., 2008; Gachanja et al., 2014; Madiba & Matlala, 2012). While some parents disclose in order to educate their children about HIV in order to protect them from HIV infections (Madiba & Matlala, 2012). Disclosure considerations for parental needs occurs when parents disclose to obtain support from children because their health was deteriorating or they were critically ill (Madiba & Matlala, 2012; Nam et al., 2009; Rwemisisi et al., 2008; Thomas et al., 2009). Parents also disclose because they are burdened by keeping their HIV status a secret from their children (Madiba & Matlala, 2012). According to Qiao (2013), the largest population of HIV-infected parents live in Africa as a result of increased access to ART. Therefore, parental disclosure of HIV status to children will continue to be the focus of research as many HIV positive parents on ART will face the challenge of parental disclosure to un-infected children (Tiendrebeogo et al., 2013). However, there is limited research relating to maternal HIV disclosure particularly in the African context (Qiao et al., 2013). South Africa is one of the countries with the largest population of adults living with HIV, a high proportion are on ART and parents of HIV-infected and un-infected children. Like in other sub-Saharan countries, the knowledge on how parents approach and perform HIV disclosure to their un-infected children is relatively limited (Gachanja et al., 2014; Tiendrebeogo et al., 2013). The study sought to determine reasons for parental disclosure and non-disclosure of HIV status to un-infected children and examine the reactions of children to parental disclosure from the perspectives of the parents. Given the limited knowledge of how parents disclose their HIV status to children, the study findings will address the gaps in knowledge on parental disclosure of HIV status to children (Gachanja et al., 2014).

Methodology

Study design

The study employed a descriptive quantitative cross sectional survey using semi-structured questionnaire with open ended and closed ended questions. The study was conducted from a primary health care (PHC) clinic which is located in an informal settlement area in Tembisa, Ekurhuleni district, Gauteng province. The

study population consisted of HIV-infected adult patients who were receiving ART from the clinic, both male and female adult patients who were the biological parents of HIV-uninfected children aged between 6-18 years were recruited. The sample size was calculated at 384 with a 5% margin of error, 95% confidence level and a 50% response distribution.

Data collection

Adult patients accessing the clinic for routine follow up and collection of ART and meet the inclusion criteria were recruited to participate in the study. A Master's in Public Health student and trained research assistants collected the data using a semi-structured, pre-tested, and translated questionnaire. The questionnaire was tested during a pilot study that was conducted with ART patients in the clinic, with about 5% of the study sample. The pilot did not form part of the final analysis but the results were used to make the necessary changes to ensure that the questionnaire can answer the research questions and was well understood by the participants. The questionnaire was administered in English or Sepedi after informed consent was obtained from the patients who volunteered to participate and met the inclusion criteria. Participants were given the option of completing the questionnaire if they so wished but the majority of the questionnaires were researcher administered. Data was collected between June and September 2014. Close-ended questions collected data on the socio-demographic information of the participants including, employment status, age, gender, marital status, level of education, number of children, and the ages of the children. The questionnaire also captured HIV testing and related information including, number of years since tested for HIV, reasons for testing, and duration on ART. Disclosure related information included proportion of parents who disclosed their HIV status to children, the time it took parents to disclose, the age of children at disclosure, intentions for future disclosure, and perceptions of parents on the right age to disclose. Open ended questions collected data on children's reactions after parental disclosure and reasons for disclosure and non-disclosure.

Ethical considerations

Ethical approval of the protocol was granted by the Medunsa Research Ethics Committee (MREC) of the University of Limpopo, South Africa. Permission to conduct the study was obtained from the management of Ekurhuleni district and from the Manager of the PHC facility. The objectives of the study were clearly explained and informed consent was obtained from the participants before data collection. Confidentiality was assured and no personal identifiers were collected from the participants.

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Data analysis

Data were analyzed using STATA version 13 (StataCorp. 2013). Descriptive and inferential statistics were computed for socio-demographic variables and to determine the prevalence of parental disclosure to children. Frequency tables were computed for reasons of disclosure and non-disclosure of parental HIV status. Pearson's chi-square tests, were used to determine the association between parental disclosure and parents' characteristics (age, gender, marital status, education level, number of years since tested for HIV, and duration on ART). Confidence interval (CI) was set at 95%, and values < 0.05 were considered to be statistically significant.

Results

The study sample included 340 male and female HIV-infected patients who were the biological parents to children aged 6-18 years. The results showed that there were more females 235 (69%) than males 105 (31%). The age of the participants ranged from 21-63 years, with mean age of 41.3 years. The majority (n=126, 37.2%) were aged between 31-40 years, 194 (57.7%) were single, 167 (49.41%) had a secondary education, and 221 (66%) were unemployed (Table 1).

Table 1: Characteristics of participants segregated by disclosure status to children

	Not disclosed	Disclosed	Total	P Value
Gender				0.663
Female	158 (68.1)	74 (70.5)	232 (68.8)	
Male	74 (31.9)	31 (29.5)	105 (31.2)	
Age category				0.004
20-30 years	42 (18.1)	3 (2.9)	44 (13.1)	
31-40 years	91 (39.2)	33 (31.7)	124 (36.9)	
41-50 years	77 (33.2)	30 (28.9)	107 (31.9)	
51-60 years	21 (9.1)	35 (33.7)	56 (16.7)	
61-79 years	1 (0.4)	3 (2.9)	4 (1.2)	
Marital status				0.001
Single	147 (64.5)	46 (43.8)	193 (58.0)	
Married	66 (29.0)	43 (41.0)	109 (32.7)	
Divorced	7 (3.1)	12 (11.4)	19 (5.7)	
Widowed	8 (3.5)	4 (3.8)	12 (3.6)	
Employment status				0.268
Unemployed	80 (34.9)	29 (28.7)	109 (33.0)	
Employed	149 (65.1)	72 (71.3)	221 (67.0)	
Level of education				0.351
No formal schooling	14 (6.1)	10 (9.5)	24 (7.2)	
Primary education	52 (22.7)	32 (30.5)	84 (25.2)	
Secondary education	119 (52.0)	46 (43.8)	165 (49.4)	
Completed Grade 12	31 (13.5)	13 (12.4)	44 (13.2)	
Tertiary education	13 (5.7)	4 (3.8)	17 (5.1)	

HIV testing and related information

With regards to the number of years since they tested for HIV, over half (n=197, 57.9%) of the participants had known about their HIV status for 1-5 years. The results indicate that two thirds (n=210, 63%) of the participants tested because they were sick (Table 2). The duration on ART for three quarters (n=215, 72.9%) of the participants was 1-5 years, 49 (16.3%) were on ART for less than one year, 28 (9.5%) for 6-10 years, and 3 (1.0%) for more than 10 years.

Table 2: Reasons for testing for HIV

Variabes	Frequency	Percent
Sickness	210	63.8
Pregnancy	51	15.5
Referred for HIV counselling and testing	10	3.1
Death of partner	14	4.3
Testing campaign	6	1.8
To know status	30	9.1
Partner sickness	8	2.4

Disclosure to children and reasons

Only a third (n=105, 31%) of the parents disclosed their HIV status to their children while almost three quarters (n=232, 68.8%) did not disclose. A total of 90 children were informed about the HIV status of their parents (number of children per parent ranged from 1-6 children). The ages of the children ranged from 6-18 years, 147 (43.4%) were aged between 10-15 years, 141 (41.6%) were between 6-9 years, and 51 (15%) between 16-18 years. The majority (n=41, 45.6%) of the children that were informed about their parents status were older than 15 years. More than a third (n=35, 38.9%) of the parents disclosed to more than one child with ages varying between 6-18 years. A quarter (n=26, 26.4%) disclosed immediately after testing (Table 3). Parents gave various reasons for disclosing their HIV status to their children (Table 4).

Table 3: The reported time it took for parents to disclose to children after testing for HIV

	Frequency	Percent
Parents disclose immediately	26	26.5
Parents disclosed after 1- 3 months	27	27.6
Parents disclosed after 4-6 months	11	11.2
Parents disclosed after one year	4	4.1
Parents do not remember when the disclosed	30	30.6

Table 4: Self-reported reasons for disclosing parental HIV status to children

	Frequency	Percent
For the child to know the HIV status of the parent	28	26.7
Parent has a close relationship with the child	7	6.7
Did not want to keep the HIV status a secret from the child	14	13.3
Felt that disclosure was the right thing to do to build parent-child trust	18	17.1
Parent was sick or concerned that their health might deteriorate	10	9.5
Wanted to educate the child about HIV and protect child from HIV	3	2.9
Wanted the child to hear of the parent's HIV status from the parent	7	6.7
The child saw the ART medication and the parent had to explain	4	3.8
The child was supporting and caring for the parent when they were ill	4	3.8
For the child to assist the parent to adhere to medication	5	4.8

Reactions of children to disclosure of parental status

Based on parents' reports, children reacted in various ways after disclosure of parental HIV status. The majority (n=74, 68%) of the children reacted negatively to parental disclosure (Table 5). With regards to how long it took the children to get over the negative reactions to parental disclosure, 20 (44%) of the parents reported that children took about a week, 20 (44.5%) reported that it took 2-4 weeks, and 5 (11.1%) said it took more than a month for children to get over their negative reactions to parental disclosure.

Table 5: Parents' reports on the reactions of children to disclosure

	Frequency	Percent
Shocked	20	21.1
Angry	10	10.5
Very sad and distressed	17	17.9
Tearful/Cried	18	18.9
Very supportive	12	12.6
Scared and confused	13	13.7
No negative reaction	27	28.4
Withdrawal	6	6.3

Intentions to disclose

The majority (n=232, 68.8%) of parents did not disclose their HIV status to children and the main reason for not disclosing was that the child was too young to understand the disease. But almost all (n=217, 94.8%) intended to disclose in the future. Non-disclosed parents were also asked to indicate the right age to disclose parental HIV status to children, almost two thirds (n=129, 57.1%) said 21-25 years was the ideal age, more than a third (n=81, 35.8%) said 16-20 years was the ideal age, only 14 (6.2%) said 10-15 years was ideal. One parent suggested that children be told when they are 30 years old. The recommended mean age of disclosure to children was 19.8 years (range 10-30 years).

Discussion

The study determined the prevalence of parental disclosure of HIV status to uninfected children. Only a third (31%) of the parents reported that their children had been informed about the parents' status. The rate of parental disclosure was very low in spite of parents having a long history of ART and an improved health status. The findings indicate very little improvements in the disclosure rates of parental status in general as the rates from the current study are consistent with those of much earlier studies (rates of 20-50%) when an HIV diagnosis was perceived as a death sentence (Delaney et al., 2008; Kallem et al., 2011; Nam et al., 2009; Palin et al., 2009; Rwemisisi et al., 2008; Tiendrebeogo et al., 2013). Tiendrebeogo et al. (2013) argue that parental disclosure of HIV status to children cannot be expected in an environment where most people living with HIV find it hard to disclose to others including partners, family, and friends. Madiba (2013) also reported on the negative influence of the social cultural contexts on disclosure of parental HIV status to children. While the social and cultural environments impacts negatively on parental disclosure, HIV counselling has also become progressively poor in relevant content and does not take into account the changing needs of HIV-infected people such as assistance to disclose to children (Tiendrebeogo et al., 2013).

Our findings also support previous studies which showed that parents disclose their status to children when the child is older and matured (Madiba & Matlala, 2012; Nam et al., 2009; Rwemisisi et al., 2008). In the current study, almost half (45.6%) of the children who were aware of their parental HIV status were older than 15 years. Consistent with existing literature, we found that parental disclosure was selective, and parents who had more than one child disclosed to the older child first (Madiba & Matlala, 2012; Ostrom et al., 2006; Tiendrebeogo et al., 2013). However, Tiendrebeogo et al. (2013) argue that parental non-disclosure cannot be explained by children's age alone because even children aged 15 or even 18 years and above, are often considered as young by their parents. A previous South African study also found that the age when the child was perceived to be old enough varied, parents planned to disclose when the child reaches puberty, after completing high school, and after celebrating the 21st birthday (Madiba, 2013). This kind of reasoning was also observed in the current study, we found a huge discrepancy between the ideal age of disclosure to children between disclosed and non-disclosed parents. Almost two thirds (57%) of non-disclosed parents suggested 21-25 years as the ideal age for parental disclosure to children, while the age of children that have been disclosed to, ranged from 8-18 years.

We found that most of the reasons for disclosure of parental HIV status were for the benefit of the children. Parents wanted children to know the parental status,

they felt that disclosure was the right thing to do, they wanted to be the one to tell the children about their status, and did not want to keep their HIV status a secret from their children. Our findings are in line with previous findings in South Africa and other sub-Saharan countries (Avornyo & Amoah, 2014; Madiba & Matlala, 2012). Although only a few, some of the reasons for disclosure were for the benefit of the parents, they wanted children to support them, care for them when they are sick, help them adhere to ART medication, and to know what to do in an emergence. Literature show similar reasons for parental disclosure (Avornyo & Amoah, 2014; Madiba & Matlala, 2012; Nam et al., 2009; Rwemisisi et al., 2008; Thomas et al., 2009).

Generally, parents decide not to disclose because of perceived negative consequences of parental disclosure to children (Avornyo & Amoah, 2014; Madiba, 2013; Nam et al., 2009; Rwemisisi et al., 2008; Tiendrebeogo et al., 2013). Consistent with literature, the majority (68%) of the children reacted negatively to parental disclosure, children were sad, worried, angry, confused, shocked, tearful, scared, and very distressed after disclosure (Avornyo & Amoah, 2014; Madiba, 2013; Palin et al., 2009; Vallerand et al., 2005). Children may show distress when they find out about their parent's HIV status because of lack of parent-to-child disclosure support services (Tiendrebeogo et al., 2013). A few children (19.6%) were supportive to their parents. Other studies reported that children hugged and comforted parents and became protective after disclosure (Avornyo & Amoah, 2014; Delaney et al., 2008; Murphy et al., 2006; Ostrom et al., 2006; Tiendrebeogo et al., 2013). Although parents believe that children will be hurt by disclosure, in this study and other, some of the children did not have any negative reaction to disclosure (Rochat et al., 2014). Our findings support other studies suggesting that children overcome the initial negative reactions to parental disclosure after a while and provide care and support to their parents (Avornyo & Amoah, 2014).

Consistent with existing literature, we found that parents delayed disclosure because they believed that their children were too young to understand HIV (Madiba & Matlala, 2012; Nam et al., 2009; Tompkins, 2007; Xu et al., 2007). Underlying the reasoning that the child is too young to understand is the belief that disclosure will worry and scare the child (Delaney et al., 2008; Madiba & Matlala, 2012). In the current study, parents believed that children are too young to be burdened with the responsibility of the parent's HIV status. Liamputtong & Haritavorn (2014) reported similar reasons for non-disclosure, mothers in their study wished to protect their children from emotional burdens of disclosure. In contrast to other studies (Corona et al., 2006; Madiba, 2013; Nam et al., 2009; Palin et al., 2009; Thomas et al., 2009), the concern that the child will tell others about the parent's status resulting in stigma and discrimination was not mentioned as one of the reasons for not disclosing in the current study. This could be explained by the fact that parents did not envisage a time when parental

disclosure could occur to children who were immature to understand the secret nature of HIV. In fact, previous studies report that non-disclosed parents planned to disclose when they think that their children are matured enough to understand HIV and could keep the parents' status a secret (Avornyo & Amoah, 2014; Delaney et al., 2008; Nam et al., 2009). The same belief was held by disclosed parents in the current study, the majority disclosed to children they considered mature enough (16-18 years old). Similar to a recent study, disclosed parents chose not to disclose to younger children and cited the same reasons given by those who had not disclosed their status (Avornyo & Amoah, 2014).

Although more than two thirds (68.8%) of the parents had not disclosed their HIV status, three quarters (71.5%) believed that children should be told about their parental HIV status, and 48% believed that children have the right to know their parents' illness. However, almost a quarter believed that children should not be told because knowing the parental HIV status would be too much responsibility for a child. They felt that disclosure will burden children and they will be anxious about their parent's health. It is important to note that more than three quarters (74.7%) of the respondents were of the view that they did not need help from health providers to disclose, mainly because they intended to disclose when their children were much older. This attitude underscores the importance of parental disclosure to children and the implications of non-disclosure to both parents and children.

The parents limited their unwillingness to disclose to their child being too young without acknowledging the burden of keeping their HIV status secret (Madiba, 2013; Tiendrebeogo et al., 2013). Nevertheless, the findings are in contrast to those of a previous South African study which highlighted that non-disclosed parents desired that their children should be prepared by health care providers before disclosure of parental status. They wanted their children to be counselled and provided with adequate information to help them cope with the parent's HIV status (Madiba & Matlala, 2012). Recent findings also show that parents prefer assistance and advice on the appropriate process of disclosure for preparation for disclosure to their children (Gachanja et al., 2014).

Limitations

The study is subject to limitations; firstly, because of the cross-sectional nature of the data, we could not examine disclosure processes and adjustment to disclosure reactions over time. One other limitation is that data are reported by the HIV-infected parents only and lack the children's perspectives on the experience of parental disclosure. Furthermore, the reactions of children to disclosure is reported by the parents and is subject to recall bias where parents might under report or overstate children's reactions to disclosure. While we used

short open-ended questions to assess the reasons for disclosure and non-disclosure as well as reactions to disclosure, more in-depth qualitative data are necessary to explore challenges to disclose the parents' status to children in order to inform the development of interventions for parental disclosure. The strength of the study is that both parents (mothers and fathers) were recruited and the views of fathers have also been captured, the sample also consisted of parents with a wide range of the duration of treatment.

Conclusions

The rate of parental disclosure to children was very low and consistent with rates of much earlier studies conducted in South Africa and sub-Saharan countries. Non-disclosure to children is rooted in social and cultural contexts where HIV-infected people continue to find it hard to disclose to significant others in their lives. Health care professionals can play a crucial role in supporting parents to disclose but also offer counselling and support to children before and after disclosure of parental HIV status.

We further found that non-disclosed parents were not totally against disclosure to children but were concerned about the burden of knowing the parental status for children. The findings suggest that parents lacked comprehensive understanding of the benefits of disclosure for themselves and their children. There is a need for specific counselling support to parents and children to address the challenges faced by parents to disclose to children.

Disclosure counseling for parental disclosure should offer relevant content including the benefits of disclosure to assist parents disclose their HIV status to children. Although parents did not mention that they did not know how to disclose, data from recent and previous qualitative studies have shown that lack of disclosure skills was one of their challenges, hence the delayed disclosure observed in study. Therefore, the role of healthcare providers in disclosure to HIV-infected and un-infected children remains crucial.

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