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## THE THORNY ISSUE OF STATUS DISCLOSURE TO CHILDREN LIVING WITH HIV: THE CASE OF HIV POSITIVE CHILDREN LIVING IN A CHILD AND YOUTH CARE FACILITY IN JOHANNESBURG, SOUTH AFRICA

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### **ABSTRACT**

*There is a dilemma regarding HIV/AIDS disclosure to children born and living with HIV/AIDS in residential settings. Since the advent and accessibility of Anti-Retroviral Therapy, most children born HIV positive live longer and have healthier lives. Some of these children find themselves in Need of Care due to abandonment, orphanhood and neglect or abuse, and are placed in alternative care such as a Child and Youth Care Centre (CYCC). Social Service Workers are then faced with this dilemma around disclosure of their HIV status, due to the complexities around the consequences of such a disclosure, and the absence of clear policies in this regard. The study explored the perceptions of social service workers regarding disclosure of HIV status to children born HIV positive living in a CYCC in Ekurhuleni, South Africa. The findings indicate that HIV status disclosure is a complex but essential process as it reinforces children's ability to adhere to medication and dispels anxiety and suspicion within themselves around their status. Recommendations relate to community education and awareness programmes, policy and practice changes and makes suggestions for future research.*

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**Keywords:** HIV and AIDS, children living with HIV and AIDS, HIV status disclosure, HIV and AIDS related stigma, child and youth care centres, social service workers

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## **INTRODUCTION**

South Africa has a fraught history around HIV and AIDS disclosure, interventions and provision of Anti-Retroviral Treatment (Heywood, 2005). After a prolonged struggle for the attainment of rights to access such treatment (Mbali, 2006), the rollout of these drugs began during 2003 and 2005. Although criticised for being uneven and insufficiently funded (Natrass, 2006), this rollout began to reach many people living with HIV and AIDS. Such availability and accessibility resulted in prolonged life spans due to enhanced immune system functioning (Van Dyk, 2008), including for children born with HIV. However, there are many complexities to be considered in this arena.

The issue of disclosure of HIV status is one of these, especially regarding children. Ethical dilemmas exist around disclosure of HIV status to children generally (Klitzman, Marhefka, Mellins and Wiener, 2008; Committee on Paediatric AIDS, 1999) and more specifically, to those living in alternative care and not with their parents in terms of statutory child protection arrangements. In Child and Youth Care Centres (CYCCs), non-disclosure results in children being on a twice-a-day medication regime without their knowledge and/or understanding of the reasons for this. Social service staff at such CYCCs, are confronted with the issue of disclosure and strategies to deal with this. There is no clear policy with regard to disclosure or non-disclosure of HIV status to children born HIV positive living at a CYCC. Social service workers (including social workers, social auxiliary workers, educational psychologists, child care workers and support staff) are among those needing to consider such decisions.

There seems to be little work on perceptions about HIV status disclosure to children born HIV positive and specifically among those living in child care facilities or in alternative care placements. This study, therefore, aimed to explore the perceptions of social service workers about the effects of HIV status disclosure or non-disclosure to children born HIV positive, living at a CYCC in Ekurhuleni, South Africa. It is hoped that the findings would contribute to raising awareness among social service workers regarding the effects of disclosure of HIV status to children; develop intervention strategies, knowledge and practice; give input into policy as the state plans to embark on voluntary HIV testing of children in primary schools; and around provision of information and procedures for dealing with disclosure of the HIV status to such children.

## **BACKGROUND**

### **Contextualising HIV and AIDS in South Africa**

While South Africa attained political liberation from Apartheid through its liberation struggle and made the transition to democracy in 1994, the struggle for socio-economic rights continues. Neo-liberal macro-economic policies such as the Growth Employment and Redistribution policy (GEAR) changed the state focus towards a conservative, market driven focus and consequently, the country is presently one of the most unequal societies in the world with extreme levels of poverty and underdevelopment (Sewpaul, 2013; Satgar, 2012; Bond, 2005). Historically and into the present, South Africa also endured the destructive consequences of colonisation and Apartheid, leaving the country with a legacy of unequal and inadequate health, education, housing and basic resources and a society stratified on a racial and class basis (Sewpaul, 2013; Terreblanche, 2012). This context includes the HIV and AIDS pandemic. Sub-Saharan Africa continues to carry the burden of

the global epidemic with almost 25 million HIV infected individuals (United Nations Children's Emergency Fund (UNICEF), 2015; Mashau, 2008), with South Africa regarded as the world's 'capital' of HIV and AIDS (Venter, 2008). It is estimated that there are between 6.3 and 6.5 million South Africans living with HIV out of a population of about 52 million (UNICEF, 2015). People with HIV and AIDS have further difficulties as they live within a context of structural difficulties such as poverty, unemployment, education and other health problems (Sewpaul, 2013; International Labour Organization (ILO), ILO Brief, 2005). HIV and AIDS contribute to this struggle, as it presents specific medical and social problems, which may include discrimination, rejection and stigmatisation.

In contexts of high HIV prevalence, HIV and AIDS becomes everyone's problem, whether living with HIV or being concerned about its transmission (Squire, 2007). Those infected and affected by HIV and AIDS undergo enormous pain and suffering due to the devastating consequences (Mashau, 2008). Three phases of the AIDS epidemic are described by Parker and Aggleton (2003) as, firstly the epidemic of HIV infection that typically enters silently and unnoticed, over many years without being widely perceived or understood; the second phase occurs over a number of years and is the AIDS epidemic itself, which is the syndrome of infectious diseases because of HIV infection; and the third phase, potentially the most explosive, the epidemic of social, cultural, economic and political responses to AIDS, characterised by challenges of collective denial, stigma and discrimination (Parker and Aggleton, 2003).

### **HIV and AIDS among children in South Africa**

At the time of the study, almost 300 000 of the estimated 5.6 million infected people in South Africa are children (Statistics South Africa, 2009), while the statistics for 2013 indicate that approximately 360 000 children are living with HIV and AIDS (UNICEF, 2015). Furthermore, approximately 2.4 million children are living as AIDS orphans. Approximately 30% of antenatal clinic attendees were HIV positive according to the Department of Health's survey of 2011 (AVERT, 2012). According to Heyns and Swanevelder (2005) HIV is transmitted to approximately one third of babies of HIV positive mothers if there is no medical intervention, such as the use of antiretroviral drugs, obstetric practices including caesarean delivery and safe infant feeding practices. According to Children's Institute (2010), a significant number of children in South Africa are, therefore, living with HIV and AIDS.

HIV and AIDS have also been identified as the major contributor to the increase of 42% of South Africa's 2008 under-five year mortality. The disease progression occurs especially rapidly among children, who experience 30% mortality during the first year of life (Van Dyk, 2008). The fact that children do not have adequate access to AIDS treatment and care because available services are mostly designed for adults, may contribute to this high mortality rate ([www.tac.org.za](http://www.tac.org.za)). In addition, serious challenges around the skills and capacities of health workers as well as the lack of appropriate ART formulations, also remain a concern ([www.tac.org.za](http://www.tac.org.za)).

### **Status disclosure to children living with HIV and AIDS**

As of 2009, an estimated 2.5 million children, under four years of age, were living with HIV globally with the great majority of these (2.3 million) living in sub-Saharan Africa (World Health Organization (WHO), 2011). In spite of these high numbers there has been

relatively little attention to issues of disclosure of HIV status to infected children, especially in resource-limited settings (Myer, Moodley, Hendricks and Cotton, 2006). Disclosure of children's HIV status to them is regarded as a difficult ethical dilemma especially in an institutional care setting. Disclosure may cause psychological harm if children are not old enough to understand the implications of the disclosure and the diagnosis, while on the other hand disclosure may be psychologically beneficial and could alleviate the anxiety of not knowing and suspecting that 'something is wrong' (Klitzman, Marhefka, Mellins and Wiener, 2008).

Two different types of disclosure are described (Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuzza, Mermin, Malamba and Bunnell, 2006). The first, complete parental disclosure, refers to a situation in which "both the caregiver and child concur that the primary caregiver has told the child about his or her HIV disease and drugs, which prevent opportunistic infections and help prolong life" (Bikaako-Kajura et al., 2006:88). The second, partial disclosure, refers to a situation in which the child is not fully aware of his or her HIV disease but is suspicious, asks questions from the caregiver about the disease and the drug, and, in many cases, assumes that the drug is a cure (Bikaako-Kajura et al., 2006:89). Non-disclosure on the other hand refers to a situation where the child is unaware of his or her infection (Bikaako-Kajura et al., 2006).

Important arguments are made for the disclosure of their illness status to children. It is argued that growing access to antiretroviral therapy (ART), means that "HIV infected children survive to older ages, and in turn discussing HIV status with infected children is an important issue in paediatric HIV care" (Myer et al., 2006:11). Furthermore, as children born with HIV mature into adolescence and begin engaging in sexual behaviour, the issue of disclosing their diagnosis to them, becomes even more important. They would be at a level of cognitive development, which would allow them to understand their HIV status. According to Mann, Long, Delap and Connell (2012:3) "All children have a right to HIV prevention information and the means to act on this knowledge. The absence of such information in residential care makes doing so impossible. It is well known that children leaving care often risk violent relationships, unwanted pregnancies and other health risks, often because of their formative experiences." Furthermore another argument for disclosure is the concern that non-adherent adolescents (who are not aware of their status) who may be sexually active, would be at risk of transmitting a drug-resistant virus (Klitzman, Marhefka, Mellins and Wiener, 2008; Pantell, 2006).

However, parents and guardians may have reservations around disclosure, despite published guidelines which encourage disclosure to school-aged children (WHO, 2011). Reasons for this may be concern over the child's reaction, fear of child telling others, or guilt about transmitting the virus to a child (Pantell, 2006). Naeem-Shaik and Gray (2005) highlight that disclosure of a child's HIV status is also an extremely sensitive issue to caregivers. It is particularly difficult for caregivers who are themselves HIV positive, and where the child's HIV positive status is a result of mother-to-child transmission (Naeem-Shaik and Gray, 2005).

According to Mbambo (2004:4), disclosure should be seen as "a process of telling a child that they have HIV disease and helping the child to understand what this means". Through the process, the child should come to know about the diagnosis, the infection and disease process, together with health changes that could occur (Hamilton, 2006). The child should know strategies to prolong a healthy life, including adherence to ART, risk factors,

responsibilities now and in the future, together with how to cope with possible negative reactions of others (Hamilton, 2006).

An additional area to consider would be whether children disclose their own status to others. Professionals in both social and health care, should explore ethical dilemmas and the implications of disclosure and non-disclosure with concerned children and help them plan for disclosure with the aim of promoting adherence and normalisation of HIV infection (Klitzman, Marhefka, Mellins and Wiener, 2008; Mtshizana, 2004).

### **HIV-related stigma and discrimination**

HIV-related stigma is particularly destructive as it occurs in multiple layers with other forms of stigma and oppression (Skinner and Mfecane, 2004). Such stigma occurs in many parts of Africa, and are still associated with shame, fear and rejection (United Nations Programme on HIV/AIDS (UNAIDS), 2003). In the South African context, existing prejudices, racist discrimination and internalised oppression has created social hierarchies (Parker, Aggleton, 2003; UNAIDS, 2003) and causes a threat of multiple stigmatisation (Skinner and Mfecane, 2004). Furthermore, stigma and discrimination are part of complex systems of beliefs about illness and disease and these are often grounded in social inequalities, which should be taken into account as they are much harder to conceptualise and identify (Goffman, 1963). Additional complexities arise from the presence of Tuberculosis, which then leads to further suspicion and stigma around HIV and AIDS (Ross and Deverell, 2010).

People become demoralised and depressed due to such alienation, rejection and disgrace (Scambler, 2009). In a South African study by Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo (2007:6), it was found that “40% of persons with HIV and AIDS had experienced discrimination resulting from having HIV infection and one in five had lost a place to stay or a job because of their HIV status. More than one in three participants indicated feeling dirty, ashamed, or guilty because of their HIV status.”

Children in institutionalised contexts are particularly vulnerable. “Not only are they more vulnerable to losing their parents at an early age, but high levels of stigma, discrimination and misconceptions about the transmission of the virus mean that in some cases they may be denied kinship care and access to foster care, adoption and some residential facilities” (Mann, et al., 2012:2). They may experience stigma in their daily encounters and face additional difficulties around stigma, as they are already vulnerable psychologically due to the pathways that brought them into care (Lumbi, 2007). Furthermore, when children have become orphaned due to HIV and AIDS, after the death of their parents, they may be ‘shunted’ among relatives and extended families before finally being institutionalised for various reasons (Lumbi, 2007). They are, therefore, at risk of compounded psychological and relational trauma with these experiences together with the resultant stigma and discrimination. The management of stigma in such a residential setting is, therefore, extremely important to manage these vulnerabilities and risks.

### **THE STUDY**

The study, which served as part of the requirements for a Master’s degree at the University of the Witwatersrand, used a qualitative research approach with an exploratory and descriptive design. Fifteen social service workers from a residential Child and Youth Care

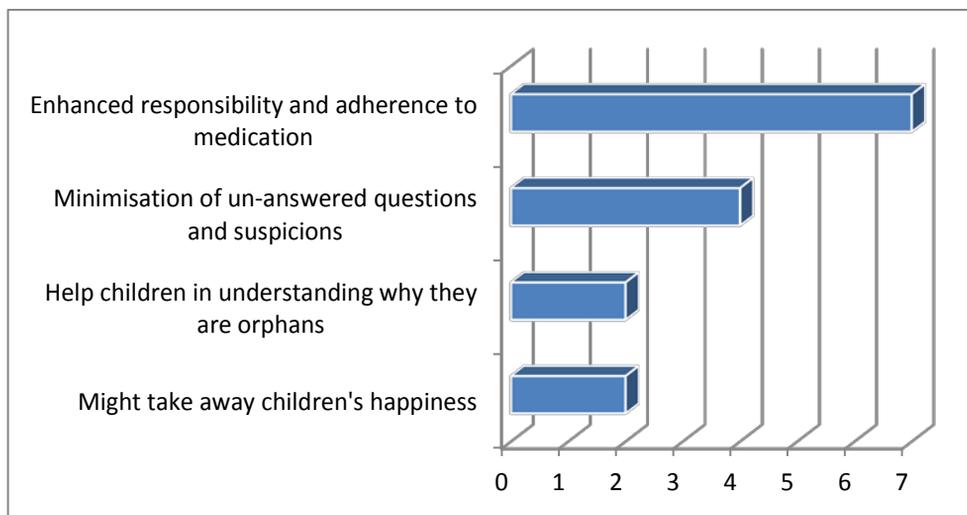
Centre in Ekurhuleni, South Africa were included, through stratified purposive sampling. These participants worked in various employee categories namely educational psychologists, occupational therapists, child care workers and social auxiliary workers. They were sampled in this way in order to include as broad a range of employment categories as possible and, therefore, obtain the broadest possible view. Prospective participants were invited to participate in the study after details about the purpose of the study, confidentiality, the fact that non-participation would not be held against anyone and that there would be no rewards for participating, were explained. The roles of these different groups of people differed in relation to the children and so it was important to explore their views from those different perspectives. The caregivers and/or child and youth care workers had a closer, more intimate involvement with the children concerned, dispensing medication and involved with their day to day lives. While the therapists had a more professional relationship with the children, and the support staff an even more distant relationship. Therefore, it was important to obtain the views of each of the groups as they would have had different perspectives on the difficulties attached to disclosure. Languages spoken by participants were English, IsiZulu and Southern Sotho. A further interview was conducted with a significant stake holder being someone in a management position in the Child Care Centre. Face-to-face semi-structured interviews were conducted with all the participants, exploring their views about the children that they worked with in relation to their HIV/AIDS status, disclosing the HIV/AIDS status to the children, management of medication and compliance of the children with the medication.

The trustworthiness of the study was enhanced through the careful consideration of credibility, confirmability, dependability and transferability of the qualitative data. Care was, therefore, taken to ensure credibility by being careful about how the perceptions of participants about their experiences and thoughts in relation to the children were represented (Maxwell and Satake, 2006). These were described in the report of the findings in as clear a manner as possible. Confirmability was enhanced through correspondence checking, whereby categorisation of themes was checked by the research supervisor as recommended by Pretorius and De la Rey (2004). Dependability, which is the qualitative equivalent of reliability (De Vos, Strydom, Fouche, Delpont, 2011), was enhanced by having the researcher conducting all the interviews personally and using the same interview schedule in all the interviews. Furthermore, consistency was applied in and following the same steps in analysing all the results. Ethics clearance was obtained from the University of the Witwatersrand Humanities Ethics Committee (non-medical).

The limitations inherent in the study included that the small, stratified sample precluded generalisation of findings to the broader population of social service professionals working with children born HIV positive. However, the study was qualitative and exploratory in nature and so generalisation of the findings was not intended. The other limitation was that as participants for the study were recruited through a stratified sample in order to include as broad a range of occupational categories as possible, finding willing participants was a challenge, especially for example therapists, due to their busy schedules. However, the researcher was flexible, and suitable times were arranged convenient to the participants' work schedules. Finally, a further limitation related to the fact that in the qualitative data analysis, some themes were articulated by only one or two participants. However, reflection on such themes is important as this would contribute to the overall understanding and interpretations made in the study.

## PERCEPTIONS OF SOCIAL SERVICE WORKERS REGARDING HIV STATUS DISCLOSURE TO CHILDREN

Perceptions about results of disclosure to children, revolved around adherence to medication, minimisation of questions and suspicion, helping children understand why they were orphaned and a negative consequence relating to the effect on children's happiness.



**Figure 1: Perceptions regarding HIV status disclosure to children born HIV positive**

### Enhanced responsibility and adherence to medication

Seven participants mentioned the notion of enhanced responsibility and adherence to medication as seen in the following example: *“If children are told about their positive HIV status, they will know how to live responsibly and also understand the importance of taking medication regularly without fail so as to live a healthy and prolonged life”*. This response emphasises the need for disclosing children's HIV status so as to protect them together with those with whom they interact. Hamilton and Lowry (2002) also stated that through the process of disclosure, the child should be helped to learn strategies to prolong a healthy life, including adherence to ART, what the risk factors are, responsibilities now and in the future, as well as to cope with possible negative reactions of others. The views of participants regarding the benefit of enhanced understanding and adherence to medication are consistent with the findings by Bikaako-Kajura et al., (2006) that children who knew their HIV status became self-motivated to adhere to their medication as they were aware of the reason why they were taking medication.

### Minimisation of unanswered questions and suspicions

Four participants in the study commented that disclosing the HIV status may result in minimised unanswered questions that children might be having about their condition: *“Most information that I have come across about HIV and AIDS in both print and electronic media emphasise on promiscuity being the major contributor to HIV infection, and this can be very confusing to a child who has never been involved in a sexual*

*relationship... and might result in the child having a number of questions that he or she cannot find answers to...therefore, remaining confused and suspicious*". This is related to what Naeem-Shaik and Gray (2005) refer to as partial disclosure, whereby the child is not fully aware of his or her HIV disease but is suspicious, asks questions from the caregiver about the disease and the drug, and, in many cases assumes that the drug is a cure. However, if disclosure is done, such questions, confusions and suspicions can be minimised.

### **Helping children to understand why they do not have parents**

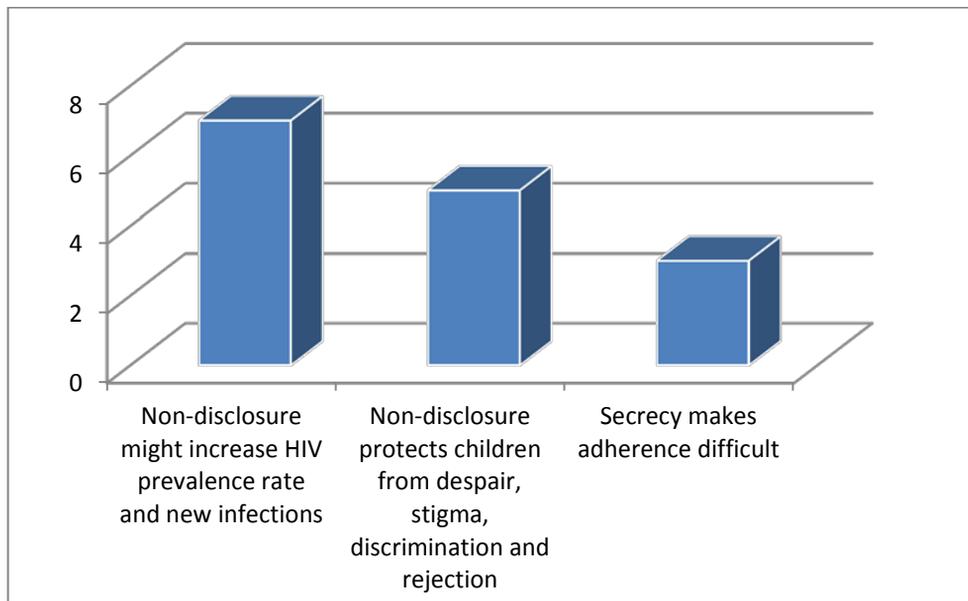
Three participants suggested that by knowing their HIV status, children can have a good sense of understanding on why they do not have parents and are institutionalised. Two participants commented: "*Disclosing to these children will help them understand why they do not have parents and why they are orphans and staying in a child and youth care centre...especially those who were abandoned when they were very young*" and "*...sometimes they are so concerned about their parents not visiting them and even though I explain to them that their mother or father passed away, they do not understand why*". Similarly, Naeem-Shaik and Gray (2005) emphasised that waiting for a better time to disclose may be appropriate, but the child may also be concerned about why the parent died and what that means for him or her. It is during this period that children may be educated about their condition and also have things clarified concerning the death of his or her parents. A holistic approach to the child's needs for knowledge and dealing with grieving processes would thus be facilitated.

### **Concern that disclosure might take away children's happiness**

In contrast to the general views about disclosure of HIV status to the children concerned, two participants indicated that they were of the view that disclosing children's HIV positive status might have an impact on their happiness: "*Childhood is a time to be happy...there is no need to burden children with sadness and worry. For me, a child who knew that he or she is HIV positive will not be able to enjoy his or her childhood in a carefree manner*". Disclosure is, therefore, perceived to have the potential of creating unhappiness in a child's life as it might be partnered with precautions and restrictions that would not allow a child to live a carefree and developmentally appropriate life. It also seems to indicate a perception that is common, that HIV and AIDS does not include hope and a positive approach to those who are negative, as there are constant issues about happiness related to death and dying due to the pandemic. Bikaako-Kajura et al., (2006) also highlights that how children experience and understand illness and death at different ages and levels of development varies greatly. This in turn affects their capacity to understand their treatment, how much they can be expected to co-operate with treatment and what they can manage in self-care. Gradual understanding that death is permanent, final and irreversible, can result in children expending much energy on issues concerning their health other than concentrating on living a carefree and simple life. However, this finding may also be an indication of social service workers' own views around disclosure and possibly their own problems and discomforts at HIV as an incurable illness.

## PERCEPTIONS REGARDING NON-DISCLOSURE OF HIV STATUS TO CHILDREN

Perceptions regarding non-disclosure were both regarding the negative and positive consequences of non-disclosure. They related to the risk of increase of HIV infections; protection from despair; difficulty with adherence.



**Figure 2: Social service workers' perceptions regarding non-disclosure of HIV status to children born HIV positive**

### Non-disclosure might increase HIV prevalence rate and new infections

Seven participants indicated that they have fear and concern that non-disclosure might contribute to the already high HIV prevalence rate and new infections among children: *“Not disclosing to these children makes me feel concerned and afraid that as they grow up they might infect others unknowingly, thereby increasing HIV prevalence rate and also new infections”*. This finding highlights the fact that non-disclosure creates a sense of concern and uneasiness in social service workers' minds as they perceive that it can lead to increased incidents of prevalence and new infections among children: *“Nowadays HIV is manageable due to the anti-retroviral therapy (ART), and children no longer die at a young age but they mature into adolescence and become sexually active and if they are not told about their HIV positive status, they might infect their peers and this worry and concerns me a lot”*. Pantell (2006) emphasised that with the growing access to ART, HIV infected children survive to older ages, and in turn discussing HIV status with infected children is most likely to become an important issue in paediatric HIV care. This was also highlighted by one participant who said: *“Some children have already reached puberty and others will be in the puberty stage very soon and by not telling them and educating them extensively about their condition, we are just encouraging the spread of the HIV related virus”*.

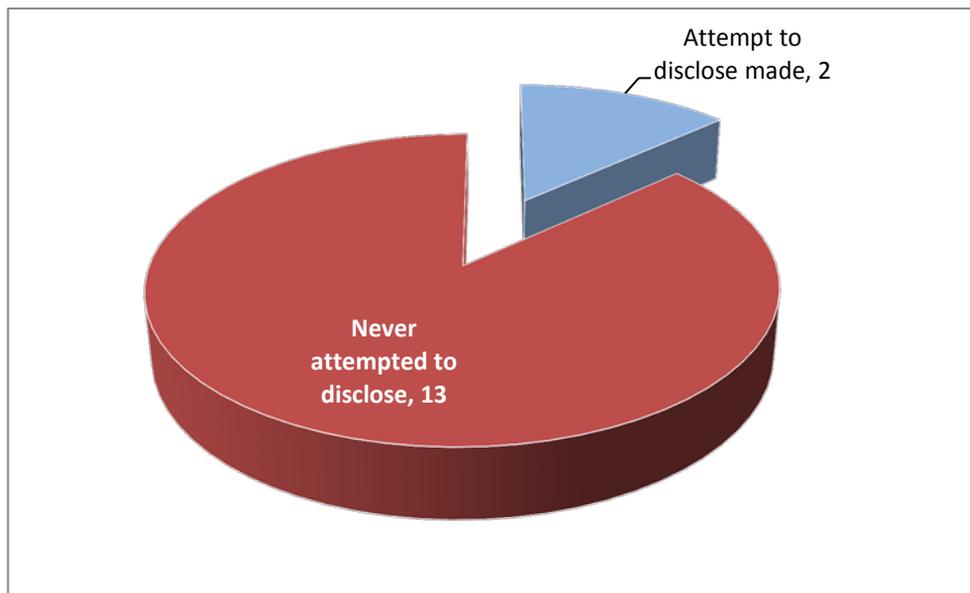
### **Non-disclosure protects children from despair, stigma, discrimination and rejection**

Some participants indicated that non-disclosure acts as a protective measure to the children from different forms of discrimination, stigma and rejection: *“For me, not telling children protects them from despair and stigma and from being discriminated by their peers when playing”* and *“...even here in the village some children tease those who take medication and make fun out of them, so it is better to protect these children from being rejected and discriminated against by keeping their status undisclosed”*. These responses suggested that some participants perceived non-disclosure as a form of protecting HIV positive children from being stigmatised, discriminated against and rejected due to their positive HIV status. HIV-related stigma and discrimination build upon and reinforce existing prejudicial and stigmatising thoughts that frequently lead a person to do or not to do something that denies services or entitlements to another person (UNAIDS, 2003). Moreover, UNAIDS (2003), highlighted that discrimination can lead to depression, lack of self-worth and despair for people living with HIV even though they are not the only ones at risk from this fear and prejudice. However, instead of encouraging non-disclosure as a protective measure, UNAIDS (2003) suggested that there is need to confront and fight discrimination and stigma experienced by those infected and affected by the HIV virus so that fear, shame, ignorance, labelling and injustice can be eradicated.

### **Non-disclosure makes adherence to medication difficult**

Non-disclosure was also seen as creating difficulties in children’s abilities to adhere to medication regimes. The participants spoke about the difficulties that they sometimes experience at the time when children are being given their pills as this would be the time that difficult behaviours emerged. Some children tended to use the taking of medication to act out, manipulate, threaten and seek attention, partly because of the little knowledge that these children have about their HIV status: *“Sometimes we end up using force and verbal abuse in order to get some of these children to drink their pills...and this is not a good thing to do but we will be left with no choice”* and *“Some children drink their pills and keep them in their mouth under their tongue, only to later on spit the medication in the bathroom besides telling them time and again that medication is important as it keeps their bodies healthy”*. One participant also commented: *“Winning them to voluntarily take their medication required a lot of energy, hard work and convincing statements, as if they do it for us yet it is for their own good”*. The first response suggested that children are sometimes coerced to take their tablets and engage in power struggles. Lack of self-responsibility around adherence to medication, even among those who are fully aware of their HIV status, is a complex and difficult issue. This is echoed in the findings from a study that was done in Uganda by Bikaako-Kajura et al. (2006) around incentives for adherence to medication regimes, where it was found that provision of special foods, such as sweetened fruit juice, ripe bananas, cakes and chocolate acted as an adherence incentive for most of the respondents who participated in the study.

## PARTICIPANTS' EXPERIENCES REGARDING DISCLOSURE OF CHILDREN'S HIV POSITIVE STATUS



**Figure 3: Attempts to disclose the child's HIV positive status**

### Never attempted to disclose status

Most participants from all three groupings of Child and Youth Care Centre employees revealed that they had never attempted to disclose the child's HIV positive status. Four participants who had never attempted to disclose, did not have any specific reason for their non-disclosure. Among the rest of those who had never attempted disclosure, five indicated that disclosure was not part of their job description, while four of them highlighted that they required more advanced training, experience and expertise for them to carry out such a sensitive task: *"I perform a lot of different tasks, but disclosure of children's HIV status is not part of my job description in this organisation"* and *"To me disclosure is not a process that any person can perform, I think it requires advanced education and training so that all emotional issues that might come up during the process might be dealt with without causing damage to the infected children"*. These findings indicate the need for policies and guidelines concerning disclosure so as to equip social service workers with necessary skills and expertise that they might need when carrying out such tasks. This is in line with the guidelines set by the South African Council for Social Service Professions (SACSSP) (2007), where it is highlighted that social service professions, especially social workers need to practice and perform duties that are within their area of expertise and competence. However, even though this could be a reflection of the need for policies and guidelines, it can also seem to be an indication of discomfort among social service workers in tackling disclosure.

### Attempts made to disclose status

Two participants who indicated that they had disclosed children's HIV status to them, expressed concern that the children, when told about their positive HIV status, were unable to keep it as private and confidential information but that they spread the news all over the centre. This makes it difficult to protect children from stigma and discrimination: *"When I disclosed to a child, the child decided to let the whole village to know that he or she is HIV positive and after that I observed that the child became embarrassed and humiliated...and peer association changed"*. The other participant emphasised that when disclosure is to be made, it should be partnered with counselling and proper education and support to the child. The participant commented: *"I think it is very important that before disclosure is attempted, the child should be prepared, properly counselled, educated and to make it a point that all the questions that he or she will be having, get answered so as to avoid putting the child at risk of being stigmatised or discriminated against, by his or her failure to keep his or her status confidential"*. This finding concurs with literature where Pantell (2006) stated that parents and guardians may have reservations because of concern over the child's reaction and fear that the child may tell others leading to child together with the whole family being exposed to stigma and rejection.

### CONCLUSIONS

It is clear that the disclosure to children of their HIV positive status, is a complex issue that requires careful thought and planning. Both negative and positive consequences may follow the disclosure and non-disclosure. The arguments for disclosing children's HIV status to them expressed by participants were that HIV status disclosure can enhance responsibility and adherence to medication; minimise suspicions and confusion that the children concerned may have relating to their HIV status; children's grieving processes could be facilitated and they could be helped to understand and come to terms with the reasons for their parent/s' death.

Although social service workers generally believed strongly that HIV status disclosure was important and necessary, there were some concerns around the consequences of such disclosure. Perceptions in this regard included that children may find it difficult to cope with the knowledge; that the knowledge would impose a heavy burden on the children concerned affecting the 'carefree nature of childhood', and that there would be an increased risk of stigma in a community such as a children's home or child and youth care centre setting. Of critical importance were the procedures and processes involved in managing disclosure of HIV in the setting. There was a need for a policy as well as thorough training to manage the complex dynamics involved. Furthermore, it was recommended that although the responsibility for such disclosure should rest with therapists, it should also occur within a multidisciplinary team approach with clear planning and collaboration between the various team members.

In conclusion, as much as it would seem that HIV and AIDS is regarded as being like any other chronic diseases, it does carry complexities when it came to disclosure and non-disclosure of the HIV positive status, especially to children born HIV positive. Organisations such as Child and Youth Care Centres offer excellent services to children in the area of alternative care and family reunification. It is important however that the difficult issue of HIV status disclosure be managed through the development of policy

guidelines that encourage disclosure without creating the possibility of increased stigmatisation and discrimination for these children.

### **Recommendations for community educative and awareness programmes**

- Although there have been extensive awareness campaigns regarding HIV and AIDS, there is a need for innovative, culturally appropriate programmes that target the specific needs of children born HIV positive particularly those residing in child and youth care centres.
- Community programmes should be introduced that will involve both HIV positive and negative children in residential care centres so as to encourage integration and reduce the effects of stigma associated with being born HIV positive and living in a child and youth care centre.

### **Recommendations for policy and practice changes regarding disclosure and non-disclosure of HIV status to children born HIV positive, living in child and youth care centres**

- It is recommended that policy guidelines concerning HIV status disclosure to children born HIV positive living at Child and Youth Care Centres be reviewed and developed, to allow a more flexible and open communication with regards to the issue. For example, there is a need to incorporate all categories of employees in the planning and management of the disclosure process so that children may be supported by all the various social service workers that they encounter.
- The developmental stage and age of the child concerned should be taken into account and so an individual assessment of a child's readiness to deal with the disclosure would need to occur. However, there should be a general policy that children should have their HIV status disclosed to them within the context of a supportive, therapeutic environment.
- Policies and processes around disclosure will need adequate thought, consideration and training of all staff to be clear about the various roles played in this regard.
- Children should be allowed the freedom to exercise their rights regarding access to information about their health status so they can, together with the childcare centre, also have control and agency over the management of possible peer and other forms of stigmatisation.

### **Recommendations for future research**

- As the research was conducted at a particular Child and Youth Care Centre only, it is proposed that similar studies be carried out in other child and youth care centres in different parts of the country in order to explore the issues further and incorporate the views and practices from other contexts.
- The present study was based on a small, stratified, purposive sample which precluded generalisation of the findings to the broader population of social service workers working in institutions that also cater for children born HIV positive. The study would be able to make more generalised findings if it were replicated using larger, more representative samples. It would also enable the exploration of more specific views and roles of the various occupational categories of social service workers without concerns about confidentiality and identification of specific participants.

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