

PSYCHO-SOCIAL EXPERIENCES OF PERINATALLY HIV-INFECTED ADOLESCENTS RESIDING IN CHILD AND YOUTH CARE CENTRES IN SOUTH AFRICA

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The psycho-social impact of HIV on perinatally infected children has been overlooked by policy makers internationally and nationally. This study explored the psycho-social experiences of perinatally HIV-infected adolescents who were residing in child and youth care centres in Gauteng in South Africa. The article adopts a social constructionist lens to discuss their biographical profile as well as four themes: knowledge and feelings towards mother; dealing with secrecy and disclosure; the way social networks affect treatment adherence; and interactions with health and social services. The paper concludes with some suggestions for health and social service professionals to help these adolescents navigate through this phase of their lives.

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INTRODUCTION

The dynamics regarding the survival of children with perinatally acquired HIV has changed with the increased availability of antiretroviral treatment in South Africa. The World Health Organisation (2011) reveals that the roll-out of antiretroviral treatment (ART) has transformed the nature and perception of HIV from being a deadly illness into a chronic illness. In fact the global roll-out of HIV treatment has resulted in increased survival rates of HIV-infected adults and children (Domek, 2012; Kumar, Mmari & Barnes, 2009). In countries such as Brazil and the United States children who were perinatally diagnosed with HIV are surviving through childhood to adolescence, with increasing numbers transitioning into adulthood (Foster & Fidler, 2011; Matida, Marcopito, Menezes Succi, Souza Marques, Negra, Grangeiro & Hearst, 2005). In South Africa adolescents living with HIV are already a sizeable and prominent sub-group, with an estimated 280 000 under the age of 15 having acquired the virus perinatally (Vujovic, Meyersfeld & Struthers, 2011). The complex scenario in South Africa, however, is that these increased survival rates of children with perinatal HIV diagnosis occurred simultaneously with developmental challenges such as high levels of poverty and poor service delivery in communities. Consequently, the capacity for extended families to provide safety, security and shelter for children, especially with a perinatal HIV diagnosis, remains a challenge in low-income communities (UNAIDS, 2011). In fact empirical data indicate that children perinatally infected with HIV experience abandonment, abuse and gross neglect as a result of their status, thus steering an increased number of admissions into child and youth care facilities (Mellins, 2011; Mohangi 2009; Moses & Meintjes, 2010).

In South Africa most HIV-infected children were institutionalised as a result of an increased need for medical attention and dealing with HIV-related stigma (Moses & Meintjes, 2010). Williamson and Greenberg (2010), Browne (2009) as well as Perumal and Kasiram (2008) provided qualitative evidence that institutional care impacts negatively on the child's psychological and social wellbeing irrespective of their status.

It is thus imperative to take cognisance of Close's (2006) assertion that managing a serious and life-threatening chronic illness within the context of an already demanding developmental life phase is an intricate process for both perinatally HIV-infected adolescents, for social workers, and for child and youth care workers who have to ensure that these individuals become psychologically healthy adults. An additional complexity to note is that the double jeopardy experienced by perinatally infected children is both the stigma of growing up in an institution and coming to terms with their perinatal HIV diagnosis. Social workers, child and youth care workers, and health professionals are often ill-equipped to deal with the psychosocial needs of adolescents perinatally infected

with HIV as well as with the complex issues of disclosure and adherence to treatment. Close (2006) suggests that it is essential to explore how these individuals construct their experiences and that psychosocial support will help these adolescents to navigate their way safely through this complex developmental stage and grow alongside their peers.

Bearing the above deliberations in mind, this paper presents empirical evidence from a qualitative study undertaken to understand the psychosocial experiences and coping strategies of perinatally HIV-infected adolescents residing in two child and youth care centres in Gauteng in South Africa. A child and youth care centre is a facility for the provision of residential care to more than six children outside the family environment in accordance with Section 191 (1) the Children's Act No. 38 of 2005. For the purposes of this study, perinatal infections refers to children who acquired HIV from the biological mother either while the baby was in the uterus or during the delivery process, or shortly after birth (Edgren, 2006). Using social constructionist theory, this paper presents a biographical profile of the participants and reflects on four important themes that are closely interconnected: knowledge and feelings towards mother; dealing with secrecy and disclosure; the way social networks affect treatment adherence; and interactions with health and social services.

The paper concludes that adolescents perinatally infected with HIV require effective, empowering and sustainable interventions from a multidisciplinary team of health and social service professionals to ensure that this sub-group is able to make safe and informed decisions as they navigate their way through the adolescent phase of life.

SOCIAL CONSTRUCTIONISM AND HIV AND AIDS

For the purposes of this study social constructionism, which focuses on the belief that there is neither objective reality nor objective truth and that reality emerges out of people's interaction with the world, was deemed to be appropriate theoretical framework (Sarantakos, 2005). Sarantakos (2005) adds that apart from the inherited and developmental aspects of humanity, social constructionism hypothesises that all other aspects of humanity are created, maintained and destroyed in our life-cycle interactions with others through time and various contexts. It is important to note that perinatally HIV-infected adolescents living in child and youth care centres face the double jeopardy of residing in an institution and having their understanding of the world greatly influenced by the perceptions that their peers and social service professionals hold about persons living with HIV. Furthermore, coming to terms with their past experiences and acknowledging their family backgrounds (which can be blurred) as well as the socio-cultural constructions of HIV are further important constructs to consider in understanding their psycho-social health and reproductive needs.

Howe (2002) aptly encourages constructionist social workers to focus during interviews on the constructs of knowledge and reflexive dialogue, which will help them understand how service users have constructed their reality. Howe (2002) adds that language is also an important factor to consider as it influences the identity of both the self and the context of the interaction, and takes the diverse elements of power involved in the context seriously (Howe, 2002). Therefore, when conducting interviews with perinatally

HIV-infected adolescents it is important for social workers and health professionals to be conscious of how their own narratives and behaviour can greatly influence their relationship with the service user. Howe (2002) indicates that constructive social workers attempt to provide questions which elicit clear goals about what the service user wants and which entail the service user taking active responsibility for change which can launch a new beginning in their lives. This study addressed an empirical gap in the literature by providing perinatally HIV-infected adolescents who were residing in child and youth care centres in Gauteng, South Africa with the opportunity to dialogue, interrogate and deconstruct their psycho-social experiences.

RESEARCH METHODOLOGY

Design

A qualitative methodology underpins this study, which utilised an interpretive descriptive design to guide the research process. This design enabled the researchers to provide rich descriptions of the narratives of the adolescents by interpreting and observing patterns that existed as well as carefully selecting the participants to participate in the study (Babbie & Mouton, 2001).

Setting

The researchers utilised non-probability, availability sampling to select two child and youth care centres that provided supportive services to children living with a perinatal HIV diagnosis in the Gauteng province, South Africa. We acknowledge that non-probability sampling does not ensure representivity and that the findings cannot be generalised. However, we believe that the rich narratives shared by the participants in this study will provide valuable insights for policy makers and health and social service professionals to consider establishing transformative interventions and to ensure that this sub-group of adolescents living with HIV receives optimal treatment, information, support and counselling to assist them to navigate their way confidently through the adolescent phase of life.

Participant selection

Adolescent participants (n=8) were recruited from two selected residential facilities in the Gauteng province, South Africa through purposive sampling. The criteria for selection were as follows:

- Adolescents who had been in the child and youth care centre for more than two years;
- Adolescents who were attending secondary school;
- Adolescents who were between 14 to 17 years old;
- Adolescents who were receiving antiretroviral treatment.

Key informants who participated in this study included social workers (n=2) and child and youth care workers (n=10), who had been employed for at least two years at the two selected child and youth care centres and had been directly involved in providing support and counselling services to adolescents living with a perinatal HIV diagnosis.

Data were gathered from semi-structured interviews and a focus group session held with child and youth care workers and social workers from each of the child and youth care centres. The use of these two data-collection methods enhanced the reliability and trustworthiness of the data. Data were collected between April and September 2011. Discussions were digitally recorded and transcribed. Additionally, the researchers had numerous meetings to discuss divergent interpretations of the data. Using Marlow's (2012) framework for thematic analysis, codes were assigned to each emerging pattern of experience and then narrative thematic analysis was used to describe the findings.

Ethical considerations

This study was conducted with due consideration of privacy and confidentiality as consistent with guidelines for research involving young people. The researchers wrote to the Boards of Management of the two selected child and youth care centres. Comprehensive information about the purpose and objectives of the study was provided to adolescents and staff who participated in the study. Written informed consent letters were signed by the eight adolescents, ten child and youth care workers, and two social workers. The University of KwaZulu-Natal's Ethics Committee provided ethical approval to conduct the study. It was an advantage that one of the researchers was also the social worker at one of the child and youth care centres, as this prolonged engagement with the participants and ensured that they were accepting and trusting of her role, which enhanced the trustworthiness of the data. Additionally the researcher was empathetic throughout the data-collection process and provided debriefing during and after the interviews to prevent becoming emotionally over-involved (Marlow, 2012).

RESULTS OF THE STUDY

The empirical findings presented emerged from eight individual interviews conducted with adolescents, the focus group sessions conducted with five child and youth care workers and one social worker at each of the selected child and youth care centre.

The discussion of the results will be presented in two sections:

- A biographical profile of the adolescents; and
- A discussion of four interconnected themes namely; knowledge and feelings towards mother; dealing with secrecy and disclosure; the way social networks affect treatment adherence; and interactions with health and social services.

TABLE 1
BIOGRAPHICAL PROFILE OF THE SAMPLE GROUP OF
PERINATALLY HIV-INFECTED ADOLESCENTS

Participant number	Age	Gender	Number of Years residing in the CYCC	Reason for admission to CYCC
1	14	Female	7	She was from a child-headed family. Mother died in her presence in the hands of an elder sister.
2	16	Female	12	Placed at M due to neglect and unstable health conditions. Had a relationship with her mother before she died.
3	15	Male	12	Both parents passed on and were left in the care his of grandmother. Placed due to neglect and ill health.
4	15	Female	12	Her mother passed on and her family resented her. She was admitted due to neglect.
5	15	Female	7	The mother passed away and she was left in the care of maternal grandparents. However, she was admitted due to neglect and need for medical attention.
6	15	Male	12	Placed at CYCC due to ill health after death of his mother. His brothers had not visited him since admission.
7	14	Female	7	Mother passed away and she was left with her sister but admitted due to unstable health.
8	16	Male	5	Mother passed on and was left in the care of his sister. Placed due to neglect by the sister.

Two of the participants were aged 14, four were 15 years and two were aged 16 (n=8). There were three male and five female adolescents. It was not surprising to note that all the participants had lost their biological mother and were left in the care of either an older sibling or grandmother prior to their admission to the institution. The core reason for many of the participants' admission to the institution was ill health and neglect by family members. It is widely acknowledged that the high rate of AIDS mortality amongst the middle generation has deprived adolescents perinatally infected with HIV of the opportunity of growing up with their biological parents (UNAIDS, 2011). Table 1 illustrates that the average number of years that the adolescents had resided in the

residential facility was 9. This implies that the mean age of the participants when admitted at the residential facility was 5.75.

Knowledge and feelings towards mother

Berk (2000) cites Erikson, who stated that birth to 8 years are the foundational phase of a child's life when safety, love and security are vital for successful psycho-social outcomes in childhood and for the formation of a coherent identity. In fact, social constructionists maintain that a child learns the basics of what is important in society from their immediate family as constructed in that particular family and this contributes to their own identity (Alvesson & Sköldberg, 2009). The adolescents in this study spoke of unresolved grief and trauma as a result of losing their biological mother at a young age. One adolescent commented: *"I have never experienced a normal childhood due to neglect, abuse and abandonment from my siblings. To date my brothers have not visited me."* Many of the participants revealed that they had not gained closure after the death of their biological mother and they had unanswered questions pertaining to their HIV status. When asked about their mother, most of the adolescents had no vivid memories and expressed ambivalent feelings towards her. Some of the sentiments shared were:

Participant 1: *"I only know my mother, I know her face."*

Participant 5: *"I have never asked about my parents but I would want to know."*

Participant 3: *"She was sick and I was with her and I was hurt and it still hurt me now ... sometimes I cry and I don't wanna talk about it."*

Participant 7: *"I only know when my mother passed away it makes me feel sad, I was even there."*

Participant 8: *"I would like to know why mother got infected because she was fine."*

These unresolved and deep-seated emotions expressed by the adolescents revealed that many of them experienced difficulty forming safe and secure relationships. As indicated in Table 1, all the participants were detached from their families at an average age of 5 and they had never experienced attention from a significant primary caregiver. This has impacted on their ability to form secure attachments with the other children and staff, even though many had lived in the residential facility for most of their lives. One participant commented: *"Sometimes I get along with the child and youth care workers, sometimes I don't, I feel like I'm not the loved one because I'm rude. I'm rude because I miss my parents and I don't want to call them mother because they are not my real parents. I want to call them aunt."*

Many of the adolescents stated that coming to terms with their perinatal HIV status as well as growing up in an institution deprived them of the opportunity to have normal psycho-social infant outcomes (Berk, 2000). They spoke about exhibiting disorganised attachments in the adolescent phase of life as a result of this double jeopardy. Attachment theory explores how the quality of a child's relationship with their carer affects their socio-emotional development, which then influences how they relate to and deal with people (Howe, 2002). Researchers such as Howe (2002), Mohangi (2009) and

Perumal and Kasiram (2008) concluded from their qualitative study of children who grow up in residential facilities that children tend not to know how to respond to other people's warmth and concern, and these children are less conducive to forming secure and confident relationships in their lives. This theme is explored further in the discussion below.

Dealing with secrecy and disclosure

With increased survival rates, one of the greatest psycho-social challenges that parents and/or caregivers of perinatally HIV-infected children face is disclosure of that status to their infected child (Wiener, Mellins, Marhefka & Battles, 2007). Wiener *et al.* (2007:155) aptly state that "HIV diagnosis disclosure entails communication about a potentially life-threatening, stigmatised and transmissible illness and many caregivers fear that such communication may create distress for the child." All the adolescents stated in the interviews that they were aware of their HIV status at the time of this study and had been informed about their status after the age of 10 years. Many of the participants expressed dissatisfaction with regards to how the disclosure occurred. Participant 6 commented: *"I am aware of my status, the doctor told me about it, I was 13 years old."* Participant 7: *"Yes I know my status, my older sister told me when I turned 14 that is why I drink this medicine. My aunt didn't want to tell me because she said I am too young."* Participant 2: *"the social worker told me my status."*

These comments were also triangulated with the perspectives shared by child and youth care workers and the social worker in the focus group discussions; as one professional commented: *"It is hard to talk about the child's status to them as we don't want them to feel discriminated."* Clearly one of the primary roles of the social workers and/or the child and youth care worker at the residential facility was to inform the child of their HIV status. This finding corroborates empirical reports from USA which suggest that many HIV-infected children, particularly those younger than 13 years, do not know their status (Mellins, Bracks-Cott, Dolezal & Abrams, 2004). In most South African hospitals paediatric immunology doctors are encouraging all care givers to disclose the HIV status to the child, especially those children who are 12 years and older.

When asked about sharing their secret with family or friends, the adolescents displayed feelings of anger, uncertainty and anxiety during the interviews. In fact six of the adolescents used blocking as a defence mechanism and coping strategy to express their emotions and they avoided talking about the subject. Two of the adolescents' however were open to share their comments:

Participant 6 said: *"I have not disclosed to anyone and I will never, I don't feel comfortable, I understand people are scared of HIV."*

Participant 1: *"No I will never tell anyone about my medication. I don't want them to know because they will start teasing."*

These sentiments were also shared by the social worker and child and youth care workers, who commented in the focus groups:

Social worker: *"We do not talk about the children's status or HIV, it's an untouchable subject."*

Child and youth care worker: *"It is hard, as they are few children who are positive whilst the rest are negative."*

These findings corroborate the assertion by Wiener *et al.* (2007) that discussing a potentially life-threatening, stigmatised and transmissible illness is one of the greatest psycho-social challenges faced by caregivers, parents, health and social service professionals with perinatally HIV-infected children. Hodgson, Ross and Haamujompa (2012) concluded from their qualitative study with 111 adolescents living with HIV in Zambia that psycho-social support includes ensuring the meaningful participation of children in issues affecting them, listening and responding to children's problems, and allowing children to express their feelings and needs. It is important for health and social service professionals at child and youth care centres to shift their mindset and consider that ongoing disclosure promotes trust and improves adherence to antiretroviral treatment (Wiener *et al.*, 2007). This theme is elaborated on further below.

Social networks significantly affect treatment adherence

The fact that adolescence is characterised by rapid changes in physical maturation, cognitive processes and life style, predicting long-term treatment adherence by the perinatally HIV-infected adolescent can be very challenging. The adolescent phase is described by Berk (2000) and Raniga (2007) as a time for growth and experimentation marked by establishing autonomy and confronting new challenges. Adolescents living with a perinatal diagnosis of HIV encounter additional challenges while passing through this phase of life, as they may appear younger and smaller in build than other adolescents. They may also experience physical changes as a result of their illness, including opportunistic infections that may cause noticeable physical symptoms which may adversely affect peer attachments (Hodgson *et al.*, 2012). In this study, when asked about ARV treatment management; participants 1, 2, 3, 5 and 7 revealed that the *"child and youth care worker manages my medication but I would like to take full responsibility when I turn 16"*; *"I will start taking care of my medicine when I'm 16 years"*; *"The house mother manages my medicine, but I take watch and set time."*

From the above responses it is clear that self-efficacy was lacking in the adolescents' lives, as there was an over-reliance on the child and youth care workers to administer their medication and appointments at the health clinic. One of the social workers at one of the residential facilities commented: *"It is hard to administer medication, they pretend to be drinking medication and they throw it away."*

What was positive to note at one of the residential facilities was that supportive social relationships amongst the staff and children facilitated adherence to medication. As one participant commented: *"Children at the house are aware of my status, hence they constantly remind them if it time for medication which is embarrassing for them."*

When questioned about their support systems, many of the adolescents stated that they had relationships within and outside the residential facility. They all admitted that they

had friends, but they stated that these were not secure relationships as they did not want to discuss their status and other personal problems with them. Two of the eight participants revealed that they were involved in sexual relationships.

One of them commented: *“I have had sex but used protection. I had sex with the girl from the village and we see each other often, maybe have sex once or twice.”*

The other mentioned: *“I had sex in Grade 7 with one of the kids, didn’t used protection.”*

Other views shared by the majority of the adolescents were:

Participant 1: *“No I will never tell anyone about my medication. I don’t want them to know because they will start teasing.”*

Participant 8: *“I used to have a boyfriend, I never told him about my status and my medication because he was not my type, if I meet my type I will tell them, that is, if I trust him enough. Trust is important for me to disclose.”*

Evidently trust and disclosure of their status to peers were determining factors in adherence to treatment. The comments made by many of the adolescents indicated that the secrecy and lack of information regarding their status impacted on their treatment adherence, as they did not understand the importance of taking medication. The child and youth care workers also shared this sentiment in the focus groups: *“They feel they are going to die soon, hence they are not concerned about taking medication.”*

The comments shared by the adolescents in this study corroborate the important finding by Mellins *et al.* (2004:1036) that once a child who is living with HIV knows his or her status, they will be able to make informed decisions about treatment adherence and disclosure to sexual partners. In this study it was evident that this is dependent on the perceptions of other children, and the quality of care and interactions with health and social service personnel in the residential facility as well as with peers and family relationships within the wider community. This theme is explored further below.

Interactions with health and social services

Adolescents who attended their immunology appointments at local clinics found it difficult to speak with medical and health practitioners and did not look forward to their monthly clinic appointments. The major concern raised by the adolescents was the lack of confidentiality at the local clinic as the consulting rooms were labelled “HIV services”, which subjected them further to the stigma that they already felt. One of the child and youth care workers commented: *“Clinic nurses do not make it easier for them as they discriminate because every room marked HIV; hence children find it difficult to go to see the doctors in these marked rooms.”* She added that this had a major psychological impact on the adolescents as some refused to take their ART and they were pessimistic about their future. At both child and youth care centres the adolescents shared a positive relationship with staff such as the social workers, child care workers and healthcare providers. Many of them acknowledged the benefits of taking the

antiretroviral treatment and that they were grateful that the child and youth care workers and nurses took primary responsibility to monitor and administer their medication.

In the focus group discussions the social workers and child and youth care workers commented with disappointment that there was a lack of available training and specialised counselling programmes to deal with the complex psycho-social challenges faced by the adolescents with a perinatal HIV diagnosis. As one social worker mentioned:

“There are no programs at this facility, we only get them when we go out and there are no workshops for child and youth care workers.”

She added that this made it difficult to respond appropriately to meet the unique psycho-social, health and reproductive needs of perinatally HIV-infected adolescents. It was suggested by the participants in the focus groups that workshops and seminars addressing the needs of perinatal HIV-infected children should be initiated by the Provincial Departments of Health and Social Development. They also suggested that there is need to liaise with other child and youth care centres providing supportive services to children living with HIV, so that this sub-group can form support networks and hopefully this support mechanism will create a sense of solidarity with other children in similar circumstances.

SUMMARY AND CONCLUSION

This paper documented the psycho-social experiences of perinatally HIV-infected adolescents who resided in child and youth care centres in South Africa. Consistent with other empirical evidence, it confirms gaps in psycho-social services at residential facilities caring for children living with HIV (Hodgson *et al.*, 2012; Pillay, 2009). These findings are corroborated in other studies (Domek, 2012; Hodgson *et al.*, 2012; Kumar *et al.*, 2009; Moses & Meintjies, 2010), highlighting the importance of the health and social service interventions that are required to manage disclosure, to deal with emotional isolation and the disorganised attachments experienced by these children residing in child and youth care centres.

In particular, this study suggests that user-friendly health services will enhance adherence to ARV treatment and promote ongoing disclosure and the emotional wellbeing of adolescents.

It is imperative to deconstruct pity amongst social workers, child and youth care workers and health care professionals who provide valuable supportive services to perinatally infected HIV-positive children. The following recommendations should be considered for implementation:

- Strengthening partnerships between National and Provincial Departments of Health, Education and Social Development to provide age-appropriate support and information to support disclosure, the sexuality needs of perinatally HIV-infected children to tackle stigma and discrimination in communities;

- It is imperative that child and youth care workers and social workers receive ongoing training to provide optimal psycho-social support to this sub-group of children who reside in child and youth care centres;
- Media campaigns to educate the public that living with HIV no longer spells a death sentence, but that it is a chronic illness which may be adequately managed because of the availability of ART.

This study represented a limited sample of 8 perinatally HIV-infected adolescents residing in child and youth care centres and does not represent children in foster families. This also warrants further qualitative research conducted with a mixed-race profile of perinatally infected children placed in foster care across different provinces in South Africa.

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