FINDING THE POSITIVES

THE REALITIES OF PERINATALLY HIV and AIDS INFECTED SOUTH AFRICAN ADOLESCENTS IN A RESIDENTIAL SETTING

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LAMBANO
RECEIVING CHILDREN & GIVING HOPE

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CENTRE FOR SOCIAL DEVELOPMENT IN AFRICA

UNIVERSITY OF JOHANNESBURG

Contents

Citation

Please cite as: Schmid, J., & Chiba, J. (2016). *Finding the positives.* Research report. Centre for Social Development in Africa, University of Johannesburg, South Africa.

Acronyms

AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral Therapy
ARV:	Antiretroviral
HIV:	Human Immunodeficiency Virus
CMR:	Christelike Maatskaplike Raad
OVC:	Orphaned and Vulnerable Children
UNICEF:	United Nations Children's Education Fund
WHO:	World Health Organisation

Please note that in this study racial signifiers are used, because these are relevant to the South African context. It is recognize d that race is a construction and that such ascriptions potentially essentialise individuals.

Acknowledgements

We wish to thank the residents and staff at Lambano Sanctuary for sharing their experiences-without their input this report would not have been possible.

We extend our appreciation also to the staff at the Centre for Social Development, in particular, Prof. Leila Patel, Prof. Eleanor Ross and Dr. Tessa Hochfeld for their valuable insights and ensuring that this report appropriately addresses the central issues emerging from the data.

Executive Summary

This study examined the lived realities of HIV positive adolescents who were perinatally infected and are living in care at Lambano Sanctuary, Johannesburg. While the academic literature examines the needs of youth affected by HIV and AIDS, there is scant investigation of the experiences of particularly perinatally infected teenagers, and of those in residential care.

Two focus groups were conducted with 20 adolescents and three focus groups with 12 staff members. One individual interview was held with an adolescent. A qualitative approach was adopted to ensure that a complex and rich text could be developed reflecting the experiences of these youth.

The research highlighted that these teens are located in the nexus of adolescence, residential care and their HIV positive status, each facet intersecting with and compounding the others to shape their experiences. These adolescents acutely feel their abandonment, the stigma of being HIV positive, the strictures of living in a children's home, and the challenges of being teenagers. At the same time, the youth suggest that their 'lives have been saved' and that they value the ongoing support in the residential care setting.

The study further suggests that the residential care facility is confronted by a series of dilemmas. The facility was established with the intent of caring for seriously ill infants for whom life expectancy was short. Because of the successes of these efforts, these children are now adolescents who can envision adulthood along with employment and family life. Lambano as an agency needs to determine how to respond to this fundamentally altered scenario, especially as Lambano staff have identified themselves as substitute parents and kin to the youth in their care. They must clarify what the implications of such a position are for the long term. This dilemma has become complicated by the fact that the relatives of nine of the 28 children have over the years re-connected with children whom it was assumed were orphaned. Another challenge is that the facility tries to function as four independent foster homes at the same time as each home is closely managed by agency leadership. This complex organisational structure has led to mixed communication regarding child rearing styles, decision-making and discipline. Issues of race and class further impact relationships including those between management and housemothers, staff and adolescents, and staff, children and biological families. The interaction of race, class and care also raises particular tensions that merit reflexivity and examination.

Lambano aims to be a reflective organisation and has identified some of these difficulties. In order to effectively address the needs of the adolescents in their care, the confluence of factors impacting the lives of the teenagers needs to be better understood and acted upon. A number of recommendations emerge from the report:

1. Facilitating individualised interventions customized for each resident to weaken the impacts of institutionalisation and to facilitate autonomy
2. Enhancing family and community integration to connect residents into the broader community and to link them specifically to their communities of origin, and where relevant, biological families
3. Reviewing the organisational management of Lambano to facilitate greater clarity regarding roles
4. Facilitating the transition from Lambano to the outside world to ensure the youth have the skills and competencies to effectively and independently navigate the external environment
5. Addressing issues of race, class and caregiving to promote a unified and appropriate form of caregiving
6. To advocate for policies that will support the cognitive, educational and skills development of the residents
7. Directions for future research

The recommendations aim to support Lambano in their caregiving role of youth where there was vertical transmission of HIV and infant abandonment.

The conclusions emerging from this study are likely to have relevance for other residential care facilities in South Africa and in countries and regions touched by the AIDS epidemic.

INTRODUCTION TO LAMBANO SANCTUARY

Lambano Sanctuary is a residential facility and hospice for children living with HIV and AIDS, located in Johannesburg. Lambano was launched in 2001, when three women responded to a request from the Christelike Maatskaplike Raad [CMR] (a non-governmental social welfare agency) to provide services to HIV positive infants. Currently, twenty-eight black children between the ages of 9 and 19 years are cared for in Lambano's four houses.   They were all born HIV positive to an HIV positive mother, which is referred to as perinatal or vertical infection. This is distinct from horizontal infection where an HIV negative person contracts the virus later in life.

The homes are situated within close proximity of one another. The children were mostly admitted as infants. They had been abandoned and were believed to be orphans. Six personnel (including two managers and four house mothers) are formally registered as foster parents. All the children are in receipt of a foster care grant. The original intent to organize Lambano as a cluster foster care scheme was not approved by the Department of Social Development (it is not clear why). CMR supervises the foster child relationships, while the local magistrate personally monitors the facility.

There are seven to eight children in each house, staffed by housemothers. There are four housemothers, four deputy housemothers, and four nightshift staff. The housemothers can have their biological children living with them on site. All the children attend local schools, including a special needs school and two high schools.

A further 16 children, mainly from Gauteng, and suffering from a range of chronic, terminal illnesses can be cared for in the step-down hospice facility, located on the same premises. Because the death rate of HIV positive children originally was high, Lambano set up this hospice- initially with only two beds. It is the only provincial facility of its kind and is staffed by 22 personnel. Children in the step down spend an average of three months in the facility and may receive follow-up services from Lambano when discharged. Regarding additional staff, aside from three managers, there is an accountant, a fundraiser, a community nurse, a driver, a counsellor, a social worker and cleaning staff.

Statement of the Problem and Rationale for the Research

Lambano identified a need to better understand the lived realities of the adolescents who are perinatally infected and live in their home. The academic research into the needs of HIV and AIDS infected youth is relatively limited, especially noting the large numbers of HIV positive adolescents globally (Lowenthal et al., 2014). Medical concerns dominate, although socio-emotional issues have also been identified. Despite the expertise that Lambano has accumulated over the years, dealing with teenagers is a new challenge for this organisation. Lambano is seeking additional support strategies, including addressing the medical and psychological aspects of medical compliance. While the literature offers insights pertaining to adolescents living with HIV and AIDS, understanding the needs of teenagers in residential settings who are HIV positive requires further investigation. It was anticipated that a nuanced, multi-dimensional examination of the emotional, social, and physiological needs of this group, as seen from their standpoint, would enable caregivers to gain greater insight into the needs of these young people and potentially adapt current interventions to ensure effective and quality support. It was further envisaged that helping caregivers affirm the expertise they already have would allow them to build on existing foundations.

Purpose of the Research

The purpose was to explore the lived realities of a group of South African adolescents in residential care, abandoned as infants and living with HIV and AIDS (vertically transmitted).

To do this, the research intended to:

- Explore the everyday social, psychological and daily life experiences and needs of these teenagers.
- Highlight Lambano's expertise regarding the appropriate care and support of teenagers.
- Identify potential gaps and areas for intervention.

An estimated 2.5% of South African children are living with HIV

Conceptual Framework

Our discussion regarding youth living with HIV and AIDS is located within a socio-ecological framework. First, adolescence is a unique life stage that incorporates particular developmental milestones. Second, HIV and AIDS impacts individuals, families, groups and communities, and the analysis thus focuses on the interaction of micro, meso and macro levels. Third, the intervention - whether primary, secondary or tertiary- is interpreted through the prism of human rights.

Literature Review: HIV and AIDS and Adolescents in South Africa

The academic literature suggests particular gaps in understanding the needs of South African youth who have been vertically infected by HIV and AIDS. Internationally, the research has focussed on adults living with the illness rather than adolescents. Furthermore, presenting an accurate, current picture of HIV and AIDS and adolescence is challenging in a rapidly changing field.

In this literature review, we employ cascading and intersecting lenses, first discussing the nature of adolescence, then profiling teens internationally and locally. Thereafter we examine the needs of those adolescents who are HIV positive, specifically those perinatally (vertically) infected. And finally, we look at the needs of children in care.

WHAT IS ADOLESCENCE?

Adolescence, according to Western developmental psychology, is a turbulent transition when young people between the ages of 10 and 19 years are no longer children, but not yet adults (Devore & Schlesinger, 1999; Van Dyk, 2008; World Health Organisation, 2013). Developmental changes are physical, sexual, cognitive, moral, social and may include shifts in legal status.

However, caution must be exercised when assuming universal notions of adolescence. Indeed, the following areas must be considered: childbearing typically associated with young adulthood is in many contexts common for under 18s (Devore & Schlesinger, 1999); the idea of individuation has been challenged (Biddulph, 1997); social determinants may shape adolescence (Acharya & Dasgupta, 2005); and physiologically, the advent of puberty now often occurs earlier than previously identified (De Leonibus et al., 2014).

South African adolescents are generally considered to follow Western constructions of adolescence, though there are some particular issues to take into account. For example, South African teenagers typically have their first sexual experience around age 16, usually when they are still at school, with this experience being even earlier for those living in precarious conditions (Van Dyk, 2008). Girls may become mothers while they are still teenagers (Jordan, Patel & Hochfeld, 2014). Moreover, certain adolescents may find themselves caught between traditional and modern norms and expectations (Behrens, 2014).

THE PROFILE OF SOUTH AFRICAN ADOLESCENTS

In South Africa in 2012, adolescents made up around 18% of the total population (Matthews, Jamieson, Lake, & Smith, 2014; United Nations Children Fund [UNICEF] South Africa, 2013). The gender distribution amongst teenagers is relatively equal (Statistics South Africa, 2014; United Nations Population Fund [UNFPA], 2014). Racially, black African teenagers are in the clear majority (Statistics South Africa, 2014). Regional and provincial differences may be marked, noting that most white, coloured and indian children live in urban settings, with African children being disproportionately located in rural areas (Matthews et al., 2014). Nine percent of those over 10 years of age find themselves in shacks, compared to 42% of their younger counterparts, while overcrowding, and access to clean water and sanitation are further concerns (Matthews et al., 2014). While almost every child aged 15 and under attends school, attendance rates drop once schooling is no longer mandatory (Matthews et al., 2014). Unemployment rates amongst South African youth are extremely high (Centre for Social Development in Africa, 2016). Even so, close to 90% of 15-34 year olds have access to cellular phones, landlines or the internet (UNFPA, 2014). In summary, the vast majority of South African teens are black and poor and lack access to the basic necessities of life.

ADOLESCENTS AND HIV/AIDS

Of the estimated 78 million persons infected with HIV globally, around 36 million were living with HIV in 2015, the majority in sub-Saharan Africa and Asia (Idele et al., 2014; Naude & Pretorius, 2003; Tarantola & Gruskin, 1998). In South Africa, in 2015 around seven million people were living with HIV (Avert, 2016). Despite a 58% global decline in new infections amongst children from 2001 to 2013, in 2013 between 2.9 and 3.5 million children were living with HIV globally (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014; WHO, 2013). Of this group, just over 2 million were adolescents (one seventh of all infections globally); most lived in middle to low income countries, where probably only 24% had access to treatment; and 520 HIV and AIDS child deaths occurred daily. In South Africa, though, where overall child mortality decreased from 53 to 28 per 1000 by 2012, many children are still dying, mostly (69%) due to HIV infection (Matthews et al., 2014).

An estimated 2.5% of South African children are living with HIV (Demmer, 2011; Garrib, Jaffar, Knight, Bradshaw & Bennish, 2006). Due to physical and social characteristics, girls are four times more likely to become infected, and are likely to contract HIV and AIDS five years earlier than their male counterparts (Idele, et al., 2014; Marfatia & Smriti, 2010; Richter, Chikovera, & Makusha, 2010; Tarantola & Gruskin, 1998; UNFPA, 2014). South African girls are at greater risk than boys also because of high rates of abuse and a lack of autonomy (Naude & Pretorius, 2003). Amongst young pregnant mothers, HIV positivity was almost 14% (UNFPA, 2014).

Adolescents are likely to take risks and challenge authority and formal directives, and so are vulnerable to (horizontally) contracting HIV and AIDS. Younger adolescents are especially at risk as they may not be able to process the importance and technical aspects of protection (Marfatia & Smriti, 2010). South African teens continue to maintain misconceptions (Van Dyk, 2008), and thus there is a need for age-appropriate, culturally-relevant, peer-directed, participatory prevention interventions, typically directed at minimizing sexual risk amongst adolescents (Acharya & Dasgupta, 2005; Blumenreich & Siegel, 2006; Boyes & Cluver, 2015; Earls, Raviola, & Carlson, 2008; Ganga, Scoloveno, & Ayres, 2014; Khashman & Park, 2009; Kruger, 2006; Ngoshi & Pasi, 2007; Vujovic, Struthers, Meyersfeld, Dlamini, & Mabizela, 2014).

The greater proportion of adolescents living with HIV and AIDS have been infected via vertical transmission (WHO, 2013). As alluded to earlier, AIDS has been a major cause of infant mortality (Walker, Schwartlaender, & Bryce, 2002): perinatal transmission resulted in 600/1000 infant deaths in South Africa prior to the introduction of ART (antiretroviral treatment which can significantly reduce perinatal transmission) (Akukwe, 1999; UNAIDS, 2013). Approximately one-third of pregnant South African women with AIDS pass the illness on to their infant (Loening-Voysey, 2002). Adolescent mothers probably have less access to ART (WHO, 2013). Of those infants that survive, not all are immediately diagnosed as infected, which is problematic as initial intervention ideally occurs within the first two months of life (UNAIDS, 2013). Fortunately, the group of infants diagnosed soon after birth and receiving ART since infancy is growing (WHO, 2013). Around one third of those infected perinatally may survive into adolescence without the illness being evident (WHO, 2013).

ADOLESCENTS INFECTED AND AFFECTED BY HIV AND AIDS

In countries where HIV and AIDS are prevalent, including South Africa, teenagers, infected or not, have had their living conditions imprinted by the epidemic. They may be supporting family members who are diagnosed, ill, or dying. Almost a quarter of teenagers aged 15 to 18 years will have lost a caregiver (Van Dyk, 2008) and may lose another (Beegle, De Weerdt, & Dercom, 2009), funerals and inheritance issues having become part of their reality (Kruger, 2006). Three percent of teenagers are running households and caring for siblings (Van Dyk, 2008). Families experience heightened poverty because of HIV and AIDS (Beegle et al., 2009).

The psycho-social fallout impacting young people living in a context of HIV and AIDS is significant, and includes prejudice, social hostility, rejection and exclusion, isolation and economic hardships. Emotionally, youth are dealing with shock, confusion, stress, sadness, grief, loss, and humiliation (Kruger, 2006). Anxiety and depression are often found amongst youth affected by familial HIV and AIDS (Boyes & Cluver, 2015; Zhao, Li, Zhao, Zhao, & Stanton, 2014). HIV positive persons are also vulnerable to mental health challenges due to the stresses of the illness (Betancourt, Meyers-Okhi, Charrow, & Hansen, 2013). Young people infected and affected by HIV and AIDS, particularly in sub-Saharan Africa, show poorer educational outcomes than their peers, such performance seemingly linked to poverty, the internalization of problems and cognitive deficits (Orkin, Boyes, Cluver, & Zhang, 2014). Communities, often already fragile, may become further strained through the losses incurred due to HIV and AIDS (Loening-Voysey, 2002). At the same time, individuals and communities can show incredible resilience in dealing with the epidemic and often demonstrate support towards those affected by the virus (Betancourt et al, 2013; Kruger, 2006). In South Africa, the health, education and social welfare response to orphaned and vulnerable children (OVC) has been inadequate (Kvalsig, Taylor, Jinabhai, & Coovadia, 2004; Loening-Voysey, 2002) and significant improvements in each area are required (Cluver et al., 2013; Orkin et al., 2014; Tarantola & Gruskin, 1998; WHO, 2013).

South African adolescents may thus be simultaneously confronted with the intersections of HIV and AIDS, illness, poverty, violence, poor health and educational services. Some may also have exceptional circumstances as migrant, refugee or trafficked children, or as sex workers. Internationally, a rights-based approach is promoted to ensure that the needs of OVC are being addressed (Earls et al., 2008; Tarantola & Gruskin, 1998; Van Rensburg & Human, 2005; WHO, 2013).

THE SPECIFIC NEEDS OF YOUTH WHO HAVE ACQUIRED HIV THROUGH PERINATAL INFECTION

While commonalities exist, the needs of horizontally versus vertically infected youth need to be distinguished. Because HIV and AIDS have been a threat for about 30 years, the concerns of young people infected perinatally are shifting into the foreground (Lowenthal et al., 2014). This group is particularly vulnerable. The appearance of symptoms may be confusing as many may not have been told of or understand their diagnosis and prognosis, and only a small group will have had access to or received treatment (Marfatia & Smriti, 2010; The Lancet, 2006). The illness may, in adolescence, be at an advanced stage, although for many, the introduction of antiretrovirals (ARVs) has rendered AIDs a chronic rather than acute illness (Cambridge, 2001; Coleman & Toledo, 2002; Earls et al., 2008; Merchant & Lala, 2012; Zhao et al., 2014). The fear of immediate death or serious illness is thus no longer dominant (Abadia-Barrero & Castro, 2006), although the long-term impact of ARVs requires further research (Souza, Rondo, & Reis, 2011). Opportunistic infections are a constant threat for teens with immature immune systems (Merchant & Lala, 2012). This group of adolescents tends to have stunted growth as well as delayed puberty and andrenarche, though poor nutrition may be a contributory factor (Isaranurug & Chompikal, 2009). Furthermore, young people are reminded daily and frequently of their illness as they take their medication and as their health is monitored. Teens sometimes become inconsistent in complying with their medical regimes due to issues such as poverty, stigma, and peer pressure, often resulting in “clinical progression of the disease, emergence of drug resistance and the risk of spreading such drug resistant HIV strains” (Lowenthal et al., 2014, p. 632). Around 18% of teens develop physical resistance to their ARVs and need to be shifted to new medication, which may cause new side effects (Lowenthal et al., 2014).

The physical sequelae of HIV and AIDS tend to spill over into the emotional arena. Overall, youth who acquired HIV perinatally experience significant psychological and psychiatric challenges (Lowenthal et al., 2014). Moreover, these teens are usually aware that they are a risk to sexual partners, though they are likely to become sexually active later than their peers. Young people infected through perinatal transmission are likely to blame their parents for their situation. Such youth also have a poor sense of agency and hence self-efficacy is adversely affected (Earls et al., 2008). Often the emotional stresses translate into mental health and substance abuse issues. There may additionally be cognitive impairments. These educational and health challenges tend to create poorer economic prospects (Earls et al., 2008; Naude & Pretorius, 2003). All these challenges are likely to occur at the same time that adolescents start to become responsible for their own care (WHO, 2013). Finally, stigma may be reinforced by inequities relating to class, race and gender (Abadia-Barrero & Castro, 2006).

Thus, children who are dealing with the impacts of vertically transmitted HIV and AIDS tend to do worse physically, psychologically, educationally and economically than their peers.

NEEDS OF ORPHANED AND ABANDONED ADOLESCENTS, AND YOUTH IN CARE

Beyond considering HIV positive teenagers, the specific needs of orphans must be examined. In South Africa, over 3 million children were identified as single or double orphans in 2012, with most located in the poorest communities (Loening-Voysey, 2002; Matthews et al., 2014; Streak, 2002). Globally, not even 10% of this group receives support and services (The Lancet, 2006). This situation combined with economic hardship exacerbates the poor living conditions of OVC and increases their vulnerability to abuse (Loening-Voysey, 2002). OVC, who also may have lost siblings, may be cared for by relatives (usually female) or may themselves be caregivers of adults or children (Loening-Voysey, 2002; National Association of Child Care Workers [NACCW], 2014). OVC tend to have lower self-esteem and self-control than their non-orphaned peers (Isaramurug & Chompikul, 2009). There is thus, once again, a constellation of practical and psychological sequelae to being orphaned.

Youth in care face yet another set of challenges. While there are positives (such as the consistent provision of food, shelter and education), there are many unwanted outcomes to long-term care (Morantz & Heymann, 2010; Roy, Rutter, & Pickles,

2000). Children in care typically display poorer self-esteem, less self-confidence, poorer scholastic achievement, and more behavioural difficulties than their community counterparts. Issues of belonging and rootedness, and disconnection from the community and peers are often concerns (Morantz & Heymann, 2010), particularly for those truly orphaned. Where mothers are HIV positive, outcomes for children are mediated by the strength of the parental relationship (Jones, Foster, Zalot, Chester, & King, 2007; Kruger, 2006), but abandoned children do not have the possibility of working through the issue with their parent/s. Additionally, young people in care may be stigmatised for not coming from or living in a 'normal' family. The residential routines do not mimic family life and may create an institutionalised mindset that emphasises external controls. Community-based options in smaller units and with foster care families are thus recommended, though these settings that simulate family care do not necessarily eradicate all risks (Chama, 2008).

One assumes that the negative consequences of institutionalisation apply equally to children with or without HIV (Dobrova-Krol, Bakermans-Kranenburg, van Ijzendoorn, & Juffer, 2010). However, the double jeopardy of being HIV positive and living in residential care is under-researched. Only two studies highlight the intersections of care and HIV positive status. A Trinidad/Tobago study determined that in a facility established to nurse young HIV positive children until imminent death, permanency planning over time has become primary, as many of these surviving children still having relatives in the community (Cambridge, 2001). A South African study investigated the experiences of 15 youth at Nkosi's Haven, Johannesburg (Dube & Ross, 2012). All were affected, but only some infected with HIV and AIDS. The youth were extremely ambivalent about their placement. They felt they had a caring, supportive environment through which their basic needs and education were met. Yet the young people also felt powerless and frustrated at the limited opportunities for decision-making and agency and felt that living in a facility focused on persons with HIV and AIDS was fundamentally stigmatizing. Some thought that medication compliance was being enforced and accordingly felt dehumanized and shamed (Dube & Ross, 2012, p. 208). It also emerged that boys wished for male caregivers and role models.

Having described adolescence and the needs of different subgroups of teens, we turn to the local policy framework regarding children with HIV and AIDS.

POLICY FRAMEWORK IN SOUTH AFRICA

South Africa is a signatory to the United Nations Convention on the Rights of the Child (UN General Assembly, 1990). The government's commitment to children's rights was further enshrined in the post-apartheid South African Constitution. The National Integrated Plan for Children Infected and Affected by HIV/AIDS, implemented as of 2000, makes provision for the state to support efforts regarding home and community-based care and support, voluntary counselling and testing, and life skills programmes (Streak, 2002). It further assumes collaboration between the Departments of Education, Social Development, Health and Agriculture as well as between government and communities (Streak, 2002). The Child Support Grant has been extended to indigent families, 12 million children now benefitting (South African Social Security Agency, 2016).

CONCLUSION

Youth who have been perinatally infected form the largest group of adolescents with HIV and AIDS. These teenagers face a unique constellation of health, educational, social and psychological challenges. Noting the effects of residential care, HIV positive adolescents raised in residential care may face added challenges and are likely to face a complex web of barriers to a healthy and rewarding life. In determining appropriate responses, the impact of disadvantage perpetuated through race, class and gender discrimination must be taken into account. A rights lens regarding appropriate intervention is imperative.

A challenge found in synthesizing the literature is that much has changed since the late 1990s when the needs of children, especially those infected with HIV and AIDS perinatally, were initially tabled. With fewer recent scholarly articles available, making conclusive assessments about incidence, health impacts of antiretrovirals and services available is somewhat difficult.

Methodology

This research examined the lived realities of a group of perinatally infected adolescents living in the Lambano Sanctuary by identifying how these young people themselves describe their experience.

A qualitative approach was utilized to ensure that the nuance and complexity of the lives of these young people and the expertise of the caregivers was captured. Focus groups of between 60 to 90 minutes held on-site at Lambano, gathered the stories of 20 teenagers: 2 focus groups of 10 adolescents each (FG4 and FG5 - Participants A-T). The residents arbitrarily chose which group they would attend. Only one of five intended follow-up interviews was held, because only one teenager was willing to participate in an interview process. This hour-long interview was also conducted on-site. Additionally, focus groups with caregivers (4 persons: FG2 -Participants 4-7) accessed their descriptions of the youths' experiences and of their caregiving expertise. It had originally been planned to interview adolescents in the hospice, but the teens had been recently discharged and no one was available for the study. In addition, the managers (3 persons (FG1 – Participants 1-3) and 7 staff members associated with the hospice (FG3 – Participants 8-14) were interviewed using focus groups.

The qualitative data gathered was complemented by some quantitative data drawn from the organisation's database. The research design thus triangulated data sources (teenagers, managers and caregivers) and data methods (interviews and focus groups).

Of the 28 children cared for by the home, 25 were between 10 and 18 years of age, with one being 19. Recognizing potential cognitive and emotional differences between 10 and 13 year olds, only 13-19 year olds were invited to participate in the focus group. Purposive sampling was used. The adolescents were informed of and invited to participate in the research by the director of Lambano. Some may have therefore interpreted the invitation as requiring mandatory attendance. Purposive sampling was also employed with the caregivers invited to a focus group. However, only those on shift were able to participate. The data were, where possible, recorded on a voice recorder and then transcribed, although detailed written notes were also taken.

The researchers utilised a semi-structured focus group guide for the groups and a semi-structured interview guide for the interview. A thematic content data analysis approach was implemented. Codes and categories were assigned to the data with the intent of illuminating relevant themes. The emerging themes were then analysed. Alvesson and Skoldberg's (2000) iterative, heuristic, reflexive process was followed, identifying the possible meanings of the empirical information, interpretation, critical interpretation, reflection of the text and language use and self-reflection. The researchers received ethics approval from the University of Johannesburg, crucial with the vulnerable population studied.

LIMITATIONS

The researchers could not, due to time constraints, build meaningful relationships with the young people or caregivers nor could they develop a participatory research intervention. Noting that this group was a particularly vulnerable one, a participatory design would have been more appropriate and would potentially have yielded more information. Similarly, considering potential social risks, the teens and personnel may in the focus group have offered guarded sentiments. Nevertheless, focus groups offer the opportunity for participants to expand a topic in relation to what other focus group members offer. English language facility may have been a challenge for some of the caregivers, although no one identified the need for interpreters when asked. Furthermore, the age and race of the researchers (White, middle aged; Indian, thirties respectively) may have both facilitated and inhibited discussion. The young people may also have associated the researchers with medical and other professionals to whom they are expected to defer.

Study conditions were not ideal: in every instance, interruptions of one kind or another occurred which limited the discussion space and almost certainly impacted both trust and concentration. In all the focus groups, it was difficult to track assenters or dissenters, as certain issues resulted in agitated discussion. The sample was also a small, nonprobability one, limiting generalizability beyond Lambano to other residential care facilities.

> They think staying
> in a home or an orphanage
> is a problem

Findings

All participants were reminded that participation was voluntary. Transcripts were distributed for correction amongst the participants, with only two transcripts being returned with minor amendments.

Barring one child who had an appointment, all the children in the residence between 13 and 19 years of age attended. The children all identify as black. There were 12 boys and 8 girls. None opted to leave the focus groups when offered the opportunity. Only one young person accepted the invitation to be interviewed, the others feeling that they had said what was necessary in the focus groups. To avoid any negative consequences for any opinions he may have expressed, this young person's feedback is generally integrated into that of the children's focus groups. We resisted giving further reminders as we did not want to exert pressure on potential interviewees.

Fourteen staff members participated, all women. Two were white, twelve were black.

A number of themes emerged. These reflected the lived realities of the adolescents at Lambano, but also described issues relating to the structure and development of the organisation.

THEMES RELATING TO THE LIVED REALITIES OF ADOLESCENTS AT LAMBANO

'Being a teenager is hard'

All the young people seemed to find adolescence challenging, with school and social transitions being especially difficult. Participant M spoke about imminently moving to high school: 'The first day… will be exciting. But it will also be boring because G and N won't be there. I will have to make new friends…'. Participant K elaborated, 'It is hard…There are different expectations at school and at home… When you are younger and you fail, you are excused because you are small.' The issue of peer pressure was seen by all the youth as a concern, particularly regarding smoking and material possessions. 'You have to have things to be cool…' said Participant K. In both focus groups, the young participants were consumed with the issue of whether or not they would be receiving upgraded, more functional cell phones. Not being able to go to friends for sleepovers was also discussed at length. Issues pertaining to dating also came up.

Caregivers also found the new phase of adolescence difficult, but from their perspective as caregivers. The work had shifted, according to the housemothers, because the majority of children in their care were now adolescents, discipline and back chatting being particularly challenging. Participant 6 said 'We have just to love them. This is not easy…They say 'I hate you' because they are teenagers'. Participant 4 added, 'You love them and they just give you talk'. The participants seemed to be suggesting that in comparison to when the children were younger, they were now being disrespectful and less appreciative. The managers, as will be elaborated on later, also noted that the work was now different.

THE PROS AND CONS OF A RESIDENTIAL SETTING

Various issues pertaining to the adolescents' realities related to living in a residential setting.

'They think staying in a home or an orphanage is a problem'

First, the young people felt that the residential setting was constricting. Participant N suggested: 'Sometimes it is like jail. You can't go to a party. You can't say 'Yes' to your friends'. Participant D observed 'the only places we are allowed to go to are the shops at E. mall and places close by'. The youth wanted to have sleep overs at school friends. Additionally, those that visited the homes of relatives or their housemothers (typically in the 'townships') felt they were freer there. Participant R described the township as being filled with music, and she believed being there gave her freedom to walk wherever she wanted, though others felt she was being naive. Participant B wanted 'more free time'. A concern raised was that the residents could not choose their school. Participant O observed 'I was sent to a hard school' when he would rather have been in the remedial school. Participant L, to general agreement, raised the fact that their pocket money was insufficient for the incidentals for which they were expected to pay. The youth did not like sharing rooms, Participant O adding 'We don't like to keep these bunk beds. We want our own beds, so that they don't wiggle'. A related concern was Participant D's plea for privacy: 'they must give us keys to the room. When we are changing they must not push the door open'. The housemothers were aware of this concern. The young people did not want to be seen simply as part of the residential collective, while also needing to feel that treatment was fair. Participant D seemed to sum up the youths' sentiments, saying 'They must let us make our own decisions… they must listen' which Participant B phrased as 'They must let us choose for ourselves'. Participant R suggested that the residents' expectations were unrealistic in a context where funds were limited and reminded the others that 'it is about the money!'

Another unappealing facet of residential life was, according to the youth that the discipline was too harsh: ‘If you do one small thing, there is no TV, no computer, no laptop’ (Participant D). They felt that children living outside of the residential setting were not punished as severely and were not required to do as many chores: ‘They just let their mothers do it’ (Participant B) while ‘some have maids’ (Participant A).

A third issue raised related to the practices of the different housemothers. The teens complained of ‘a lot of gossiping’ between the housemothers (Participant D); mamas berating everyone when they were upset with one person; and mamas being inconsistent, and not adhering to promises made (Participant Q, T, N, D). Participant D and M emphasized that there should not be ‘favourites’, such as the director’s adopted son. This situation was particularly confusing to the youth because the staff call the residents their children. The housemothers understood some of the dissatisfaction. Participant 5 observed: ‘They think staying in a home or an orphanage is a problem… They are staying in a group when they want to stay with their parents…They may be stigmatized for living here…’ Indeed, the teens were concerned about the public identification with the home, because it was shameful to be associated with a facility that was known to house HIV positive children. Participant T noted that ‘Lambano has a lot of sponsored cars…We don’t like to ride in this transport-everyone knows it is Lambano’.

At the same time, staff felt that expectations were appropriate for teenagers. Participant 1 stated, ‘The intention is for each house to feel like a normal home, not an institution. The kids sometimes see it differently and feel they are being too controlled.’

‘It is nice’

Despite raising the above issues, all the young people were positive about living at Lambano. Examples included: ‘[It is] really nice. I have everything I need here.’ (Participant R); ‘We get good treatment, good care, shelter, expensive schools…’ (Participant A); ‘keep us healthy’ (Participant B) and ‘[they] let us live our dreams (Participant C). The latter comment was related to the following: As researchers we heard staff and residents talk about the importance of being able to live out one’s dreams and not be limited by one’s health status. The teens added that outings to church or the townships were important. Participant M appreciated that ‘One can rest here’, suggesting that Lambano was a place where one could be oneself and not worry about stereotypical expectations and stigma.

A number of the children also explicitly stated that they felt loved, as Participant B emphasized, ‘and most important of all, we are being loved’. Giving love and life were consistent themes that emerged amongst the personnel. The staff in FG3 felt that it was a combination of attention to the medical regime as well as the love, support and services that were received that helped the children. Participant 14 noted ‘They are not sorry for themselves’. The managers also concluded that ‘We give them life’ (Participant 1). There was general assent when Participant 5, a housemother, stated: ‘They really do a lot for the children’.

‘These are MY children’

The managers frequently referenced the notion of Lambano as a family and consistently reinforced the notion that they viewed these children as their own. Participant 1 said explicitly: ‘These are MY children. The children can therefore stay as long as they need to. The foster care grant gets paid until a child is 20.’ The expectation from the managers was also that the house mothers be mothers to these children, be available to them ‘24/7’, and develop an emotional connection with each of the children in their care. This idea seemed to be integrated into the housemothers’ view of their role. Participant 5 elucidated that the housemothers would take residents home with them on weekends because ‘A mother does not have a break’.

The youth did not spontaneously describe the residents and staff as a big family, and while referring to ‘mamas’ they typically did not identify fellow residents as brothers or sisters, though they seemed aware that they were viewed as part of a larger family network. Participant T stated, ‘Sometimes we have meetings where they say we are a family, they love us like a family, but it does not feel like that’. However, Participant M felt that he ‘would mourn for his housemother’ even though she was not his (biological) mother. Participant M talked about another resident as ‘one of the sisters here’ and suggested ‘some of the kids here feel like family to me. I think I will continue with them through my life’. It was not clear therefore if the residents felt that the other residents and caregivers felt like kin or not.

This conceptualization of Lambano as an extended family with all staff parenting was challenged when biological family members entered the picture. While it was assumed that all the children had been abandoned by their families as infants, at the time of the study nine children had connections with family. For two this contact came about within the first two years of living at Lambano; for others, families only contacted Lambano many years after placement. Participant 1 observed: ‘The children are given the choice as to whether they want to contact their families and whether they want to maintain a relationship. We let them go.’ According to the caregivers, the children would sometimes go home for holidays, but, although they loved the freedom

and fewer rules, the youth did not ultimately want to remain with their families. This was reportedly linked to the family's inability to provide materially. Participant 5 explained 'They should have the opportunity to see their family so that they see we are providing them with enough...Our kids find it better here.' The staff were concerned that the children did not receive emotional care from their relatives. Participant 4 explained that 'The children are not getting love at home, otherwise they would not have been abandoned'. Participant 5 felt 'They promise the child things and then they vanish'. The general sentiment from the staff was that, as Participant 5 stated, 'the children are better off without contact'. However, she also said 'But a child is a child. It needs to hear the voice of their granny. Not promises, just 'Hello, how are you doing''. Participant 2 added 'The house mothers love them; we love them in the office. They don't see that. They still say 'My parents are coming'. The counsellor was in part 'appointed to help the children who have to work out their feelings about their families' (Participant 1).

The youths' comments indicated that they indeed wanted information about and ideally contact with their families. Participant D observed '[not knowing one's parents] makes a person feel empty inside'. Participant M reflected: 'I did not understand why parents were fetching others and not me... Mama Lyn told me they found me in the hospital. My parents left me there...The social workers don't know anything about my parents'.

Language

An issue related to the uniqueness of this residential setting was reflected in the matter of language, the children having been raised to speak English rather than the vernacular. Most youth were adamant that having only English was problematic. Participant P protested 'They call us coconuts'. It was a problem in taxis (Participant Q) and at school where friends distanced themselves by speaking 'deep Zulu' (Participant T). The managers and housemothers also were concerned about this lack of familiarity with other languages. Participant 6 explained, 'We take them home with us sometimes on the weekends. They must be able to speak there.' Participant 8 felt it was important for the children to be multilingual to survive in the community but that they also needed this facility with languages for their future professions.

'We have indulged them'

For the managers, the notion that the residents were their children (and thus had access to certain resources and were protected) conflicted with a sense that the children had been indulged. On the one hand, they felt that the Lambano children were being unjustly denied certain life experiences. Participant 1 noted: 'Even me, I went to the coast. Immediately I thought we need to get them down here'. They felt strongly that the children in their care should not be stigmatised. They were angry with prospective donors who were surprised at the physical comfort of the homes and who then '... ask themselves if these children are not poorly off, what is our role? What do we have to give? Should they have less because they are orphans? Should they live in a shack because of that?' (Participant 1). The housemothers also were resentful that outsiders needed to see the children as ill and poor in order to assist.

On the other hand, the managers struggled with what adequate and appropriate care meant. Participant 1 and 3 spoke about having 'over-indulged', 'overprotected' and 'over-compensated' the children. Participant 1 was unhappy because: 'They have a sense of entitlement'. The staff cited their inclination to immediately address residents' (material) concerns as one example of overindulgence: 'They need to learn to wait like children in any normal family' Participant 2 suggested. The staff felt they had overprotected the children by limiting opportunities to take public transport or visit beyond designated venues. At the same time, they worried about the children

Learning you have HIV/AIDS: 'They will run if they know you are HIV positive'

having limited life skills. Participant 2 warned her colleagues that the children required greater exposure to society. Participant 1 observed. 'She [as an African woman] grounded us: It could harm the children later if they are not self-sufficient. They have to learn to take a taxi...they have to be able to pack a parcel at the supermarket'. Participant 1 also noted that 'They need to develop an awareness of the outside world. I would not do this [viz. limit opportunities] with my own child- it would never occur to me. I want them to be aware and prepared for life...it is hard out there'.

Living with an HIV positive status

Learning you have HIV/AIDS: 'They will run if they know you are HIV positive'

Between the ages of 8 and 11 the youth were informed of their status by the staff. However, the youngsters did not understand at the time what the implications were. Participant L said 'It meant nothing to me. I just thought it meant 'take your medications and eat better'. Participant S said, 'I thought it was a power!' Another did not understand the importance, saying, 'One teacher just made jokes out of it. I did not think it was serious'.

The young people became aware of the full weight of their status through Life Skills class at school. Such classes posed a dilemma, because if one offered information one was quickly thought of as being HIV positive, but if one was 'too quiet' one would also be assumed to have HIV and/or AIDS. Most of the children worried about being shunned and generally did not share their HIV status with others. '[the other students] won't come near you, they will run' informed Participant A. Participant B explained, 'They are scared they will also get it'. Some of the teens were upset that 'someone' had spoken up at school, effectively labelling them all. This boy was adamant that although he had not wanted to 'embarrass' the others, he did not want his health status or residential status to be a secret and needed to declare himself. The participants listed misconceptions others had regarding HIV and AIDS, including 'you must have kissed a monkey', and 'you got HIV/AIDS from sleeping around'. Some of their schoolmates suggested that 'HIV/AIDS is like Ebola' and that 'you will get AIDS from sitting on a toilet' or from 'hugging or kissing someone'. Appearances mattered: any *'skinny'* child was labelled as HIV positive.

The young participants, however, generally felt they were physically capable of *'doing everything'* their peers could and did not feel that the HIV and AIDS impeded their physical functioning. Some pointed to other health concerns: for example, Participant F noted 'I also have...asthma and a heart condition', D adding 'Some people have kidney conditions'. The issue of how children presented physically was raised by the caregivers, who often inferred not only that the youth were well, but that they *'looked'* well. Participant 1 pointed out that some of the residents were *'shorties'* and one child was bullied for her stature, although the connection between her height and her illness was not made by outsiders.

When the youth were asked what had helped them to live with their HIV, they listed the school, the office, the mamas, social workers, friends and counsellors. '[The mamas] try to help you turn your life around' (Participant A); 'They give you pressure' (Participant B); and 'Watch you' (Participant D). A belief in God and *'listening to your heart'* were internal supports. Additionally, the medication, good health, doctors, and nurses were seen as helpful.

Managing the HIV status of the residents was a concern for staff. The managers struggled with when and how such information needed to be shared with the children in their care. Participant 1 noted in confusion: 'We worry that we will ruin their hopes and dreams... How do you tell them you have a disease that will make your relationships more difficult?' Participant 2 added, 'Some...don't want to know...This is too serious for this child'. Participant 3 related that while this issue was discussed a lot in the office, it was not discussed enough directly with the youth. The managers observed that living with HIV and AIDS would become more difficult for the children as they grew older. As described by Participant 1:

> *[the residents] understanding changes. Although we have spoken about transmission, WE as adults haven't realized what it means, so they haven't...You are in a relationship now... When do you tell this person you are positive? ... As a teenager you are going to have many relationships...your story gets out there. Are you ready for that? ...This is why we employed a counsellor...You can't just go out and blurt out you are HIV positive. You will have everyone running into the sunset.*

Moreover, staff seemed to be caught between wanting to inform children about their status and the implications thereof, and wanting to treat the children 'normally'. Overall, the staff felt one should not focus on the HIV but allow the teens to live their childhoods fully without being marginalised. Participant 8 felt 'if they accept it, it helps them to realise that they are no different to other children. Except that they have to take medication...They can free themselves to do more for themselves'. Participant 6, expanded: 'When they grow up they have to have ambitions, they have to do something. Then they don't see HIV/AIDS as an excuse when they are older. It is also not the end of the world- they can get better education and can still have ambitions'.

'They have difficulties in learning'

The agency personnel had only belatedly understood that the diagnosis brought cognitive limitations for many of the children, and had been surprised at the number of children who needed to attend a remedial school. Participant 1 confirmed:

> *When I started no one had any expectation that the children would live as no one was surviving...Now the children are adolescents and one had not anticipated that the meds and the HIV would have an impact on their intellectual capabilities, but we have more recently been realising that this is a big problem, and thus have been using an educational psychologist to assess the children. The psychiatrist has also identified that many of the children have ADHD/ADD and many of the children now are on meds for that... Many of the children attend a remedial school. One needs to find some form of sheltered employment for these children.... S, who is 19, is mentally challenged, sexually aware and quite vulnerable. A secure, safe environment is needed for her.*

As explained by Participant 1, many children had developmental delays because of the co-morbidities of the illness (e.g. TB Meningitis or a stroke). One child had cognitive challenges because of foetal alcohol syndrome, and another due to cerebral palsy. It was necessary to attend to the cognitive limitations many of the teens had. As Participant 1 elucidated:

> *One is trying to develop a child with limited mental capabilities. This is a huge drain on resources. One is also trying to empower parents to care for their child, but this is a big ask as the children are profoundly affected by their HIV/AIDS...in SA there are many special needs kids, HIV/AIDS having created this through the associated illnesses. There is a huge lack of facilities, both day care and residential... social workers are faced with a dilemma: there is no placement for orphans or special needs kids...There should not be an expectation of long term care [at the hospice]...*

'Without it we are dead'

Another facet of living with HIV and AIDS is the medication regime. The young participants noted that taking their medication was routine, with four explicitly identifying that 'without it we are dead' (Participant R). While the majority of the adolescents agreed that they needed to take their medication, this requirement was not a neutral facet of their lives. Participant D found it disruptive: 'It's a thing that is spoiling my life'. There was envy of the older youth, Participant P stating: 'We have to get up early. Only when you are older, you only have to take meds at night'. And as Participant C clarified, there were additional pills: 'also there are different tablets to help us concentrate'. A number of youth explained that they did not want others to know they were taking medication, for example, at school camp. Nevertheless, it appeared that the housemothers' support the taking of medication being routinized and the recognition of the importance of the medication, all fostered compliance amongst the youth in the residences.

While the residents adhered to their medical regimes, Participant 1 explained that teens coming into the hospice often defaulted on their medication, because sometimes 'resisting the medication regime is the only form of control available to them'. Participant 6 acknowledged that the medication was tough for the youngsters: 'There are side effects on their hormones and appetite. Also their mood.' Participant 9 maintained: 'Those that are older know that if they drink their meds properly they can think about their future...'. Whereas the housemothers initially charted the use of the medication, the older children were being encouraged to do so themselves. Regarding teens, the staff, in particular Participant 1 observed: 'There is a fine line between forcing them and getting them to understand it is their responsibility'. It was also useful to get 'feedback from doctors...Those

They have difficulties in learning

Telling children their histories has been traumatic

that are older could maybe go to support groups at clinics …The doctor at Hospice also tries to explain' (Participant 5). Participant 3 wondered if it helped teens to see that those defaulting suffered: 'What do they know about death?'

Another health aspect was the close monitoring of the residents' physical condition. Participant 1 observed that there was extreme vigilance and reflected that she monitored the residents' health in a very different way to her son's health. While such close scrutiny was seen as necessary to maintain the children's health, there seemed also to be an awareness that the teen's bodies were placed in the foreground in a way that would not happen with a healthy teen.

'One has to have boyfriends and girlfriends'

The housemothers noted that it was difficult for their charges to be teenagers and live with their diagnosis. Participant 7 explained, 'There is peer pressure at high school. One has to experience a lot of things. One has to have boyfriends and girlfriends. The main thing is one is HIV positive. One has to be extra careful…they…have to take precautions and use protection'.

The youth articulated that their HIV positive status directly affected their intimate relationships, though all maintained that they were not sexually active. Participant K wondered whether or not one could have children without passing on the disease to the child. Participant L asked what constituted a good time in a relationship to disclose one's status. They felt that the disclosure would be accepted by someone who 'truly loved' them. Participant D had informed his girlfriend and 'she understands'. The group discussions suggested that the youth felt comfortable posing questions, but also that they were either insufficiently informed or struggling to grasp or accept the issues at hand. For example, Participant K asked when a girl's period stopped, as he thought it might be after having sex for the first time.

Locating one's self in a past and planning for a future

'Telling children their histories has been traumatic'

Although nine of the Lambano residents had contact with relatives, the majority had 'not been claimed by anyone' (Participant C). The information about their families was not always positive. The youth were sad about their past. Participant D explained, 'I remember everything, and it does affect me', while Participant B said, 'I want to [think about my past] but my brain stops me'. Participant M had engaged in this study hoping that 'If you publish this in the whole world and in South Africa, maybe my parents will read this and find me.' Knowing one's past not only provided clues to family, but heritage also. Participant M stated: 'I know I am Zulu because the mamas [at the hospital] knew my surname'. In fact, this aspect was all that he was able to assert regarding his heritage. Sadly, it is possible that the nursing staff made up a name for him, and thus his assumed heritage could be in dispute.

The housemothers noted 'Their lives are complicated. Most want to know where their parents are and why they were abandoned' (Participant 5). The Lambano caregivers were frustrated by the questions youth have about the past, as on the one hand, they may have no information to share, but on the other, they may choose to protect the children from the information they do have. As Participant 1 explained:

Telling children their histories has been traumatic. No child wants to know that their mother was drinking in the shebeen when they were found on a railway track. When the children ask, I am as truthful as can be. Sometimes one does not know if the children that were left in hospital were named by their family members or by hospital staff...

The Future

The young people framed their future primarily regarding relationships and hoped they would be able to marry and have (healthy) children. Participant K said, 'You can't have a partner' to which Participant L retorted: 'Don't be silly, you can use a condom', Participant T following up with 'Well, the child will be HIV positive. Maybe we need to adopt' and Participant R ending the discussion with 'No, there is medication now to make sure the child will be okay'. Furthermore, in their exchanges it became clear that they expected to complete post-secondary education. Many had careers mapped out: 'accountant'; 'registered professional nurse', 'fashion designer', 'games developer'. All agreed that their HIV status would not dampen their aspirations. None of the youth had negative expectations nor did they consider the prospect of death, and so assumed that they would continue to be well as long as they adhered to their medical regimes.

'Those with non HIV have freedom'

It emerged that when the youth spoke about persons who were HIV negative, they thought of young people whose circumstances were substantially different to their own. Participant M explained: 'Those with non HIV have freedom and have places to go. They don't have lots of tablets to take...They can go out with their parents'. It thus seemed that the teens associated being HIV negative with having and living with family.

THEMES RELATING TO THE ORGANISATIONAL STRUCTURE AND DEVELOPMENT OF LAMBANO

Organisational identity: 'There is a spiritual, Christian component'; 'We organize well'; 'We learn as we go'

The staff described Lambano as a Christian organisation. Participant 1 expanded:

> *There is a spiritual, Christian component. All those in the office are committed Christians as are the housemothers...The staff begin the day with prayer and the youth go to church... and to youth camp.*

Personnel noted that it was their Christian faith that allowed them to deal with jobs that were consuming, 'unending' (Participant 1) and 'emotionally draining' (Participant 2). Participant 3 affirmed that 'Without the support of the Lord, prayers, and my sisters in Christ, it would be impossible, it would not be doable. I don't care what others say. We do not have outside counselling-we are each other's counsellors.' A number of the staff confirmed that this work was a 'calling' and 'a passion'. Participant 6, a house mother, emphasised that it was a vocation for her both in terms of her religious beliefs and personal conviction, saying that 'It is a religious calling and out of me. Otherwise we would not have made it.'

Another facet of the organisation was, as Participant 1 suggested, that the staff 'are very bonded and committed as a team'. The housemothers, through Participant 6, said they were proud to work for Lambano and would rate the organisation as '10 out of 10'. 'A lot of us are hard workers. There is prayer every day. It is hard work, dedication, love, commitment.' Additionally, the work was satisfying. Participant 4 stated, 'we have learnt a lot: how to raise a child from a young age to be a teenager...This job is challenging my brain. I am getting matured from what I am doing, I can see that keeps me going'. The housemothers appreciated the weekly meetings: 'we can express our feelings; discuss problems; sit down together'. The housemothers liked being responsible for their own space, that their biological children could live with them and that they could be relied upon when the management was on holiday. There was considerably more turnover in the hospice staff, but they too felt 'privileged' to work with these children. One individual exclaimed 'That God called me to do this!' Staff were united in their mission to save lives. Participant 8 suggested: 'I have enjoyed getting to know the children, seeing them literally come alive as they improve on their medication'.

However, the question of how one dealt with the emotional fallout of loss and hospice deaths was also pertinent. Participants 1 and 3 commented that 'We have survived like this all these years. We are very practical...We just say 'Suck it up, buttercup'- that's how we were raised... We have many deaths in the hospice. We pray and we bury them and we get on with it...By the time the child passes away we have made peace with it- the child has suffered too much and we see the value of them passing...[Nevertheless] We have to find the balance of empathy with the staff'. Participant 2 elaborated: 'We forget about peoples' feelings.' Indeed, Participant 8 said 'One becomes aware of how short life is. Every day matters...' The Hospice staff identified that it would be useful to specifically mark a child's death perhaps through further rituals/processes.

While the managers emphasized that ongoing needs existed and that funding was always sought, it also appeared that this organisation was successful on a number of levels. For example, they were able to consistently engage donors to support their activities. Indeed, Participant 3 noticed 'We organize well'. The donor support around the provision of school fees, transport, outings, clothing and Christmas gifts was repeatedly remarked upon.

Despite successes, the managers often noted that 'Hindsight is a wonderful thing and mistakes have been made...we are on a huge learning curve' (Participant 3). Participant 1 made the point that 'We came in without experience and expectations. We have learnt as we go'. Participants were referring to issues such as the promotion of residents' independence and encouraging greater responsibility on the part of the housemothers within the organisation. Learning has been internal. Participant 1 was careful to clarify that their experience of outside involvement had not always been positive. Participant 3 emphasized: 'These are OUR children. You can't just come in and say we now need to move a child because you have decided so or are used to it...would you do that to your own children?' Participant 3 felt there were particular areas where training could be useful. While Lambano is linked into a hospice network and is supervised by CMR, the organisation does not have connections with other networks, such as National Association of Child Care Workers.

'We are empowering them'

The managers have been responsible for developing the direction of the organisation; fundraising; interfacing with schools, CMR and various government institutions; and managing the training and ongoing development of the house mothers. Additionally, Participant 1 noted that 'We make rules, we discipline'. While this team was clear about the tasks they take on, the presence of Participant 2, who joined the management team two years ago and is black, has led to a re-evaluation of the role of the leadership in the organisation. This re-evaluation has included reassessing the functions of the managers versus the house mothers, as well as reviewing what exposure to give the youth to the world outside.

The managers felt that the housemothers should take on further responsibilities. Participant 3 explained: 'We are trying to get the housemother to be more self-sufficient. Things I do they can do, such as fixing geysers on the weekends...We get called [on weekends] if the kids have misbehaved, if they can't deal with a child'. Participant 1 added: 'We are empowering them to take responsibility. They are a bit nervous about that. They don't feel they have the capability'. It appeared that the motivation for such change was twofold: on

the one hand, the managers were overwhelmed, Participant 1 observing, 'I feel like a dog with too many titties', but Participant 3 clarifying 'It is our own fault…we want to fix things immediately…we have always done it like this'. On the other hand, the housemothers themselves had suggested that they be given more responsibility particularly with regard to discipline to avoid the residents 'divid[ing] and conquer[ing]' (Participant 2). A difficulty was that 'the housemothers don't understand 24-hour care' (Participant 1), this being 'a cultural thing'. The participant was suggesting that the housemothers did not comprehend that taking on the caregiving in a residential setting was like mothering, a full time job, and was not limited to a particular shift. In contrast, the housemothers, proudly described their role as follows: 'As housemothers we are in charge of the kid's lives, everything happening in the houses' (Participant 6). These different perceptions must be examined, as must the contradictory desires of the managers who want to be able to focus more on management issues, while wanting also to remain and even be more engaged with the children.

The future of the organisation

The agency has established that its focus needs to be on caring for perinatally infected and orphaned children. Participant 1, referring to previous projects that had failed, explained that

> *The organisation is defined by its mission statement. Lambano has realized one has to stick to this. Work was done in Kathlehong…But one is then chasing money for outside projects and then loses the main focus. Also trying to help people who don't want to be helped is pointless. Lambano is now focused on bringing up the 28 children.*

Short term recommendations were made. In speaking about the mothers of children in the Hospice, Participant 1 suggested 'The skills and sustainability centre should help mothers to be independent of boyfriends who come and go'. The housemothers would like Lambano's work to be recognized by politicians and government, Participant 6 noting 'The parliament has never visited. It is their job. They must see that we save lives.' Local volunteers should not only want to help

We are empowering them

if they were paid for their services. The Hospice FG participants recommended that there be a place where more than one parent could stay for more than one day; programs be put in place to help parents be more financially stable; children be enabled to be multilingual; and greater dialogue and support between the Hospice and the houses be ensured.

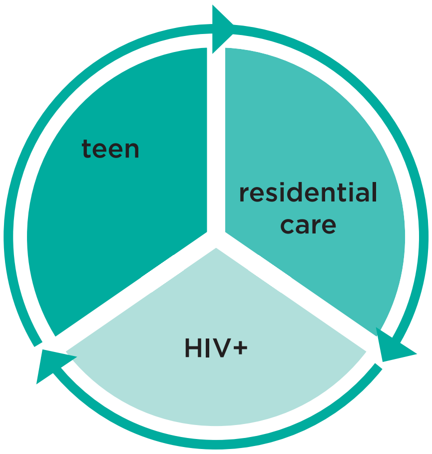
Even so, the organisation's future seems unclear. The intent of the organisation is to exist as long as the youth 'need' the organisation. Participant 3 stated 'we can't send them anywhere at 18. There is nowhere until they have a job...They will pay rent, but you can't toss the 18 year old out the door.' Participant 2 noted 'I also see myself as a parent. This is long term'. At the same time, Participant 1 explained 'We are always talking about how life is going to be like after Lambano. We are always talking about how maybe the girls can get together in a flat'. They also worried that being an aging staff, they would not always be available to the youth.

A number of issues were thus raised, both about teen's lived realities and the organisation.

Discussion

This research was initiated to understand the lived realities of perinatally infected HIV positive youth in residential care. The findings reflected the ways in which being a teen, living with HIV, and residing in alternative care intersects for the young people at Lambano. The study further highlights a number of issues which need to be considered in responding to this group of young people.

THE INTERSECTION OF RESIDENTIAL CARE, HIV POSITIVE STATUS AND ADOLESCENCE



The findings demonstrate that for these teenagers their adolescence, HIV positive status (including their abandonment) and life in residential care overlap intricately and compound each other. The youth at Lambano in many ways present as regular adolescents: they struggle with the limitations imposed on them by adults and want to assert their own positions. Finding ways of fitting in with peers, struggles around identity, managing intimacy, resisting authority and pondering the future are all appropriate developmental tasks (Devore & Schlesinger, 1999).

The experiences of Lambano youth as adolescents are shaped also by the residential setting. The findings suggest that the youth feel undermined by being subject to uniform rules and procedures: they do not see their individual identities and needs being addressed, and feel choice and control over their individual lives is limited. Adolescents with HIV and AIDS are socially constructed as particularly difficult (Thurman et al., 2008), with the potential causes for their disruptive and challenging behaviour not being fully understood. This dynamic may play into the residential situation at Lambano.

Despite Lambano providing individual houses, warm relationships, and prompt responses for a relatively small number of children, the effects of institutionalization may emerge from the (physical and organisational) closeness of the management of the organisation to the management of the houses. The 'office' is central to the dynamics of the setting, for example, with regard to discipline. The managers appear to be torn between running the organisation and having daily contact with the children. This results in the housemothers' authority being undermined both with regard to discipline and other responsibilities. It also means that the managers are overwhelmed as they try to be all things to all people. This proximity further promotes notions of institutionalization rather than family units in individual, autonomous homes.

The ambivalence of the staff towards biological family creates further tensions for these youth in residential care. Those without family contact envy the teens who are in touch with relatives and perceive that such contact provides a sense of belonging. At the same time, according to the caregivers and managers, the teens are let down by families who are unable to provide material or consistent emotional care. This ultimately undermines the adolescents' identification and connection with their families of origin.

Furthermore, for the Lambano adolescents, the stigma of their health status is conflated with discrimination related to living in substitute care. These youth associate residential care with having HIV and being (in most cases) orphaned. This association may be because their own lived realities are compared not with peers who are HIV positive, but primarily with the lives of school friends who are HIV negative and live with their families of origin. The fact that they are transported in labelled vehicles, have basic phones, and all attend the same outings, not only highlights their institutionalization, but serves to stigmatize them as regards their HIV status. This conflation also seems to present challenges for the caregivers, as it is difficult to identify which issues arise out of the residential setting and which emerge from the children's abandonment and challenges of living with HIV.

The context further demonstrates how the medical and residential care of the children is intertwined. Bodies are regularly monitored to ensure that medication is taken and physical indicators are noted. Using multiple strategies, Lambano has been successful in ensuring medical compliance (and thus the maintenance of life and physical well-being). This is a significant achievement, noting that adolescents struggle with medication regimes. The health situation is further complicated because children may have health issues parallel to their HIV, or emerging out of the illness. The subjectivity of carrying the HIV positive label changes the adolescents' interaction with their body and sense of self. These adolescents note that their medications mark them as different and impact their peer relationships. Also these youth, like other teens who are HIV positive, could not conceive of their sexuality without consideration of the dangers inherent in their sexuality (Campbell & MacPhail, 2002). What should be a life-giving force becomes tempered with notions of illness, danger and potential death.

A central issue emerging from the research is when, what and whom to tell regarding the HIV status. The caregivers are uncertain about what to share with the children and at which developmental phase to undertake this disclosure, particularly as they are not only sharing the HIV status, but often needing to explain tragic circumstances leading to the child's abandonment. At Lambano, the approach is to not let young people become discouraged by their health status or their abandonment. Participant M commented, 'Mama Lyn told me to reach for my dreams...' The teens themselves have to make decisions regarding whom to tell and when, but in their developmental phase they may not have the necessary ability to discern what should be shared when and with whom. Living in a residential setting limits individual choice, thereby creating difficulties for those individuals who want to be open, to be seen, and to be accepted for who they are in all their dimensions. Hence, Participant M sharing his status at school created problems for his fellow residents, though he was adamant 'I want people to know who I really am... I want to have a chance with who I am'. The Lambano youth cannot share their roots, typically having no location in the past; may not be able to say who they are in the present; and have to fear for the future. Where youth have sexual identity issues, this process of disclosure becomes infinitely more convoluted and challenging.

By including both the residences and the hospice, Lambano has taken on a complex mission. On the most essential of levels, Lambano has been successful: 'We have given them life!' However, while seeing what happens in the hospice has helped some residents understand the critical importance of their medical regime, the proximity of the facility may serve as a stark, unwelcome reminder of how HIV and AIDS and death are connected. Additionally, the intersection of the medical and residential setting in the case of the stepdown program serves to blur the impact of longer term residential placement. Where it is indicated that a family network may not be able to support the medication regime children may remain in the hospice for up to a year, even two. This timespan appears to be an inordinately long period of time, and overlooks the manner in which the child is disadvantaged by such lengthy placement, including losing networks and the loosening of their place in the family.

A final aspect of the intersection of HIV and the residential setting pertains to educational delays. Vertical HIV infection and the associated medication may impact cognitive competencies. Children in care are known to have educational delays (Zolotor et al., 1999). HIV positive teens living in care are thus doubly impacted. While the teens do not seem to link their educational, health and residential status, staff are dealing with these educational difficulties and have needed to develop close relationships with local educational institutions and professionals. The personnel are also concerned about the vulnerability and future employment prospects for these youngsters.

CONSTRUCTING FAMILY AND BELONGING IN A CONTEXT OF RACE AND CLASS

In addition to the challenges identified above, race and class appear to impact the residential experience of these youth. It is essential to understand these macro factors and how they impinge on the daily realities of the residents (Abadia-Barrero & Castro, 2006).

Regarding the residents, Participant 1 acknowledged that race affected the managements' perception of the teens, though just what this meant was not stated: 'We don't see the kids as with HIV...We do see them as Black and White...Ironically when you ask the children which culture they want to be, it is White'. The adolescents' worldview is shaped by their interaction with the predominantly white Lambano leadership, administration, volunteers and donors on one side and the housemothers, counsellor, social worker and nursing staff who are predominantly black on the other. Participant 2 felt that the children associated their (black) housemothers with discipline and noted in reference to corporate Christmas donations, 'Remember, to them love is giving stuff. The mothers are not giving them a R500 voucher. They notice the company that comes once a year...'. This participant thus believed that the residents equated care and affection with the receipt of material goods and thus valued the donors more

Organisational identity: ‘There is a spiritual, Christian component’: ‘We organize well’, ‘We learn as we go’.

than the housemothers, who provided intangible care. While their disadvantage is recognized, the teens are simultaneously viewed by all staff as being privileged and often as insufficiently grateful. The children have accordingly been taken on visits to a local informal settlement to provide them with perspective regarding their privilege. These residents are thus dealing with being relatively privileged while at the same time being disadvantaged. While this idea of being more privileged than another orphan may be a feature of residential care, the complexity of intersecting privilege and disadvantage is intensified by the residents’ HIV status.

The findings highlight the fact that the teens have not had the opportunities to learn some of the life skills they will need to live independently, and it was implied as black youth they needed to acquire these skills. The ‘over-protectiveness’ has restricted their language development to English and thus their ability to move in a multilingual social milieu, and led them to being labelled ‘coconuts’ – the derogatory term for black persons who behave like and identify with white persons and culture. This lack of the vernacular marks these adolescents as ‘other’ and limits their identification with their communities of origin and thus potentially further compromises their sense of belonging. The adolescents must also make sense of their friends’ realties: HIV-negative youth, who are black and white, who have particular freedoms and are not called to account for their lifestyle.

It is not only race, but aspects of class that impact the lives of the Lambano residents. The reality of these young people’s lives is that they must learn to manage both in middle class society (which continues to be dominated by white norms) while simultaneously being able to negotiate the townships and working class contexts. Mahery, Jamieson and Scott (2011) further point out that providing assistance to children who have reached the age of 18 is important as part of the transitioning process. It is not clear whether these young people, despite their aspirations, will because of their social location and for many, cognitive limitations, transition into a middle class adulthood. These adolescents therefore are at risk of significant social exclusion.

International literature identifies the problems of children in care straddling the residential setting and the difficult circumstances of their family of origin. This can put residential staff against biological families, as staff engage in a discourse of ‘worthiness’ to receive help (Parton, 2014). Lambano caregivers view the residential setting as better than the family environment, and seem relieved that the children ultimately prefer Lambano. In cases where contact with the child has been resumed by families, there may be ongoing frustration with biological families. The staff assess the biological families as inadequate and inappropriate, and carry anger at the initial abandonment.

However, the youth share the sense of rootlessness and a quest for identity with other children who have been orphaned and are in residential care, and yearn to know and be claimed by their families of origin. At the same time these youngsters also know that their story is a shameful one: a mother, infected with HIV and AIDS became pregnant and abandoned her child. All the caregivers view these mothers as inadequate. In their anger at the abandonment and desire to protect, there is little sympathy for or understanding of mothers who have abandoned their children and limited appreciation of the role of structural issues, such as the historical legacy of apartheid, poverty and the broader HIV crisis on family life that may prompt a mother to abandon her child. There is a lack of understanding particularly when the mother has exhibited other socially unacceptable behaviours (such as substance use or streetwork). In the cases where relatives have come forward, the Lambano staff personalize the reasons for abandonment even when recognizing that the children frequently have come from deprived, disadvantaged contexts. They thus feel anger and disapproval regarding biological relatives. For housemothers there may also be internalised shame: other black people are abandoning their children. There is however, tolerance for grandmothers who have taken on the responsibility of raising perinatally infected children, and insight where extended relatives have 'chosen' to leave the responsibility of raising the child with Lambano. This is seen as the right choice. Managing connections with families of origin and settling the issue of to whom the child belongs is an ongoing debate in the child protection arena. Mechanisms such as family group conferencing being used to negotiate relationships. Although it is not the norm for Lambano children to be in contact with relatives, adolescents who should not feel that they must somehow choose between their blood relatives and Lambano. It is difficult to know how to interrupt this discourse of who is deserving, particularly when staff members are sacrificing in many ways to care for these children; and the middle class care these children are receiving has to be so strongly defended.

Notions of race and class seem to affect the way in which the managers assess the housemothers' competencies. The managers view the housemothers (who have mostly been with Lambano since its inception) as not having the same concept of caregiving (as noted earlier, management believe housemothers do not share their notion of mothering). Additionally, housemothers are viewed as not disciplining in the appropriate way. For example, as Participant 2 noted, despite instruction, housemothers would shout at the residents and not 'speak properly' to the children. In these reactions, management are playing out central discourses in Anglophone child protection which privilege white, middle class parenting approaches and de-value other parenting styles. Participant 2, as an educated young black professional, quite consciously acts as a bridge between black and white staff, trying to help her leadership colleagues see how closeted the children have been from the 'real' world- which is a black, working class world -, and getting the housemothers to parent in ways that conform to white, middle class expectations. The black women look on as the Lambano children benefit from decent housing, regular water and electricity provision, good education and outings, their own children perhaps not having the same life advantages.

A developmental social services orientation recommends that children be raised within their families and within their communities, even when these children are orphaned. While the Lambano children are not far from their physical origins, they also have not been raised within their communities. Their sense of displacement and dislocation appears profound, even if they have colleagues at school who share their skin colour.

This data suggests that unspoken biases of race and class require further examination.

THE ORGANISATION IN AN ADOLESCENT PHASE

An issue impacting the care of the residents is Lambano's organisational phase. Fifteen years ago Lambano began without the expectation that the children would survive. Because of the agency's commitment and intervention, these infants have grown into relatively healthy adolescents. However, the whole context of Lambano's work has changed: not only have these adolescents survived, but they can envision a future that is not threatened by death. The Jamaican agency cited by Cambridge (2001) seems to have followed a similar arc. There is an interesting parallel between the developmental phase of the residents, and the organisational developmental phase. In some senses, Lambano is an established organisation, but in others it represents an adolescent phase (Brothers & Sherman, 2012). Lambano learnt how to manage younger children, but is in the process of acquiring knowledge of how to deal with teens. Roles are shifting and formalizing, and there is the questioning of what housemothers are capable of and what they should be doing. The managers

Consideration might be given to discussions around shared parenting. Family group conferences, that bring together the wider circle around a child, are a method that could be employed to arrive at joint plans for the adolescents.

feel overwhelmed and sometimes do not feel they can meet everyone's needs. As an organisation, Lambano can proudly look back on what it has learnt, but there seems to be an insistence that one ought to learn from one's own mistakes and that outside help can be threatening. [The management saw this research as useful because it focused on the agency itself, rather than promoting engagement in any networks]. The organisation thus prefers to work on its own where possible. Repercussions of this position include Lambano not benefitting from general organisational development experience or learning in the field, and internal reflection occurring without the benefit of outside input. Ongoing outside staff training and external exchange are limited and the residents are not involved in external groups with children in similar situations. The organisation appears also to live very much in the moment and although the future is sometimes mentioned, it appears a strategic planning discussion for the medium to longer term must still take place.

Ultimately, Lambano needs to reflect on the manner in which the adolescents' HIV status and residential experience intersect, the impact of race and class on the organisation, and a preferred future.

Recommendations

A range of recommendations emerge from the study. It is clear to the researchers that many of these recommendations require additional resources, which may be challenging in this environment.

INDIVIDUALISED INTERVENTIONS

More attention needs to be paid to heightening the teens' perceptions of individual care and a sense of control over their environment. The youth need to perceive interventions, routines and rules as fair. At the same time, each young person wants to be dealt with individually and to feel that their unique circumstances are being considered. This occurs to some extent with the teens being able to pursue sports that interest them. Each adolescent needs the opportunity to develop personal friendships and networks and develop individual interests. Interventions need to be customized as far as possible, thus replicating patterns in family life. For example, older youngsters might be given X amount towards a phone, which they then would need to manage rather than everyone receiving the same phone.

The dilemma regarding the content and timing of HIV status disclosure has been discussed by Dube (2012), and Dube and Smith (2016), who emphasize that thoughtful disclosure is necessary to promote adherence to a medical regime, and to address any anxiety and suspicion related to the youth's status. In order to mitigate some of the concerns regarding disclosure careful policies and procedures are required. Dube and colleagues recommend that a therapist share the information with the young person, but do so with the backing and support of a multidisciplinary team. At Lambano it might be useful to include the director, counsellor/social worker and housemother in sharing the disclosure with the young person, rather than leaving it simply to the director. Strategies for supporting the person post-disclosure should be identified and made known to the young person. Youth need the opportunity to engage outside of Lambano with peers who find themselves in similar circumstances. This could be through formal support groups.

ENHANCING FAMILY AND COMMUNITY INTEGRATION

Ways of promoting involvement of (biological) families in both the hospice and houses must be considered. As noted earlier, the staff themselves have made valid recommendations regarding the hospice such as increasing the amount of time that relatives can stay over at the hospice and making it possible for a number of parents to stay over at one time. The agency might identify mechanisms by which to actively build a stable community-based solution for the children in the step-down program, including developing circles of support. Such circles, including relatives, peers and where appropriate service providers, provide a network of support to the youth. These circles also facilitate the integration of the teen into the broader community. Relatives of children in the houses might be invited to spend recreational time with the youth at the facility. Consideration might be given to discussions around shared parenting. Family group conferences, that bring together the wider circle around a child, are a method that could be employed to arrive at joint plans for the adolescents. Conferences are also a means of activating informal and formal resources to support the adolescent and caregivers.

The youth asked for increased contact with non-resident peers, as well as opportunities to go beyond currently designated outside destinations. Learning to take on greater responsibilities in the residence and having greater autonomy will also facilitate the confidence and independence needed to negotiate community spaces.

Lambano is encouraged to prioritise the development of a language policy –matched to the age and stage of each resident- that expands the languages with which residents are conversant. Ideally, residents should become familiar with the dominant language in their community of origin.

A community-based approach requires that Lambano actively facilitate the connections of children with their family networks and their communities. The youth need to be tied into community activities in their communities of origin, even if they remain living at Lambano. Youth might be supported to participate in faith structures, sports clubs and other activities in their community of origin. For those youth who have contact with their biological families, active, intentional intervention to develop realistic plans is required. While the youth seem to benefit from visiting the housemothers' homes, it must be emphasised that the mamas' community is not necessarily their own.

Another area of consideration pertains to sexuality. It appeared that not all residents understood aspects of sexuality. Staff reportedly have regular, open conversations with the youth. Ongoing education and support is required in this area.

REVIEWING ORGANISATIONAL MANAGEMENT OF LAMBANO

The leadership team is aware that the emotional impact of the work on staff is not always acknowledged. Personnel might feel more supported if there was more explicit discussion about the psychological toll of the work. In the hospice, formal rituals that acknowledge loss and go beyond prayer could be meaningful.

A clearer institutional division of roles may be useful with the Lambano leadership focusing on running the organisation, and housemothers doing the child care. Such demarcation and ensuring autonomous residential units would likely require the re-allocation of resources and may cost more than the present arrangements. It would mean that non-housemothers could be involved in the children's lives as additional supports, but not as primary parental figures, this role being left to the housemothers. The leadership could focus more effectively on management tasks. The managers might review the appropriateness of seeing themselves as 'mamas' and in a mothering role. Greater reflexivity regarding the expectation that housemothers be 'normal' mothers is needed. For example, increased recognition is required that housemothers raising their own children in addition to eight HIV positive children and working shifts is far from normal. These women are also employees of an organisation with a particular mission, and are not simply parenting figures.

In this respect, Lambano needs to reach out and learn from the vast experience of residential care for children. This might include examining child and youth care models for staffing, understanding more specifically how cluster homes ideally operate, and linking into relevant training. The organisation could connect with networks such as the National

Association for Child Care Workers. CMR may also offer learning platforms for the residential facilities under its auspices. Such participation is important in order to facilitate learning and exchange, as well as support, and to prevent Lambano from needing to re-invent the wheel.

FACILITATING THE TRANSITION FROM LAMBANO TO THE OUTSIDE WORLD

This aspect is important for the children who live in Lambano as they have to develop skills to straddle the intersections of life at Lambano with life outside. This developmental task includes the interface of being able to live independently as an adult, to become part of a community that they have not lived in and to be able to navigate their identity (race, culture, age and gender) within society. This will be particularly challenging for Lambano residents, who may have physical, cognitive and emotional challenges.

Lambano needs to formally consider future scenarios for the children's lives and decide what this means for the organisation, including such issues as how the notion of family will be perpetuated when residents are older than 20, the foster care grants end and staff age; and whether young children will be admitted if spaces become available. The organisation needs to consider whether or not its purpose becomes to support the young adults as they create independent lives, being the support network that biological relatives may have been. The implicit mandate arising from the data suggests that Lambano needs to adapt to become a long term resource to the residents. This would be an unusual step, but may break new ground in caring practices. To prepare for this purpose it may be advantageous to explore longitudinal studies about young people leaving care. If Lambano chooses the route of longer term support, the houses might be transformed into shared living for adults. Those choosing to live outside Lambano might require ongoing assistance with budgeting, managing relationships, and managing their health. Noting that many have cognitive challenges, identifying ways to support these young adults becoming financially independent could be explored. This might involve skill development planning, finding jobs in the regular market that could coach and mentor these individuals, working with existing sheltered workshops, or engaging with youth employment programs.

Should the organisation choose to follow the route of more traditional residential facilities where the young person 'ages out', and at that point no longer receives formal support, the facility might then continue to fill vacancies with younger HIV positive children. If this option is selected, consideration will need to be given to addressing the needs of a cohort of children and youth at markedly different ages and stages.

The youth were very aware that Lambano was labelled as a facility providing alternative care specifically to HIV positive children. The intensity of the stigma might be reduced where the residents are both HIV positive and HIV negative, although this would require an entirely new focus for Lambano.

ADDRESSING ISSUES OF RACE AND CLASS

Race and class dynamics impact the quality of caregiving at Lambano. Managers need to develop a greater awareness of the manner in which race and class factors are played out in the Lambano context, perhaps through a series of facilitated workshops facilitated by an outside expert in such issues. It is a delicate area, and will require transparency and courage. Personnel will need to be willing to examine the assumptions they may have made about each other based on stereotypes of race and class. However, embarking on such a journey of trust will bind the employee body. More importantly, the adolescents will be able to more freely examine issues of identity. Understanding how and when to facilitate the autonomy of residents may also become more evident.

Thereafter, the managers and house mothers need to develop clearer consensus about the roles of the management and housemothers. Caregiving strategies will need to be agreed upon. Such strategies may relate to approaches to discipline and caring behaviour. The regular meetings are already seen as valuable by all parties and thus seem to offer an appropriate forum for such discussion.

POLICY SUPPORT FOR THE POPULATION OF YOUTH MADE VULNERABLE THROUGH PERINATAL INFECTION

In the policy arena, it is essential that the South African government consider expanding supports for this vulnerable population regarding daily care, but also education and future employment. Nationally, increased attention must be paid to the critical numbers of perinatally infected children, noting the protections and services that are required along their life path. It must also be considered whether planning in this regard intersects with the country's planning for learning disabled and intellectually impaired children and adults. The degree to which particular communities find themselves more burdened than others and how this limitation influences human and social capital must be taken into account.

State policies need to pay closer attention to the model of community-based care, ensuring that children are actively networked into the community. This cohort of children should not be overlooked, even as it is hoped that the number of children affected by vertical transmission will consistently decrease. Countries dealing with significant rates of HIV and HIV mother-child transmission must even as they consider and implement preventive mechanisms, identify how the needs of perinatally infected individuals are to be met on a short term and long term basis.

Vertically-infected adolescents living in residences are simultaneously confronted with a legacy of abandonment, residential life and the implications of HIV positive health status. Caregivers and policy makers must plan holistic, long term, community-based interventions that factor in issues of race and class. As regards practice, agencies providing services to vulnerable youth need to more carefully investigate models of care to ensure community integration and connection with relatives. Approaches are needed that are delivered by a multidisciplinary, trusted team that address all aspects in a developmentally appropriate way (Earls et al., 2008, Marfatia & Smriti, 2010; Zhao et al., 2014 p. 304). The intersection of various forms of discrimination and structural violence must be addressed (Abadia- Barrero & Castro, 2006). For example, public subjectivities (in the media, but also amongst caregivers) of HIV positive youth as either innocent victims or potential delinquents (Abadia-Barrero & Costra, 2006; Meintjies & Bray, 2004) need to be challenged, noting the use of ARVs recasts the illness from dangerous into manageable. Finally, communities must be strengthened to ensure that vulnerable and HIV positive youth receive needed supports (Betancourt et al., 2013; Mistry et al, 2012).

FUTURE RESEARCH

This study aimed to also examine the experiences of youth at the hospice, but could not be implemented as there were no young people in the hospice at the time. This remains an area of interest.

Another area that was not sufficiently examined was factors contributing to resiliency.

There are a range of issues that would be useful to examine retrospectively with adults who were perinatally infected, regarding the development of relationships and shifts into forming their own families. It would be helpful to understand also how young adults feel the issue of their HIV status as well as the circumstances of their abandonment should have been shared with them.

Moreover, it would be advantageous to understand what dynamics led to the apparent abandonment of children whose family members have subsequently initiated contact.

A key finding in this study relates to the cognitive limitations of these adolescents. Educational policies need to consider not only the psycho-social needs of children living with HIV, but in the case of those with perinatal infection, the influence of cognitive limitations. A broader study regarding the incidence of cognitive impairments amongst perinatally infected youth is needed so as to guide policy interventions.

Conclusion

Adolescents who were perinatally infected, abandoned and live in substitute care face a number of life challenges. The developmental concerns faced by teens and the issues for adolescents living with HIV have been well documented. The impacts of residential living have also been thoroughly researched. This study does not add information in these areas. However, the research demonstrates that for HIV positive youth in care, the residential setting, their HIV status and their adolescence intersect to create a unique situation. The research thus reinforces and extends the work by Dube and Ross (2012), Cambridge (2011) and Hayden and Otaala (2005). These youth are structuring identities with almost no genealogical history; dealing with ongoing health concerns (even if this aspect means ‘only’ taking medication but otherwise being well); managing issues regarding double stigmatization and the impact of stigma on intimate relationships and future child rearing; coping with educational lags; and in this particular instance, negotiating conflicting race and class subjectivities. The study highlights the fact that educational, health and psychological resources support the children’s resilience. However, where organisational management and parenting intersect, effects of institutionalisation may emerge. Conflict or uncertainty also emerges where the organisation itself is in an adolescent developmental phase.

Noting its success in having brought the teenagers to a point where they can realistically consider a future, Lambano can draw some lessons from the research. Additionally, the study may have relevance for community organisations that emerged post-apartheid to provide alternatives in view of the AIDS crisis. Community-based alternatives for OVC are advanced in the literature as well as in the

Children's Act of 2005- in part to avoid residual notions of care. These alternatives include kinship care but also cluster homes with non-relatives. Such options are believed to minimize the impact of institutionalisation, ensuring that young people retain community ties and identity. There are some studies that challenge this notion, suggesting that the conceptualisation of community itself has been romanticised in that many communities are not as cohesive as portrayed; children left in various forms of community care are stigmatised and marginalised (Thurman et al., 2008); and certain children are overlooked, including those in child headed households or those abused by caregivers (Daniel & Mathias, 2012). This study highlights the fact that being physically located in the c
is not sufficient on its own. Children mu
reside in their communities of origin;
the community must be actively facilitated and the youth should become an inherent part of community life.

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APPENDICES

Information sheets and Consent Forms

INFORMATION SHEET

FOCUS GROUP WITH YOUTH

Finding the Positives

Hi, I am Jeanette Schmid. I live in America, but I work for the Centre for Social Development in Africa, which is part of the University of Johannesburg. I am a social worker and a researcher. Jenita Chiba is here with me. She is also a social worker and works for the Centre.

Lyn wants to know what works well and what needs to be improved for young people at Lambano. I am helping Lyn to answer this question.

You are invited to be part of this study. The reason for this study is to learn

- about the way young people living with HIV/AIDS experience their life.
- how young people feel about taking their medications and if there are ways of better supporting young people to take their medications regularly.
- what Lambano is doing well and where it can improve its work of supporting young people who are HIV positive.

INFORMATION

I would like to talk to youth between 10-19 years living at Lambano.

First, I would like to talk to the young people as a group for about an hour and a half.

Then, I would like to **talk individually to about 5** of you. That conversation would also be for about an hour and a half.

Next, I will talk to Lyn and the caregivers from the houses and the hospital. This will also happen in a group and should also be for about an hour and a half.

I will write down what I hear and tape it all on my phone. When I write the information down, I will not use anyone's name. Instead I will use a number. This means that I can keep the information confidential and anonymous, so nobody's name is linked to what has been said. It means that you can trust that no one will ever know what you told me in the interview.

RISKS

I will only be at Lambano for a week. This is unfortunately a short time, so you may not get to know me very well.

It may be easy to talk about what is working well. It might be harder to say what is not working well. You might worry about what other people think. You might feel sad if you talk about what is not working well.

If what you talk about makes you feel sad in any way, you can ask to talk to the consulting psychologist.

Although everyone in the group will decide to keep confidential what was talked about in the group, it is possible that later someone says something about what was discussed.

BENEFITS

There are many young people in the world who got HIV/AIDS from their mothers when they were born. However, there is very little information about what it means to be a young person and live as HIV positive. There is even less information about what it means to be HIV positive and to live in residential care.

1. Even though not many people will be part of this study, it can help the staff at Lambano know what they are doing well, what they are not doing well, and how they can improve.
2. Lyn thinks it also will help Johannesburg Hospital because they want to do more to help young people living with HIV/AIDS.
3. It can help other young people in South Africa and in other countries also, because their caregivers, teachers, social workers, and medical team can learn from your experience.

CONFIDENTIALITY

I want to write a report for Lyn and for the Board. I also want to write at least one article in a journal that shows what I learnt from you. Your name is not going to be on any paper connected with this study. No one will ever be able to tell that the information came from you.

I will be the only person that will be working with the information. I will keep it in a safe place on my computer. In 5 years' time I will destroy all this information.

In the focus group, I will encourage the participants to keep whatever has been talked about in the group as part of the group and not tell anyone outside.

In my report for Lyn and the Board, and in anything else I write, I will include quotes of what you have said. I will not say you said it.

CONTACT

If you have any questions, you can phone me this week on this number: 076 890 6797. After that, you can sms me at 1 585 754 7735 (c) or you can email me at jeabry@gmail.com

PARTICIPATION

You should only help in this study if you want to do so. You will not get into trouble with Lyn and other staff if you do not want to talk to me.

You only have to answer the questions you want to answer.

Even after you have talked to me, you can decide that I should not use what you have said to me.

FEEDBACK AND PUBLICATION

I will give Lyn a report about what comes out through the study. If you are interested in these outcomes, Lyn can give you a copy.

CONSENT FORM

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature____ Date ___________________

Investigator's signature____ Date ___________________

INFORMATION SHEET

INTERVIEWS WITH YOUTH

Finding the Positives

Hi, I am Jeanette Schmid. I live in America, but I work for the Centre for Social Development in Africa, which is part of the University of Johannesburg. I am a social worker and a researcher. Jenita Chiba is here with me. She is also a social worker and works for the Centre.

Lyn wants to know what works well and what needs to be improved for young people at Lambano. I am helping Lyn to answer this question.

You are invited to be part of this study. The reason for this study is to learn

- about the way young people living with HIV/AIDS experience their life.
- how young people feel about taking their medications and if there are ways of better supporting young people to take their medications regularly.
- what Lambano is doing well and where it can improve its work of supporting young people who are HIV positive.

INFORMATION

I would like to talk to youth between 10-19 years living at Lambano.

First, I would like to talk to the young people as a group for about an hour and a half.

Then, I would like to **talk individually to about 5** of you. That conversation would also be for about an hour and a half.

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RISKS

We will only be at Lambano for a week. This is unfortunately a short time, so you may not get to know us very well.

It may be easy to talk about what is working well. It might be harder to say what is not working well. You might worry about what other people think. You might feel sad if you talk about what is not working well.

If what you talk about makes you feel sad in any way, you can ask to talk to the consulting psychologist.

BENEFITS

There are many young people in the world who got HIV/AIDS from their mothers when they were born. There is though little information about what it means to be a young person and live as HIV positive. There is even less information about what it means to be HIV positive and to live in residential care.

1. Even though not many people will be part of this study, it can help the staff at Lambano know what they are doing well and how they can improve.
2. Lyn thinks it also will help Johannesburg Hospital because they want to do more to help young people living with HIV/AIDS.
3. It can help other young people in South Africa and in other countries also, because their caregivers, teachers, social workers, and medical team can learn from your experience.

CONFIDENTIALITY

We want to write a report for Lyn and for the Board. We also want to write at least one article in a journal that shows what we learnt from you. Your name is not going to be on any paper connected with this study. No one will ever be able to tell that the information came from you.

We will be the only persons that will be working with the information. I, Jeanette, will keep it in a safe place on my computer. In 5 years' time I will destroy all this information.

In my report for Lyn and the Board, and in anything else we write, we will include quotes of what you have said. We will not say you said it.

CONTACT

If you have any questions, you can phone me this week on this number: 076 890 6797. After that, you can sms me at 1 585 754 7735 (c) or you can email me at jeabry@gmail.com

PARTICIPATION

You should only help in this study if you want to do so. Lyn and other staff will not feel bad or create any consequences if you do not want to talk to me.

You only have to answer the questions you want to answer.

Even after you have talked to me, you can decide that I should not use what you have said to me.

FEEDBACK AND PUBLICATION

We will give Lyn a report about what comes out through the study. If you are interested in these outcomes, Lyn can give you a copy.

CONSENT FORM

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature____ Date ___________________

Investigator's signature____ Date ___________________

INFORMED CONSENT STATEMENT

FOCUS GROUP WITH CAREGIVERS

Finding the Positives

Hi, I am Jeanette Schmid. I live in America, but I work for the Centre for Social Development in Africa, which is part of the University of Johannesburg. I am a social worker and a researcher. Jenita Chiba is here with me. She is also a social worker and works for the Centre.

Lyn wants to know what works well and what needs to be improved for young people at Lambano. I am helping Lyn to answer this question.

You can be part of this study. The reason for this study is to hear about the way young people living with HIV/AIDS experience their life. We also want to learn how such young people feel about taking their medications. We want to find out if there are ways of better supporting young people to take their medications regularly. Finally, we also want to learn what Lambano is doing well and where it can improve its work of supporting young people who are HIV positive.

As a caregiver, you will be able to provide your ideas.

INFORMATION

We would like to talk to youth between 10-19 years living at Lambano.

First, we would like to talk to the young people as a group for about an hour and a half.

Then, we would like to talk individually to about 5 youth. That conversation would also be for about an hour and a half.

Next, we will talk to **Lyn and the caregivers** from the houses and the hospital. This will also happen in a group and should also be for about an hour and a half.

We will write down what we hear and tape it all on my phone. When we write the information down, we will not use anyone's name. Instead we will use a number. This means that we can keep the information confidential and anonymous, so nobody's name is linked to what has been said. It means that you can trust that no one will ever know what you told us in the interview.

RISKS

We will only be at Lambano for a week. This is unfortunately a short time, so you may not get to know us very well.

It may be easy to talk about what is working well. It might be harder to say what is not working well. You might worry about what other people think. You might worry that if you say something that it will put your job at risk. I hope that the information shared will help build up Lambano further. But I cannot guarantee what might happen in the future based on what everyone says.

Another risk is that although everyone that joined in the group should keep what they discussed confidential, they might later say what was discussed here.

BENEFITS

There are many young people in the world who got HIV/AIDS from their mothers when they were born. There is though little information about what it means to be a young person and live as HIV positive. There is even less information about what it means to be HIV positive and to live in residential care.

1. Even though not many people will be part of this study, it can help the staff at Lambano know what they are doing well and how they can improve.
2. Lyn thinks it also will help Johannesburg Hospital because they want to do more to help young people living with HIV/AIDS.
3. It can help other young people in South Africa and in other countries also, because their caregivers, teachers, social workers, and medical team can learn from your experience.

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We will be the only person that will be working with the information. We will keep it in a safe place on my computer. In 5 years' time Jeanette will destroy all this information.

In the focus group, the participants must decide to keep whatever has been talked about in the group as part of the group and not tell anyone outside.

In our report for Lyn and the Board, and in anything else we write, we will include quotes of what you have said. We will not say you said it.

CONTACT

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FEEDBACK AND PUBLICATION

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CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature____ Date ____________________

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FOCUS GROUP AND INTERVIEW FORMATS

SCRIPT FOR FOCUS GROUP WITH YOUTH

Hi. Thank you for being here today. I am Jeanette Schmid/Jenita Chiba. I am a social worker and a researcher. I am part of the University of Johannesburg. I try to find out why things are the way they are and how things can be different.

Lyn wants to know what works well and what doesn't work so well and needs to be improved for young people at Lambano. I am helping Lyn to answer this question.

You are here today because you decided to be part of the study. The reason for this study is to hear about the way you as young people living with HIV/AIDS experience your lives. I also want to learn how you as young people feel about taking your medications. I want to find out if there are ways of better supporting you to take their medications regularly. Finally, I also want to learn what Lambano is doing well and what Lambano is not doing so well and where it can improve its work of supporting young people who are HIV positive.

You signed a paper to say that you are okay with sharing some of your experiences. But, you do not have to answer all or any of the questions.

I want to remind you that I am going to write down the things you say, and if you agree, I will also record them with my phone. I am not going to write down your names now or in my notes later. This means that what you say is not going to be linked to your name anywhere- your views are anonymous and confidential.

Of course, others in this group will hear what you are saying. Can we agree that what is said in this group is not going to be repeated outside?

I also want to tell you again what I am going to do with what I learn from you. First, I am going to write a report- without names, for Lynn and the Board. Then I am going to write an article (like a composition) about what I have learnt for a journal. This article, if it is printed, will be read by many people in South Africa and in other countries.

We hope that we can learn from what you tell me to

- improve what happens here at Lambano
- know what everyone at Lambano should carry on doing because it is right for you
- help Lynn and the caregivers understand how to help with the medications
- help other people in South Africa and elsewhere to understand what it means to be a teenager that is living with HIV/AIDS, especially a teenager living in residential care

Do you have any questions?

Is there anything that worries you about being here in this group?

At the end I will ask you to think about whether you would like to tell me a bit more about your experience, but just you and me without the rest of the group. If you are willing, we will make a time sometime this week.

We will spend about one and a half hours together today.

Now, I will ask you questions and you can answer them however you like.

1. Can you tell me a bit about what it is like to be a teenager?
2. Can you tell me what your daily routine looks like?
    a. Prompts:
        i. What do you do around the house you live in?
        ii. Where is school? What do you do at school?
        iii. Do you have friends? Are they all from school, or are some from here? Do you hang out with or visit friends after school?
3. What does it mean to live at Lambano?
    a. Prompts:
        i. How do you think living here is the same or different to somebody that lives with their family?
        ii. What is good about living here?
        iii. What is tough about living here?

4. How would you describe what it is like to live with HIV/AIDS?
    a. Prompts:
        i. How do you feel same or different from people your age who do not have HIV/AIDS?
            1. In terms of your health
            2. In terms of school
            3. In terms of friends
            4. In terms of boyfriends or girlfriends
            5. In terms of what you can do or cannot do
            6. In terms of thoughts about the future
            7. In terms of thoughts about the past
5. Can you tell me how it works with people taking their medications?
    a. Prompts
        i. What works well?
        ii. What does not work so well?
        iii. What would help?
6. What has helped you personally to manage to live with HIV/AIDS?
7. What do you think the caregivers and Lynn should know about your life at Lambano?
    a. What should they carry on doing?
    b. What should they do differently?
8. Is there anything else you feel I should understand?

Thank you for your time today!

SCRIPT FOR FOCUS GROUP WITH CAREGIVERS

Hi. I am Jeanette Schmid/Jenita Chiba. I am a social worker and a researcher. I am part of the University of Johannesburg. I try to find out why things are the way they are and how things can be different.

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- help Lynn and the caregivers understand how to help with the medications
- help other people in South Africa and elsewhere to understand what it means to be a teenager that is living with HIV/AIDS, especially a teenager living in residential care

Do you have any questions?

Is there anything that worries you about being here in this group?

We will spend about one and a half hours together today.

Now, I will ask you questions and you can answer them however you like.

1. Can you tell me a little about what your work involves?
2. From what you have observed, what do you think it is like for the young people of Lambano to be teenagers with HIV/AIDS?
    a. Prompts
        i. In which ways are they like their peers who do not have HIV/AIDS?
    ii. In which ways are their lives different?
3. What do you think works well at Lambano for the young people in your care?
4. What do you think are gaps at Lambano for the young people in your care?
5. What happens around the medication regimes?
    a. Prompts
        i. What works?
        ii. What are challenges?
        iii. What are consequences?
        iv. What do you think needs to be continued?
        v. What do you think needs to change?
6. How does this work affect you?
    a. How is this job different from other jobs?
    b. What is difficult about this job?
    c. What are positive sides of this job?
7. What helps you as a person to do this work well?

8. What works well for you here as a caregiver?
9. What would help you to do your work better as a caregiver?
10. Is there anything else you feel I should know or understand?

Thank you for your participation today!

SCRIPT FOR INDIVIDUAL INTERVIEWS

Thank you for meeting with me again. Earlier this week you shared some things about your experiences as a teen who is living with HIV/AIDS in Lambano. You also heard what some of the other young people had to say.

1. What do you want to make sure I understand about your experience?
2. Can I go through the questions we had in the group to see if there is more you would like to add?

Thank you for talking to me today!