Sanctuary or double-edged sword? Challenges confronting adolescents living at Nkosi's Haven in Johannesburg, South Africa

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Abstract

Living in an institution associated with HIV and AIDS is likely to exacerbate difficulties experienced by teenagers who have to cope with the normal stresses of adolescence. The aim of the study was to explore the challenges that adolescents living at Nkosi's Haven encounter and whether they experience any problems when interacting with their peers and other members of the community. The study was located within a qualitative research paradigm and utilised a purposive, non-probability sample of 15 participants recruited from two Nkosi's Havens. A semi-structured interview schedule was employed as the research tool, with in-depth one-on-one interviews adopted as the method of data collection. Thematic content analysis was used to analyse the data collected during the interviews. The main finding that emanated from the study was that Nkosi's Haven is indeed a place of care and nurturing as adolescents are afforded the opportunity to continue with their educational needs while basic and psychosocial needs are also addressed. However, it also emerged that rejection, discrimination, social exclusion and stigmatisation associated with the setting make it difficult for resident adolescents to integrate freely with their peers at school and in the community. The conclusion drawn is that Nkosi's Haven can be regarded as a double-edged sword as it presents both positive and negative factors that impact on its resident adolescents. Results are discussed in terms of their implications for community awareness programmes, policies and practice changes regarding employment and training of staff, and visiting of parents as well as future research.

Keywords: *HIV and AIDS, adolescents, stigma, discrimination, institutional care, orphanage*

Résumé

En vivant dans une institution qui est associée au VIH et SIDA; c'est probable d'empirer les difficultés que rencontrent les adolescents qui ont encore devant eux toutes les angoisses de l'adolescence. Le but de cette étude était d'explorer les problèmes que les adolescents du 'Paradis de Nkosi' rencontrent et aussi d'expérimenter des problèmes relatifs aux interactions avec leurs semblables ou même avec d'autres membres de la communauté. L'étude est menée dans un concept de recherche qualitatif et elle est utilisée comme une méthode scientifique. Apres que le prélèvement des échantillons auprès de 15 participants recrutés à partir de deux différents « Paradis de Nkosi »ait été fait; un programme d'interview semi-structuré était déployé comme outil de recherche avec comme support de profonds interviews à tête à tête adopté comme méthode de collection de données. Une analyse de contenu thématique était utilisée pour analyser les données prélevées durant les interviews. Le résultat principal tiré de cette étude était que 'le Paradis de Nkosi' est une place idéale pour les soins et de développement des pensionnaires surtout qu'à ces derniers il a été donné l'opportunité de continuer les études tout en ayant une prise en charge de leurs besoins psychologiques et sociaux. Cependant, il s'est aussi avéré que le rejet, la discrimination, l'exclusion sociale ainsi que la stigmatisation ont fait en sorte que les adolescents résidents se sont retrouvés devant des situations du genre difficultés d'intégrer librement la communauté ainsi que le milieu des amis à l'école. La conclusion tirée est que 'le Paradis de Nkosi' peut être considéré comme étant une épée à double tranchant dans ce sens qu'il présente à la fois des facteurs négatifs et positifs qui peuvent se répercuter sur les adolescents. Les résultats sont discutés en terme de leurs implications des programmes de connaissances; de polices et le changement de pratique concernant l'emploi et la formation du personnel, la visite des parents et aussi les recherches futures.

Mots clés: *VIH et SIDA, adolescents, stigma, discrimination, soin institutionnel, orphelinat*

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Introduction

Nkosi's Haven is a registered NGO and a place of safety in Johannesburg, South Africa, that was established with the aim of caring for mothers and children with HIV and AIDS. Founded by Gail Johnson, Nkosi's Haven was officially opened on 14 April 1999 and was named in honour of her foster son, Nkosi Johnson, who died of AIDS at the age of 12 years, and in memory of his biological mother, Nonthlanthla Nkosi, who was unable to care for him. Born HIV positive and prior to the advent of anti-retroviral (ARV) therapy, Nkosi Johnson was South Africa's longest surviving victim of AIDS, whose life was characterised by his brave fight for the rights of persons living with HIV (Nkosi's Haven, www.nkosishaven.org). Nkosi's Haven is committed to the policy of keeping mothers and their children together for as long as possible. It is the belief of the organisation that no mother should be separated from her child because of her HIV status. Moreover, the objective of Nkosi's Haven is to ensure that destitute mothers living with HIV and their children and orphans of HIV-positive parents have a safe, caring and dignified place to call home, equipped with acceptable living standards. Nkosi's Haven in Berea and Nkosi's Haven Village in Alan Manor, Johannesburg, currently cater for approximately 158 persons including mothers, teenagers, children, toddlers and babies (www.nkosishaven.org).

The problem that stimulated this research was the idea that adolescents residing at Nkosi's Haven were likely to be confronted with the situation of having to cope with the normal issues of adolescence and being accepted by their peers. However, in addition to these difficulties, it was anticipated that they might be required to cope with having a parent who was diagnosed with HIV and living in a residential setting associated with the virus. It was therefore expected that they might have to cope with stigmatisation, discrimination and social exclusion. While there is extensive literature on stigma and HIV (Lumbi 2007; Sontag 1989; UNAIDS 2003), there seems to be a paucity of research focusing on the stigmatisation of adolescents living in settings associated with the virus. Thus, the aim of the study was to explore whether or not Nkosi's Haven was perceived as a sanctuary or a double-edged sword by examining the challenges faced by adolescents living there. It was hoped that the findings of this study would contribute to bringing about awareness among social service professionals regarding the challenges experienced by these teenagers with a view to enhancing knowledge and intervention.

Literature review

The HIV and AIDS pandemic

According to the 2012 Global AIDS Report for South Africa, South Africa continues to be the world's capital in terms of HIV and AIDS, with 5.6 million South Africans living with the virus out of a population of approximately 46 million. Squire (2007) highlights the fact that people with HIV and AIDS can have more pressing issues in their lives than the virus itself, for example, struggles against poverty, unemployment, education and other health problems, which may take precedence. Nevertheless, the virus is a constant part of their lives because it presents certain medical and social problems, which include discrimination, rejection and stigmatisation. It is also argued that HIV and AIDS are no longer medical issues only, but also social justice issues that challenge all areas of life (Dube 2009). Moreover, those persons who are affected by HIV within families and neighbourhoods and who are HIV negative or who do not know their status may also have their lives shaped by concerns of HIV transmission and illness (Squire 2007).

Adolescents affected by HIV and AIDS

According to Erikson's life-cycle theory (cited in Ross & Deverell 2010:302), adolescence is characterised by the development of secondary sexual characteristics, while the task of adolescence is to establish independence and freedom from the family as well as to establish an identity and social role. Establishing a sense of identity is a complex process, which is influenced by significant adults within and outside the family. The peer group also assumes great importance and adolescents tend to want to be the same as their peers. Failure to establish an identity during adolescence can potentially lead to gender and role confusion and can hinder the transition from childhood to adulthood. The term 'AIDS orphans' refers to children who have become vulnerable because their parents or caregivers can no longer care for them because they either are very ill or have died as a consequence of HIV and AIDS (Department of Social Development 2003:33). In these situations, adolescents are often called upon to cope with the deprivation of childhood and the imperative to assume adult responsibilities as household providers and functional heads of households while still being children themselves (Louw & Joubert 2007). Furthermore, some adolescents end up nursing their terminally ill parents or siblings and others have to rely on already poverty-stricken extended family members for support and nurturing (Meintjes, Budlender, Giese & Johnson 2005). Normal developmental tasks of these adolescents become complicated due to the added stress brought about by their orphaned care status (UNICEF 2003) and the stigma associated with HIV and AIDS.

Social stigma

As early as 1963, Goffman developed what has become the benchmark social theory of the association between stigma and disease. Goffman (1963:13) described stigma as 'an attribute that is deeply discrediting' and is socially constructed on the basis of what society regards as being different or deviant (Green 2009). Ross and Deverell (2010) highlight the issue of dual stigma in the context of TB and HIV/AIDS, where it is argued that if someone is diagnosed with TB, the assumption is that this person is also HIV positive due to the dualisation of these two distinct diseases.

Scambler (2009) argues that stigma places a mark or label of disgrace or reproach on an individual and society still discriminates and stigmatises people due to HIV and AIDS. In addition, Parker and Aggleton (2003) state that much of what has been written about stigma and discrimination in the context of HIV and AIDS has emphasised the complexity of these phenomena and has attributed people's inability to respond to them more

effectively, to both their complex nature and their high degree of diversity in different cultural settings.

Scambler and Hopkins (1986, as cited in Green 2009) distinguish between enacted stigma and felt or perceived stigma, where enacted stigma refers to discrimination whereby sanctions are applied to people with a condition, whereas felt or perceived stigma relates to feelings of shame and oppressive fear of enacted stigma. Perceived stigma is said to be more prevalent in people living with HIV and predisposes the stigmatised persons to conceal their condition to protect themselves from experiencing discrimination (Green 2009). However, both perceived stigma and enacted stigma may have severe social consequences for people in terms of their rights, self-identity, freedom and social interaction, and both may have psychopathological effects that continue beyond the duration of the illness itself.

Evans (2010) elaborates on the different types of stigma. External stigma is the stigma from others directed towards people living with HIV and AIDS (PLWHA) and is characterised by avoidance, moral judgement, unwillingness to invest in PLWHA, discrimination and abuse. On the other hand, internal stigma is the response of the PLWHA to outside stigma and results in the PLWHA stigmatising themselves and is characterised by self-exclusion from services, alienation and social withdrawal, loss of identity, poor self-image, overcompensation and fear of disclosure (Evans 2010). Cameron (2006) describes the internalisation of stigma as the 'fear, self-disablement, feelings of contamination, self-rejection and self-loathing experienced by people with HIV and those who fear they have HIV, even when they know that they will receive support, protection, treatment and acceptance'. Secondary stigma is the stigma experienced by those associated with the PLWHA such as family and friends.

Furthermore, Green (2009) describes the several concepts that go hand in hand with the stigma trajectory. These include, but are not limited to, labelling, where human differences are noted and labelled; stereotyping, where labels are imbued with negative stereotypes; and othering, where labelled persons are categorised as 'other' or 'them' in order to clearly separate 'them' from 'us'. The trajectory of stigma further consists of status loss, where labelled persons are perceived by others and themselves as devalued and inferior; power reduction, where it is said that stigma can only emerge if there is a clear power differential between 'us' and 'them'; and finally discrimination, where labelled persons experience discrimination that subsequently leads to rejection, social exclusion and marginalisation (Green 2009).

Discrimination

According to UNAIDS (2003), discrimination follows stigma and involves the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination, together with stigma, can breach fundamental human rights and can occur at a number of different levels including political, economic, social, psychological and institutional levels. HIV-related stigma and discrimination build upon and reinforce existing prejudices and also play into and strengthen existing social inequalities – especially those of gender, sexuality and race (UNAIDS 2003). Discrimination plays a key role in producing and reproducing

relations of power and control, as it causes some groups to be devalued and others to feel that they are superior (UNAIDS 2003). Again, prejudicial and stigmatising thoughts frequently lead a person to do or not do something that denies services or entitlements to another person. For example, he or she may prevent persons living with HIV and AIDS from using health services or terminate their employment on the grounds of their HIV status (UNAIDS 2003). According to Lumbi (2007), loss of a family safety net due to HIV and AIDS may further deny children access to other social networks such as school, friends and community due to stigma and social isolation.

Discrimination occurs when a distinction is made against people that results in their being treated unfairly and unjustly on the basis of their belonging or being perceived to belong to a particular group (UNAIDS 2003). The human rights framework provides access to existing procedural, institutional and other monitoring mechanisms for enforcing the rights of PLWHA and for countering and redressing discriminatory action. According to UNAIDS (2003), appropriate reporting and enforcement mechanisms ranging from legal aid services to hotlines for reporting acts of discrimination and violence can provide a powerful and rapid means of mitigating the worst affects of HIV- and AIDS-related discrimination.

Moreover, discrimination can lead to depression, lack of self-worth and despair for PLWHA even though they are not the only ones at risk from the fear and prejudice (UNAIDS 2003). Ensuring that PLWHA also contribute to society can be an effective way of breaking the cycle of stigma and discrimination. In order to win the fight against discrimination experienced by those infected with and affected by HIV, there is a need to confront stigma and discrimination so that fear, shame, ignorance, labelling and injustice can be eradicated.

UNAIDS (2003) maintains that HIV and AIDS continue to ravage, mainly, the adult population of sub-Saharan Africa, leading to many children becoming orphans with little or no prospects of a real future. This scenario also leads to children, after the death of their parents, being shunted among relatives and extended families and finally being institutionalised for various reasons (Lumbi 2007).

Institutional care

Institutional care is a facility for the provision of residential care to more than six children outside the children's family environment in accordance with a residential care programme(s) suited to children in the facility (Children's Act No. 38 of 2005, amended in 2008). The Act further specifies that therapeutic programmes must be designed for children in such alternative care placements, with specialised programmes for vulnerable children such as those with physical and mental disabilities or chronic illnesses. Perumal and Kasiram (2009) conducted a study of children living in foster care and in children's homes and their findings showed that there were both positive and negative issues around staying in these two safety facilities. A lack of trained staff, negative peer influence and survival of the fittest were some of the highlighted concerns of living in children's homes.

However, another assumption was that although both foster families and children's homes may be inadequately equipped to deal with the challenges of children in need of care, children's homes may be better resourced by the State than many foster families to cope with vulnerable children, therefore challenging the dominant view of families always providing the best environment for caring for vulnerable children (Perumal & Kasiram 2009).

According to Altshuler and Poertner (2002), youth living in institutional care often take more risks, have more threats to achievement and have poorer peer influences. An interesting finding was that youth in their study tended to do well in terms of resilience, problem-solving skills and feelings of safety. However, Hobbs, Hobbs and Wynne (1997) maintain that many children in residential care tend to develop long-standing emotional, behavioural and learning difficulties, due to a distinct weak human resource component that exists in residential care. Furthermore, De Vos (1997) highlights the fact that children's homes were historically established for orphaned, needy and child victims of epidemic outbreaks; however, Perumal and Kasiram (2009) maintain that at present a child in a children's home tends to come from a life world characterised dysfunctional families, lack of appreciation, neglect, inadequate and destructive relationships, impaired communication and even ill-treatment and may require emotional support, which is not always available in residential care.

According to Perumal and Kasiram (2009), the ecological approach needs to be considered when placing a child in a children's home or with a foster family. The ecological perspective recognises interactions between people and their environments and focuses on wholeness, interdependency and complementarity in order to fully understand people (Perumal & Kasiram 2009). It is further argued that people act on their environments, thereby shaping responses of other people, groups, institutions and even the physical environment.

In relating ecological theory to child care, a child who is found to be in need of care in terms of the Children's Act 38/2005 and placed in an alternative care setting is removed from his or her natural environment (Perumal & Kasiram 2009). The child may be placed either in foster care or in a children's home and is expected to adapt to this change in environment in order to cope successfully and function in synchrony with this new system. However, if this adaptation does not happen, imbalance and stress are experienced (Perumal & Kasiram 2009). Therefore, it is of paramount importance to take cognizance of ecological theory as it provides an overarching framework for understanding child care in relation to the multiple influences that impact on the child and his or her care directly and in interaction with the environment (De Vos 1997). This theory is of particular relevance in understanding the needs of adolescents living in institutions catering for persons living with HIV and AIDS.

Methodology
Objectives
The objectives included eliciting (1) the adolescents' perceptions of the general attitudes and reactions of their peers and other members of the general public towards them; (2) whether they experienced any problems in interacting with other learners at school and members of the community; (3) their ways of coping with challenges; and (4) their views of the roles that social workers and other social service professionals play in equipping them with coping strategies.

Research strategy
The study took the form of an exploratory–descriptive research design located within a qualitative paradigm. The qualitative research approach 'is based on the interpretive perspective, which states that reality is defined by the research participants' interpretations of their own realities' (Williams, Unrau, Grinnel & Epstein 2011:53).

Population and sampling procedures
The targeted population was adolescents residing in residential settings associated with HIV and AIDS. The researcher used a purposive, non-probability sample of participants recruited from two Nkosi's Havens, one situated in Berea and the other in Alan Manor, Johannesburg. In terms of the inclusion criteria, participants needed to be adolescents between the ages of 14 and 19 years and they were required to be residents in one of the two Nkosi's Havens. However, finding participants willing to participate in the study, especially females, was somewhat challenging because some of them felt that even though they had participated in so many different research projects their conditions had not changed and they felt exploited and over-researched. It was noted that some of the participants were HIV positive, while others were not; however, the study did not require participants to disclose their HIV status. Saturation was reached after 15 participants had been interviewed.

Research tool
A semi-structured interview schedule was used to address the aim and objectives of the research. Issues that were explored during the interviews included the challenges of living in an institution associated with HIV, stigmatisation, rejection and social exclusion.

Pre-testing of the research tool
In order to enhance the instrument's validity and reliability, the researcher conducted a pre-test of the research tool with two persons who met the selection criteria but were excluded from participating in the final study. Recommended changes were incorporated into the final version of the instrument.

Data collection
In-depth, one-on-one interviews were utilised, and all interviews were conducted at Nkosi's Haven in an environment that was conducive to privacy and sharing. In order to establish rapport with potential participants, the first author spent some time explaining the purpose of the research and clarifying any issues raised. The interviews lasted between 30 min and 1 h and were conducted individually in the garden where there were minimal levels of disturbances and interruptions. Audio-taping of the interviews was conducted based on the participants' written consent. However, some of the participants did not agree to audio-tape recording, which might have led to the loss of very

important data as the researcher could not write down everything that they said.

Data analysis

Data were analysed using thematic content analysis and incorporated the steps recommended by Terre Blanche, Durrheim and Painter (2006), namely (1) *familiarisation and immersion*, which involved reading through the transcripts and interview notes many times, brainstorming and drawing diagrams; (2) *inducing themes*, which allowed for the identification of themes emerging from the participants' responses; (3) *coding* or marking different sections of the data in different colours as being instances of, or relevant to, one or more themes identified; (4) *elaboration*, which involved exploring themes more closely to ascertain whether some of them could be combined or broken down into sub-themes; and (5) *interpretation and checking*, where responses were interpreted and the categorisation of themes was checked with an independent researcher for correspondence.

Credibility, confirmability, dependability and transferability were also considered in order to enhance the trustworthiness of the qualitative data. According to Leininger (1994 in Maxwell & Satake 2006), credibility refers to the truthfulness, believability and the value of the researcher's findings in representing the real world as perceived by the participants. To enhance *credibility*, the researcher described the setting, targeted population and theoretical framework guiding the study. To enhance *confirmability*, the researcher made use of correspondence checking recommended by Pretorius and De la Rey (2004), whereby the categorisation of themes was checked by an independent rater. A limitation of the study related to the fact that in the qualitative data analysis, some themes were articulated by only one or two participants. *Dependability*, which is the qualitative equivalent of reliability (Lincoln & Guba 1985), was enhanced by having the same researcher (the first author) administer all the interview schedules, asking all the participants the same questions and following the same steps in analysing all the results. In terms of *transferability*, the small, non-probability sample precluded generalisation of the findings to the broader population of adolescents living in residential settings catering for persons with HIV and AIDS. However, since the study was qualitative and exploratory in nature, generalisation of the findings was not intended.

Ethical considerations

Ethical principles that were taken into consideration included the following: avoidance of harm to participants by offering debriefing sessions and gaining informed consent via an explanation of the purpose of the research and the rights of participants. Voluntary participation was emphasised and the participants were assured of their right to withdraw from the study at any given time without any negative consequences. Confidentiality and anonymity were respected by not including any identifying details in the report and subsequent publications. Permission to conduct the study and use the organisation's name was obtained from Nkosi's Haven. In addition, the research protocol was submitted to the university's ethics committee for ethics clearance and approval.

Table 1 Socio-demographic profile of the participants (N = 15).

Demographic factor	Sub-category	No.
Gender	Female	8
	Male	7
Age range	14–19 years	15
Racial group	Black African	15
Educational level range	Grades 8–12	10
	F.E.T College[a]	5

[a]Further Education and Training College.

Results and discussion

Demographic information

Table 1 presents the profile of the participants. Among the 15 participants who took part in the study, seven were male and eight were female, with English and IsiZulu being the primary languages of communication of all the participants. As the researcher could understand both languages, there was no need for an interpreter. In response to a recommendation made by one of the participants in the pre-test, specific ages were not requested, which constituted a limitation in terms of data analysis.

Reasons given by adolescents for living at Nkosi's Haven

The analysis of the findings revealed that seven participants were residents of Nkosi's Haven because of their mothers' HIV status and six of the participants had lost both their parents to the disease. However, it also emerged that one participant was living at Nkosi's Haven because of the failure of his caregivers to comply with medication requirements that led him to not taking his pills regularly as prescribed. He explained 'Sometimes my granny will forget to give me medication and this was problematic to my health and I was placed here at Nkosi's Haven'. Also one participant reported that she came to live at the agency in order to pursue her educational goals, indicating that Nkosi's Haven, even though primarily concerned with persons affected by HIV and AIDS, goes beyond HIV and AIDS in assisting vulnerable children and affirming their rights.

Number of years that adolescents had been living at Nkosi's Haven

Eight participants had been living at Nkosi's Haven for 6–10 years, while seven of the participants had been residents of the residential care centre for 0–5 years. This finding suggested that some teenagers had been residents of the care centre since its inception and also underscored the fact that the agency continues to provide long-term shelter to those infected with and affected by HIV and AIDS.

Perceptions of adolescents regarding living at Nkosi's Haven

When the perceptions of the adolescents regarding staying at Nkosi's Haven were analysed, the following themes emerged.

Gratitude and thankfulness
A theme mentioned by five participants was the notion of gratitude and thankfulness for being given a second chance in life after the death of their primary caregivers. This theme was starkly captured in the following response:

After the death of my father ... the only alternative that we had was to go to rural Eastern Cape to stay with my mother's distant cousins ... thus I thank being in this place because maybe I was not going to be able to continue with my education and I was also worried about my mother's health.

This response emphasises the harsh impact of HIV and AIDS on families, particularly when a breadwinner dies, and the struggle for survival intensifies especially if there are no contingent measures to guard against such occurrences. Whiteside (2002) highlights the complex relationship between poverty and HIV and AIDS, the breakdown of social support networks, households' reconfiguration and the increased dependency burden following the death of income-earning individuals.

Nkosi's Haven resembles a normal home
Four participants in the study commented that staying at Nkosi's Haven was not different from staying with one's family, as the place provides its inhabitants with their day-to-day requirements. The organisation was perceived to not only provide adolescents with shelter and accommodation, but also empower them by allowing them to continue with their education. This theme was encapsulated in the response by one participant who stated:

This place is just like a normal home for me and I find it quite interesting to stay here because all my needs are being taken care of, for example I eat, go to school, have clothes to wear and have a roof on top of my head.

This theme was consistent with the finding of Demmer (2004) that access to proper clothes and school uniforms appears to be a constant source of worry and humiliation for children whose parents or primary caregivers become ill or die of HIV and AIDS.

Bitterness, resentment and unanswered questions
Three participants indicated that Nkosi's Haven had affected their social status, and from the tone of their voices, they seemed bitter and resentful and were asking themselves questions that they themselves were unable to answer. These feelings were reflected in the following responses: 'You know, sometimes I ask myself that Why me? ... this place has reduced me to nothing' and 'I hate this place, and I hate it but there is no one who can look after me and provide me with all that I need in order to survive'.

These findings again highlight the issue of poverty and vulnerability of children orphaned by the AIDS pandemic and their dependency on organisations such as Nkosi's Haven for care and support, as alluded to by Whiteside (2002).

The place evokes feelings of worthlessness and powerlessness
The responses of three of the adolescents suggested that they felt powerless and worthless as they were unable to do anything for themselves due to the fact that they were placed in the care of Nkosi's Haven. They perceived Nkosi's Haven as a place where they were made to come face to face with real issues confronting them, including the fact that they were being cared for in an alternative care system, and were unable to be independent and self-sustaining. One participant commented: '... at my age some teenagers are independent and helping their parents but I can't even help myself and by being here makes me feel that I have no control of my life whatsoever'. In this respect, Santrock (2003) emphasises that adolescents should be viewed not simply as sexual beings but as individuals seeking to find out who they are and searching to find their niche in the world. There was a feeling among the study participants of restriction due to the absence of full support from parents who might be expected to be guiding these adolescents. In a study that was conducted in connection with child-headed households, Louw and Joubert (2007) highlighted the fact that the absence of a formal family decision about their future is a constant source of disappointment and humiliation for many adolescents in different alternative care systems.

It is of interest that when the responses to this question were compared with the responses to the question regarding feelings of being a resident at Nkosi's Haven, differences emerged between those who had only been there for a short period and those who had been living there for six years or longer. Those who had been there for a short period found the environment nurturing, and one participant commented: 'Ever since I had been here, this place is good and really caters for my needs as a child'. However, those who had been there for six years and longer expressed different feelings. One respondent said:

I feel I have no power for anything and I have been here for long yet I cannot do anything for myself ... relying on handouts and not being able to do something for yourself is very painful and it make me feel worthless.

It was initially expected that the longer a person stayed at Nkosi's Haven, the more he or she adjusted to the environment; however, the findings depicted a different picture.

Adolescents' views on the general attitudes and reactions of their peers and other members of the general public towards them

Two themes were identified in respect to the adolescents' views on the general attitudes and reactions of their peers and other members of the general public towards them.

Mixed attitudes, both positive and negative
The responses of eight adolescents indicated that they experienced both positive and negative attitudes and reactions from their peers and the general public. This theme was encapsulated in the following response:

Some of my friend's friends are sometimes gently and loving to me but sometimes I hear them back biting me with some of my classmates . . . and this confuses me because really I don't know what they think of me being a resident of Nkosi.

This finding highlights the fact that these adolescents from Nkosi's Haven experienced both positive and negative attitudes from their peers in their day-to-day interaction with them. Also reflecting this theme, one respondent commented: 'I lost trust to most of my classmates because one minute they are good to you and say good things and the other they say nasty things to you or about Nkosi's Haven'. These findings were consistent with Lumbi's (2007) assertion that children whose lives are affected by HIV and AIDS through illness or death of their parents suffer the consequences at emotional, social and economic levels. The inability to predict daily experiences was also highlighted by one participant who said: 'When I leave this place in the morning my mind will be not at ease as I constantly ask myself what is in place for me for the whole day and I rarely get to relax my mind fully'.

Supportive and empathetic

The analysis of the responses also revealed that 7 of 15 adolescents felt that they received support from their peers and that some members of the community, together with their peers, displayed a great deal of empathy towards them. One participant commented:

My friends are very supportive to me and sometimes they volunteer to the agency on weekends and they accompany me to the village when I visit my mother and you could see that they are doing it from their heart

and 'One of my friends said to me this is not your own problem but I am here for you, because who knows one day it might be me'.

In line with these findings, Santrock (2003) emphasises the need for peer support for adolescents, which is vital for their personal development from both a cognitive and an emotional perspective.

Challenges experienced by adolescent residents of Nkosi's Haven

The analysis of the challenges confronting teenage residents at Nkosi's Haven revealed the following themes.

Stigmatisation, social exclusion and concealment of the condition

The study also highlighted the fact that stigmatisation still played a major role in a context involving issues of HIV and AIDS. The participants spoke about feeling that they were not part of the broader community and needed to conceal their true identities for them to maintain their relations with those with whom they interacted outside Nkosi's Haven. This theme was encapsulated in the following responses: ' . . . I wish I had time to meet other people within this community and make friends so that I don't feel as if I live in a vacuum' and

. . . not even one person knows that I'm from Nkosi's Haven. They just know that I stay in a flat in town . . . I am not sure if they will accept me after I say that, so I better keep it to myself.

The responses seemed to suggest that these adolescents wished to integrate with other community members, but due to the fear of the unknown and the stigma attached to institutions associated with HIV, they needed to resort to hiding their identities. The fact that one participant had never disclosed or informed his colleagues about Nkosi's Haven is consistent with views expressed by Taylor and Field (2005), who argue that those who are stigmatised are confronted with a series of decisions about their spoilt identity, in terms of both their interactions with others and their own self-concept. This interpretation was also reinforced by one participant who said: 'I am very cautious about what I say and to whom I say it, because I don't know how people will react anymore. I can't afford to lose friends anymore . . . I need them more than they need me'. In addition, it emerged that by telling others that one was a resident of Nkosi's Haven, one could experience isolation and rejection, even by those who might have been close friends previously. This theme was illustrated by the following response. ' . . . sometimes they discriminate you and if they see you walking and talking to someone they can call him and leave you walking alone and that might be the end of your friendship too'.

These findings were similar to those documented by Lumbi (2007) in his study of the emotional well-being, social adjustment and coping strategies of orphans and vulnerable children affected by HIV and AIDS. He concluded that social exclusion usually results in the feeling of being cut off from familiar social contacts, leaving one with a belief that he or she is alone without anyone to rely on.

The stress of visiting parents at Nkosi's village

Four participants articulated the trauma that they go through when they visit their sick parents at the village, as illustrated by the following verbatim response:

Going to the village is one stressful and most traumatic thing for me . . . but I don't have a choice, I have to be there for my mother and show her all the support and love that she needs.

Another participant also reflected: 'Every time when I think of visiting my mother at the village, I sometimes cry and pray so that God Almighty gives me the strength'. This theme might be an indication that the process is traumatic and stressful, but at the same time these adolescents are faced with the duty of showing support and loving their mothers that they have to fulfil.

These findings underscore the fact that HIV affects not only those who are diagnosed with the virus but also those who are closely related to the infected person. In a similar vein, Ross and Deverell

(2010) posit that any stigma which society attaches to one person extends automatically to the person's close associates, as highlighted by one participant who stated, ' . . . Every time I visit I realise that her health deteriorates . . . and it's really difficult to watch your mother go through such a painful process'. This experience underscores the trauma for adolescents who are compelled to watch helplessly as their mothers' health condition deteriorates until the latter finally succumb to death. Furthermore, this finding indicated that in addition to the normal stressors associated with adolescence, these adolescent residents at Nkosi's Haven were required to carry the burden of additional stressors associated with having a parent who is living with HIV, as they struggled to achieve acceptance, belonging and social inclusion.

Gender-sensitive issues

Four male adolescents felt that they needed a male figure who would teach them about male issues as they sometimes found it difficult, if not impossible, to discuss some of their concerns with female staff, who ironically constituted almost all of the agency's staff in the Berea setting of Nkosi's Haven. This theme was illustrated by one participant who articulated the view:

> We are surrounded by a 100% female environment . . . as a growing up man, without a father figure to guide me, I feel let down because there are some things that I feel I should ask from a man but here 'kunama O-lady kuphela' (it's women) full time.

Due to the sensitive nature of these issues, these concerns were not probed further.

As this stage of psychosocial development is characterised by issues of identity and finding out who they are, there is a need for adolescents to have role models whom they can look up to so that they can shape and make informed choices about their future. Santrock (2003) argues that the other important dimension is the exploration of alternative solutions to roles, where career exploration becomes paramount. Hence, there is a need for male role models who can interact with these adolescents as they struggle to find their niche in the world (Santrock 2003). Also within many African cultures, it is unacceptable to discuss certain male issues with persons of the opposite gender (Delaney 2004).

The shame associated with the administration of ARV medication

The availability of the ARV therapy has been a welcome move to those living with HIV and AIDS. However, it emerged that there were also negative experiences associated with medication for adolescents residing at Nkosi's Haven. One participant commented:

> I hate medication and the manner in which it is administered . . . I know that I am on medication and I am supposed to take it on a daily basis . . . but when I delay taking it by a few minutes someone will shout your name even if you are with

other guys in the garden and this makes me feel so small and belittled.

This lack of sensitivity represented a violation of the adolescent's basic human rights to be treated with respect and dignity regardless of his or her health or HIV status.

Feelings of discrimination were also reflected in the words of another participant who said: 'Sometimes I am made to feel that I am not their daughter because they will not do this to their own children . . . well I know that I am positive but why is it supposed to be publicised like that'. This response appeared to contradict earlier findings about the perceptions regarding staying at Nkosi's Haven where four respondents described the setting as a place to call home, suggesting that the home provided both nurturing and hostile experiences for the adolescents.

Moreover, there is also the possibility that some of the participants might have furnished socially desirable responses to the earlier question, which might be a limitation of the study. Another issue that was raised by one participant related to medication and safe sexual practices, where he commented:

> I don't want to see myself on medication, but sometimes I feel that the restrictions are too much as we are not allowed to have our girlfriends to visit us and we are not taught about safe sex, instead we are to abstain but, till when . . . and I think it is putting these young boys and girls into risk of contracting the virus just like their parents.

Coping strategies

The analysis of the responses revealed that adolescent residents of Nkosi's Haven employed a number of ways to deal with these challenges that confronted them on a daily basis.

Making use of social service professionals and praying to God

Seven participants utilised the available resources at the agency and consulted with social service professionals, who included psychologists and social workers. However, these seven participants also relied on the power and will of God as a source of strength and inspiration. One participant commented: 'I told myself that I am here because of the power and will of God. Whatever problem I face, I pray to God and if it persists, I talk to the social worker'. The trust and belief in God differed from the findings of Louw and Joubert (2007), who noted that the young people in their study had ambivalent feelings towards God and the church.

Ignoring negative aspects and living a double life

Five of the 15 adolescents used denial and concealment as a means of coping with the challenges with which they were confronted, whereby they did not act on them while at the same time resorting to lying as a means of avoiding perceived stigma. To illustrate this theme, one participant commented: 'I live two different lives, if I am here at Nkosi's Haven I behave differently and if I go out I

change, and this keeps me going'. This response seemed to suggest that these teenagers faced difficulties in integrating and socialising with people from the community who did not live at Nkosi's Haven as they resorted to living a double life due to the fear of rejection and being labelled. UNAIDS (2003) states that to win the fight against discrimination experienced by those infected with and affected by HIV, there is a need to confront stigma and discrimination so that fear, shame, ignorance, labelling and injustice can be eradicated. However, it is understandable that exercising this option might be difficult for vulnerable adolescents who lack support systems.

Friends and family as a source of support

Three participants relied on friends and family as a source of support. This theme was illustrated by one participant who said: 'I only talk to my friend, because she is special and she understands me. I also trust that she won't gossip about my problem'. However, besides using friends as a source of support, trust also played a major role in the adolescents' choice of coping mechanisms; thus, they talked to someone whom they could trust so as to avoid disclosure of sensitive information. In support of these findings on coping mechanisms, Castrogiovanni (2004) asserts that the role played by peers in adolescence is critical as they help the adolescent to define his or her identity. However, the strain of being an orphan may complicate these relationships.

Perceptions of the roles played by social workers and other social service professionals in equipping adolescents with coping strategies
Counselling and education

The provision of counselling education was highlighted by eight adolescents living at Nkosi's Haven. It was noted that social workers and other social service professionals were perceived to be of great help to the adolescents as they provided them with a wide range of services including counselling and educating them on different techniques that they could use to deal with the outside world. This theme was articulated by one participant who said: ' . . . and they teach you skills of dealing with different things that I encounter out there, especially when I meet other learners from my school'. This finding confirmed that there were initiatives in place that were designed to help these adolescents to cope with different issues that they encountered. Counselling, according to Zastrow (2010), is also important as it covers almost all emotional and interpersonal problems that the client might be presenting. Also the provision of education helps to equip the adolescents with the necessary skills that might be of help to them when interacting with others.

Advocacy

This theme was reflected in the responses of 7 of the 15 adolescents who participated in the study. An example of this theme was encapsulated in the following response: 'You know... they arranged for an information session at my school and spoke on our behalf...in a bid to get us better treatment'. This response suggested that concerted efforts were being made to address issues, not only at the micro and meso levels but at a macro level as well. According to Zastrow (2010), social work recognises an obligation to advocate for the powerless, oppressed and the dispossessed, to eradicate discrimination and protect civil rights of service users. The profession is also committed to the belief that society has a responsibility in respect of all of its members to provide security, acceptance and satisfaction of basic cultural, social and biological needs.

Conclusions

The results from the study revealed that Nkosi's Haven was perceived as a home and a place of care, nurturing and safety as adolescents were afforded the opportunity to continue with their education while their basic and psychosocial needs were also being addressed. However, it also emerged that in addition to the normal stressors of adolescence, resident teenagers experienced rejection and stigmatisation associated with the setting, which made it difficult for them to integrate freely with their peers at school and in the community.

Implications
Community awareness programmes

Although there have been extensive awareness campaigns regarding HIV and AIDS, there is a need for innovative, culturally appropriate programmes that target the specific psychosocial needs of adolescents affected by HIV and AIDS, particularly those residing in residential settings, as ARV medication focuses only on the physical aspects of the disease (Mason, Carlisle, Watkins & Whitehead 2001). Such programmes need to involve both adolescents in the community and those in residential care centres so as to encourage integration and reduce the effects of stigma associated with living in an institution associated with HIV and AIDS.

Policy and practice changes regarding employment and training of staff and the issue of visiting of parents

In terms of gender issues, consideration needs to be given to changing policies regarding the type of social service personnel that are recruited. For example, there is a need to incorporate house fathers who can act as father figures to these adolescents. There is also a need for education regarding safe sexual practices for adolescents living at Nkosi's Haven. The findings from the study highlight the need to train and retrain staff on how to administer ARVs sensitively to infected adolescents so as to avoid eliciting feelings of dehumanisation, social exclusion and shame. It is also recommended that adolescents at Nkosi's Haven be given intensive support and opportunities to discuss their feelings about visiting parents – especially mothers – who are terminally ill.

Future research

The present study was based on a small, non-probability sample, which precluded generalisation of the findings to the broader population of adolescents living in institutions catering for persons infected with and affected by HIV and AIDS. Hence, the study needs to be replicated using larger, more representative samples in other residential settings in different parts of the country in order to compare findings. Some of the teenagers highlighted the fact that they needed to conceal from the broader community the fact that they lived at Nkosi's Haven; hence, it is important to study the impact of living with dual identities on

the psychosocial development of adolescents. Another fruitful area of research would be to explore the sexual or 'manly issues' alluded to by respondents and which could not be discussed with female caregivers. It is further recommended that research focus on the perceptions of community members regarding institutions that cater for persons infected with and affected by HIV and AIDS, so as to come up with intervention strategies that can help reduce stigma, discrimination and social exclusion and promote acceptance and social inclusion.

Concluding comment

In conclusion, it would seem appropriate to revisit the words spoken by Nkosi Johnson when he addressed delegates at the 13th International AIDS Conference held in Durban in July 2000. He made the following plea:

Care for us and accept us – we are all human beings. We are normal. We have hands. We have feet. We can walk, we can talk, and we have needs just like everyone else. Don't be afraid of us – we are all the same.

While these words inspired the world to de-stigmatise HIV and AIDS, eradicate discrimination and promote social inclusion and acceptance, it would seem to be a sad indictment on our society that a decade after the passing on of Nkosi Johnson, communities still isolate, stigmatise and label persons infected with and affected by the virus. At the same time, one needs to acknowledge that not all the young people in the study felt stigmatised and discriminated against and in fact seven of them talked about how much support and empathy they received from peers and the community. Hence, we need to highlight the contradictory and mixed experiences of adolescents living in institutional settings such as Nkosi's Haven and the challenges that these experiences pose for their psychosocial development.

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