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## Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa. A qualitative investigation

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### Abstract

**Introduction**—While the roll-out of ART in South Africa should lead to a reduction in mother to child transmission (MTCT), mortality and orphaning, it will also be accompanied by a large number of children entering adolescence and adulthood with a chronic infectious disease. Adolescence is a particularly vulnerable period for HIV-infected people in relation to mental health problems and engagement in high risk behaviours, including non-compliance with medical treatment. The goal of this qualitative study was to develop an understanding of the psychosocial challenges as well as protective influences promoting socio-emotional coping in HIV+ adolescents in order to inform mental health promotion and HIV prevention programming for this population in South Africa.

**Method**—In-depth qualitative interviews were conducted with HIV+ adolescents (25) and caregivers of HIV+ children (15) at a large HIV/AIDS Clinic in South Africa. Data were analysed thematically using NVivo8 software.

**Results**—Psycho-social challenges for adolescents included dealing with loss of biological parents in the case of orphans; coming to terms with their HIV+ status including identity difficulties; external stigma and discrimination; and disclosure difficulties. For caregivers, disclosure and lack of financial, family and social support emerged as key challenges. Medication, HIV information, a future orientation and social support was identified as important for coping and general well-being of adolescents, with financial and social support emerging as key for promoting supportive caregiving contexts.

**Conclusion**—While HIV+ adolescents in South Africa experience similar concerns to those in high income countries, socio-emotional coping may be compromised by increased levels of loss due to the late rollout of ARVS and challenges to caregiving contexts including poverty, stigma and minimally supported foster care arrangements. There is a need for mental health promotion programmes for adolescents to adopt an ecological approach, strengthening protective influences at the individual, interpersonal, community and policy levels.

### Keywords

HIV-infected; adolescents; mental health promotion; HIV prevention; South Africa

## Introduction

It is estimated that 90% of children in sub-Saharan Africa aged 0–14 years and living with HIV are infected through mother-to-child transmission (MTCT) (WHO/UNAIDS/UNICEF, 2008). The recent roll out of antiretroviral therapy (ART) in South Africa should reduce MTCT, mortality, and orphaning. While in 2006, 73% of HIV+ pregnant women received ART for PMTCT (UNAIDS, 2008), a relatively high proportion of infants in South Africa are still vulnerable to HIV infection prenatally as well as during childbirth. Further, postnatal vertical infection through breastfeeding is a further risk (Ferrand et al., 2009). While the roll-out of ART in South Africa promises a longer lifespan for infected children, as in other countries with longstanding access to ART, it will, however, also lead to a growing number of HIV+ children entering adolescence with a chronic infectious, and highly stigmatized disease.

Preliminary work from the United States (US) suggests that HIV+ youth are at risk for health and mental health problems, as well as substance use, early sexual debut and unprotected sex which presents a public health concern (Havens & Mellins, 2008; Ledlie, 2000; Mellins, Brackis-Cott, Dolezal, *et al.*, 2006). Adherence to ART is also a challenge for HIV+ adolescents given their changing developmental stage, partial reliance on caregivers, interference with daily routines, peer affiliation needs, and complex dosing regimens, all of which may lead to increased non-adherence, and ultimately ART resistance (e.g., Bikaako-Kajura et al., 2006; Havens & Mellins, 2008; Reddi et al., 2007).

Compared to the US, HIV+ children in South Africa may be exposed to greater risk influences for emotional and behavioural problems, including poverty and family disruption as a result of the ramifications of apartheid and the loss of one or both biological parents to AIDS due to the late roll-out of ART. International studies consistently link parental loss to poor child mental health (Atwine, Cantor-Graae & Bajunirwe, 2005; Kranzler, Shaffer, Wasserman, Davies, 1990; Makame, Ani & Grantham-McGregor, 2002). A recent study of South African children who had lost their parents to AIDS showed elevated rates of PTSD, depression, conduct problems, and delinquency in orphans compared to controls (Cluver, Gardner & Operario, 2007). These problems were mediated by the experience of AIDS related stigma (Cluver, Gardner & Operario, 2008).

Given the growing population of HIV+ children who will reach adolescence in South Africa, there is a need for targeted mental health promotion and HIV prevention programmes. However, there are few efficacy-based interventions designed for this population, and limited data on the psychosocial needs of South African HIV+ youth to inform such programs. The goal of this study was thus to examine the psychosocial challenges and protective factors for adolescents and their caregivers affected by paediatric HIV within the socio-cultural context of South Africa with the aim of using the data to inform mental health promotion and HIV prevention interventions for this population.

## Method

### Site

The study site was an urban-based hospital in the city of Durban in the KwaZulu-Natal province of South Africa. KwaZulu-Natal has one of the highest HIV prevalence rates in the world (UNAIDS, 2008). The hospital has a large HIV/AIDS clinic that provides voluntary counselling and testing, medical treatment, and support services to children and adults. There were 755 children (0–14 years) enrolled for HIV care in January 2008 when this study commenced.

## Sample

Purposive sampling of clinic attendees was used to recruit HIV+ youth and their caregivers independently at the clinic. Eligibility criteria for youth were that they had to be HIV+, know their status and be 14–16 years of age; for caregivers they had to be caring for an HIV + adolescent, who may or may not also be participating in the study. Participation of all stakeholders was voluntary. A stipend equivalent to US \$9 was given to the participants to cover transport costs. The research officer who was a registered clinical psychologist recruited the participants. There was 100% participation rate of eligible participants approached to be part of the anticipated sample (n=25 youth; 15 caregivers). The sample demographics are contained in Table 1.

## Data collection

Qualitative individual interviews were conducted by the research officer with each participant (25 adolescent and 15 adult caregivers) in an office at the clinic in either isiZulu or English, depending on participants' home languages. A range of topics were covered, including major psychosocial challenges for HIV+ adolescents (e.g., stigma, discrimination, disclosure, adherence, identity issues, peer pressure, and general stress) and coping mechanisms. Participants were asked to provide written consent (adults) or assent (children). All interviews were recorded with the permission of respondents. The English interviews were transcribed verbatim and isiZulu interviews were translated and transcribed into English, with back-translation checks by an independent bilingual English-isiZulu speaker. The study received approval from institutional ethics review boards at the study site and from the US collaborating institution.

## Analysis

The data were analyzed thematically using NVivo8 software. The data analytic process involved 1) Immersion in the transcriptions; 2) development of a thematic coding framework comprising the major codes, based on the interview questions for each stakeholder group as well as new emergent codes; 3) coding; and 4) separate comparative analysis of the coded responses across respondents for adolescents and for caregivers (Terre Blanche & Kelly, 1999). Finally, where the two stakeholder groups reported on the same issue, emergent themes were analysed in relation to the perspective of each stakeholder group. Preliminary themes and results of the study were validated at a participants workshop which provided extensive feedback and clarified themes.

## Results

The critical emergent themes relating to psychosocial difficulties and socio-emotional coping are described below.

### Psycho-social Challenges

**Loss of biological parents**—Over half of adolescents interviewed were orphans (n=16). Loss of biological parents was emotionally painful for 80% of the orphaned participants. When interrogated further about what was painful about the loss, current circumstances as well as the circumstances surrounding the loss of their parent/s appeared to influence how they experienced the loss. Worrying about who was going to care for them, loss of someone who loved them, as well as families fighting over them emerged as sub-themes as reflected in the following quotations.

I felt stressed because my parents had passed away I thought there won't be anyone to look after me. Luckily I was able to find someone who is helpful like my aunt (participant 2, male adolescent).

R: If my mother was still alive maybe it would be alright.

I: You said if your mother was still alive things would not be happening the way they are now. Is there anything that you think would happen differently if your mother was still around?

R: Yes.

I: What is that?

R: Like love (participant 24, male adolescent)

Of the three who did not experience the loss of their biological parent/s as painful, two indicated that their parent/s had died such a long time ago that they could not remember them, and one indicated that his mother was an alcoholic so he was never close to her.

**Disclosure of HIV+ diagnosis**—For almost all adolescent participants (22), receiving their HIV+ diagnosis was also emotionally difficult. Of the three who indicated that they didn't experience it as difficult, one indicated that she was too young and didn't really understand, and the other two indicated that as a result of their parent/s being HIV+, they were very well informed about the disease and did not see it as a terminal illness as suggested in the quotation below.

I: Were you expecting it?

R: No, you know I already knew about the virus, I already knew it was nothing

I: And what made it easier for you?

R: Education you know, my knowledge...

(Participant 6, adolescent female).

A common response of those who experienced emotional difficulties was distress at feeling alone in the world with the disease. Further, a perceived foreshortened future related to a lack of information about treatment as well as a sense of loss at not being able to lead a normal life was reported:

It upset me because at that time I did not know very well what HIV is and I had not learned about it so I only knew that someone with HIV dies, you see so it really upset me that I was going to die, it really upset me.(Participant 19, adolescent female).

it's like the cloud ...it's trying to block me from seeing the sunlight, the sunshine, and the happiness, like you always uncertain...you are sad and... maybe in the future I've got a girlfriend and she finds out...we will split.(participant 9, adolescent male)

Further, a number of children's family circumstances (8) did not permit them to express their distress because of AIDS related stigma in the family as reflected in the following quotation.

As I found out in 2006 I did get stressed but I did not show/tell them anything at home I just kept quiet because I did not want to talk... even when they asked me what is wrong I told them nothing was wrong, even when they said but I love talking I told them that I don't love talking anymore. (Participant 2, adolescent male).

The caregiver interviews revealed that disclosure to a child about their status was easier if the caregiver was also HIV+ which was the case for 6 of the caregivers interviewed (40%). They typically used themselves to show the adolescent that they could lead a healthy life.

When I started to talk to him I give him the example using myself, I said you see I am HIV and I am living. I was young when I was diagnosed with HIV. I am telling him this so that he can accept it better by knowing that HIV is not a death sentence. It does not mean that when you are HIV positive you are already dead but you can live longer if you accept your condition. He has accepted it, he does not have a problem. (Participant 36, caregiver, aunt).

For the other caregivers, having a health care provider assist in disclosing to the child proved helpful, with 18 (72%) of the adolescents interviewed indicating that they had been told of their positive status by a health care provider.

**Identity issues**—A related difficulty for adolescents upon finding out about their HIV+ status was coming to terms with an HIV+ identity. Thirty six percent of adolescents (9) reported that they withdrew from their friends and social activities on finding out their status. Feeling ‘different’ to other youth, even though they wanted to be normal was commonly reported.

I don’t know what it is I couldn’t accept it until after a long time, maybe after some months...I just couldn’t accept it because sometimes I would be sitting with other children and I would feel like I am different from all of them... even now there is still that but I have tried to forget about it, but it’s hard. (Participant 3, adolescent female).

A few caregivers (3) also reported encouraging their children to stay at home as this was also one way they could protect their children from exposure to risk behavior, but this also emphasized their difference.

Internalized stigma was evident in over 50% of adolescent participants (13) who felt uncomfortable when people were talking negatively about HIV+ people, internalizing these negative attributions as reflected in the following quotes:

the year before last I was in an Indian school ...and the teacher’s said only black people had HIV the most and ...I just got up, there was just like a push and I felt like he was seeing the inner me... (Participant 17, male adolescent).

Sometimes it’s difficult for me to cope with it. Like at school they say bad things about HIV and all those things and sometimes you find that I will be hurt... (participant 23, female adolescent).

Linked to these identity issues were concerns about heterosexual relationships. Only 6 adolescent participants indicated that they had a girlfriend (3) or boyfriend (3), with two choosing partners who were also HIV+. There was a general concern about how to negotiate future heterosexual relationships as reflected in the following quote.

“we teenagers sometimes it’s hard for us, because we always ask ourselves that what if... we fall in love with someone and we want to marry the person and it’s hard...where, are you gonna... start and tell that person about your status that you are HIV+ and everything. And maybe you will love that person and maybe that person will just leave you like that...” (Participant 13, female adolescent).

**External Stigma, discrimination and disclosure to others:** Just over half (13) of the adolescent participants had not disclosed their status beyond their immediate care-giving family for fear of stigma and discrimination, with disclosure beyond the family normally

involving the school (10) and/or one friend (3). In the context of widespread stigma and discrimination, disclosing beyond the immediate care giving family emerged as an issue that needs careful consideration for both adolescents and their caregivers. It could have positive consequences in affording greater support, or negative consequences of increasing stigma and discrimination. Disclosure to teachers was reported by both adolescents and their caregivers to mostly provide greater academic support with the school being more understanding of the child's situation. Only 4 adolescent participants' expressed difficulty with having experienced external stigma and discrimination. In one instance, the teacher had not been informed and ridiculed the child for frequently attending clinics. In the three other cases, positive status had been revealed via malicious gossip or rumor as a result of having an HIV+ mother or friend. Stigma and discrimination was experienced in the form of insulting comments and exclusion as demonstrated in the following excerpt.

They say look at how skinny she is, she is sick, she has AIDS. Look at how her head is heavy for her... our friends are slowly moving away from us (participant 10, female adolescent)

**Poverty**—While only a couple of adolescents indicated that they lacked money to attend the clinic regularly, a third of caregivers (5) complained that poverty reduced their capacity to adequately care and protect their HIV+ children. They mostly complained about not having sufficient funds to provide nutritious food as well as transport for medical checkups and medication, with two caregivers also indicating that their girl children were vulnerable to being abused by men in exchange for money.

It is because (crying) I sometimes get short of the money... it is sometimes so difficult for me to come and collect her medication because of the lack of money... I am unable to buy the right food for her because she has a special diet since she is sick (Participant 39, caregiver, mother).

Moreover, in the context of poverty, the burden of care was increased for those who lacked sufficient support as reflected in the following quotation.

Like those days where he becomes very sick maybe for a day, you have to stay with him since his sisters are working...you have stay with him and look after him, and if you had some plans you have to put them on hold because you cannot just leave him alone (Participant 35, caregiver, aunt)

## Positive socio-emotional coping

### Medication, information and future orientation

At the individual level, adolescents uniformly cited the availability of life prolonging medication as assisting them to cope with their HIV+ status. Linked to this was counseling and information on medication and importance of adherence.

I: What made it possible for you to be able to accept and move on with your life after finding out that you were HIV+?

R: ...Like now I believe in the medication that we are given and with counseling... I now understand ...that if I take the medication in a proper way...I will live. (Participant 3, female adolescent).

All adolescent participants as well as caregivers indicated good adherence, with caregivers being identified by both participant groups as playing an important supportive role in reminding adolescents, who at times did forget.

Also at the individual level, a couple of adolescent respondents indicated how positive thinking and having goals for the future helped them to cope and suggested that instilling these in other children may be useful, as reflected in the following quotation:

maybe you can talk about... what you need to do to succeed in life, because there are people who are sad because they have HIV+. So us who are older maybe we can talk to them and give them hope because even myself when I first came here I did not have hope. (Participant 23, adolescent female).

### Family, peer and community support

At the interpersonal level, family and peer support emerged as key to assisting adolescents to cope. Five adolescent respondents who indicated that they received little family social support displayed either emotional numbing or reported behavioural or emotional problems, including suicidal thoughts and aggressive behaviour. Adolescents who had strong family social support, appeared to cope better. It also appeared that having more extensive supportive networks was associated with better coping with HIV. In this regard, the support group and counseling service provided by the hospital emerged as a very important community resource, providing adjunct support in addition to family support. This service afforded the opportunity to talk to counsellors about issues, such as sex, that they could not talk to their caregivers about. Further, being with other HIV+ children was reported to be particularly helpful as the youth could see other HIV+ children living healthily and did not feel alone.

It's because at home they gave me support all the support that I need, they showed me that they care about me, and then when I got to (hospital) and I met (counselor) ... and then my life went well...here at (support group) they really helped me because when I came here I would see that there were children who say that they have had HIV for more than five years but they still live with it and they are healthy you see that...(Participant 23, female adolescent).

The service was also helpful in mediating coping outcomes in a positive direction for those with weak family support as reflected in the following quotation from an adolescent who experienced an unsupportive discriminatory home environment.

R: I do not enjoy life sometimes. I feel like it would have been better if I also died...

I: So what would stop you from doing it as you said you do not enjoy life?

R: Talking to the aunts (counselors). Participant 20, adolescent female).

In addition to the need for financial assistance, supportive home environments also emerged as important in helping caregivers to cope with the task of caring for an HIV+ child. Those caregivers (3) who were experiencing difficulty in coping were either living on their own with their children or in an unsupportive family arrangement. They expressed the need for a support group for themselves as reflected below.

...we just need a support group and I don't know how it can be done. Some people believe they can just sit at home and cry which does not help, I know I have cried and I am still crying and have not found help yet (participant, 36, caregiver, mother).

## Discussion

Previous studies from high-income countries with longstanding access to ART have indicated that HIV+ adolescents are at particularly high risk for experiencing stressful life

events and emotional and behavioural problems (Havens and Mellins, 2008; Ledlie, 2000). Our data suggest that South African HIV+ youth have similar stressful experiences and emotional challenges. The loss of biological parents due to AIDS as well as associated poverty and stigma in the context of minimally supported foster care arrangements are likely to magnify the risk for poor outcomes.

Having to cope with the loss of biological parents due to AIDS emerged as a key emotional challenge that amplifies the stress experienced by HIV+ children in South Africa. Over half of adolescents interviewed were orphans. Further, a sense of loss at not being able to lead a normal life as well as a perceived foreshortened future was experienced by the majority of youth, with some not being able to express their distress because of AIDS related stigma. Expression of grief for a loved one and loss in general is a normal aspect of the bereavement process across all cultures and being unable to express one's distress can result in "disenfranchised grief" (Doka, 2002) which has been associated with physical and mental health problems (Parkes, 1998).

Similar to previous work (Havens & Mellins, 2008; Doningberg & Pao, 2005), HIV+ adolescents in this study had difficulty incorporating a chronic and stigmatizing illness into a healthy identity. Identity development is a key psychosocial developmental task during adolescence, often based on social comparisons (Coleman & Hendry, 2002). Studies have reported that persons living with HIV often incorporate negative stigma into their sense of self, resulting in internalized stigma associated with being a member of an 'outgroup' (Joffe, 1999). Our data indicates that over half of HIV+ adolescents interviewed demonstrated internalized stigma and may be at risk of developing a 'spoiled identity'.

Further, our data suggest that a common response to receiving their HIV+ diagnosis was to withdraw from previous social groups and activities. This has the potential to result in social isolation. Peer support groups for HIV+ youth emerged as important for providing alternative protective peer networks as has been found for this population in other countries (McKay et al., 2006).

Further, as is the case in other countries (Weiner et al., 2007), disclosure beyond the immediate caregiving family was a key concern for infected children and their caregivers due to stigma and discrimination. Disclosure to schools by caregivers generally resulted in greater academic support for the HIV+ adolescents. Disclosure through gossip and rumour, however, had the potential to result in stigma and discrimination.

Similar to previous work (cf. Breinbauer & Maddeleno, 2005), factors that emerged as helping adolescents to cope with their HIV+ status included HIV information, a future orientation as well as family and peer support. A review of the role of families in adolescent HIV prevention reveals that adolescents with low levels of parental and family support are more likely to engage in sexual risk behaviours (Perrino et al., 2000). Atwine, Ani and Grantham McGregor (2005) found that access to support groups was predictive of higher levels of self-concept amongst AIDS orphans in Uganda, helping to reduce feelings of stigmatization and shame.

The importance of financial support and supportive family environments in helping caregivers to cope with caring for an HIV+ child also emerged as important findings of this study. The need for support groups for caregivers, particularly for those who do not have supportive home environments, is highlighted. The psychosocial impact of caring for people living with HIV on informal carers, is receiving increasing attention in South Africa and elsewhere, with stigma and discrimination as well as isolation and lack of support contributing to caregivers' distress (Akintola, 2006, 2008; Orner, 2006). Caregivers, who are often relatives and grandparents, may require their own therapeutic interventions to address



issues of loss and bereavement, as well as family or support based interventions to strengthen the protective influence afforded by a caring and supportive caregiver-child relationship.

## Recommendations

The results suggest that in order to promote socio-emotional coping in HIV+ adolescents, mental health promotion and HIV prevention programmes in South Africa would benefit from an ecological approach that strengthens key protective influences at the individual, interpersonal, community and policy levels as suggested by Earls et al. (2008). At the individual level, there is a need for interventions to help HIV+ adolescents develop a positive sense of self that is not based only on their HIV+ status. Youth with stronger self-concepts report fewer emotional problems, engage less in sexual and drug-use risk behaviour, and perform better in school (Breinbauer & Maddeleno, 2005). Helping adolescents to set goals for themselves, including non HIV-related goals, would be useful in supporting positive identity development through the formation of an 'ego ideal' that adolescents can envision and strive towards.

Given that social identities are formed in relation to others, developing a healthy social identity for HIV+ adolescents also requires the involvement of peer social groupings at the interpersonal level that can challenge the pervasive negative attributions projected onto HIV + people. Given the dominance of collectivist cultures in Africa, where the self is defined in relation to others, the importance of others in the development of identities is amplified. Support groups were reported to be particularly helpful by HIV+ adolescents in this study. They can provide a reference group which promotes health enhancing behaviours and where HIV+ adolescents can develop healthy identities which are not tainted by stigma or a sense of difference. The development of social networks for HIV+ people also affords the opportunity for individual social capital in the form of social support and social leverage as well community social capital (Carpiano, 2006). Through the latter, members of HIV+ social networks can begin to collectively challenge stigma and discrimination at a community level and fight for the rights of HIV+ people, exemplified by the Treatment Action Campaign in South Africa.

Also at the interpersonal level, group-based psycho-social support interventions for caregivers, could help them manage the stressors related to caring for infected children. Strengthening support for caregivers is particularly important in low resource settings where studies have found multiple competing demands on parents' time compromises their emotional and physical availability (Barbarin, 2003; Govender & Moodley, 2004; Paruk et al., 2005). In these contexts, support networks have been found to assist in strengthening protective parenting through increased social support and informal social controls at a community level (Paruk, Petersen & Bhana, 2009).

At the community and policy levels, given the high levels of stigma associated with HIV, it is important to encourage the development of youth-friendly reproductive and health services which include counselling and mentoring services for HIV+ adolescents that provide opportunities to develop future life goals discussed at the individual level. Further, clinics and hospitals need to provide resources for the programmes discussed at the individual and interpersonal level that aim to assist youth to develop positive self concepts as well as strengthen peer, caregiver and family support networks. Moreover, while foster care grants are available in South Africa, the burden of caring for an HIV+ child is far greater than for a healthy child and extra financial support for carers of these children needs to be considered at a policy level.

## Conclusion

There are several limitations to this study, including the use of a convenience sample already involved in medical care and support services. The use of a treatment facility that is better resourced than most government hospitals may also have biased the range of clients who use the facility and their experiences. Nevertheless, we believe that this exploratory study has assisted in understanding the plight of HIV+ children and their caregivers living in South Africa. While the findings suggest that they experience similar concerns to those from high-income countries, including issues related to identity development and disclosure, the South African context of a late rollout of ARVs has exacerbated issues of loss and bereavement for HIV+ adolescents who have lost their biological parent/s. Further, for caregivers, the stressors of caring for HIV+ adolescents are amplified by a context of minimally supported foster care arrangements, poverty and stigma.

These findings indicate the need for mental health promotion and HIV prevention programmes for HIV+ youth in South Africa to move beyond the dominant individual level prevention interventions that characterize most youth HIV risk reduction interventions, towards strengthening protective influences within families and communities. Cluver et al. (2008) came to a similar conclusion with respect to suggestions for psychosocial interventions for non-infected AIDS orphans. One notable family-based programme for infected youth in the US, which has the potential to strengthen protective influences at all levels, is CHAMP+ (McKay et al, 2006). This programme has been successfully adapted for non-infected youth in South Africa with good effects (Bell, Bhana, Petersen et al., 2008; Paruk et al., 2009; Petersen, Mason, Bhana, Bell & McKay, 2006) and may serve as a model for HIV infected youth as well.

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**Table 1**

## Sample Demographics

<b>HIV+ Adolescent (n=25)</b>		
<b>Gender</b>	Female	12
	Male	13
<b>Orphan status</b>	Orphan	16
	One/more parents living	9
<b>Current caregiver/s</b>	One or more biological parents	9
	Grandparent/s	7
	Aunt and/or uncle	7
	Children's home	2
<b>Caregiver Participants (n=15)</b>		
	Biological mother	5
	Grandmother	2
	Aunt	5
	Uncle	1
	Children's home caregiver	2