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## Psychological functioning among vertically infected HIV-positive children and their primary caregivers<sup>†</sup>

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### ABSTRACT

The current study sought to explore the association between primary caregiver depressive symptoms and the psychological functioning in children vertically infected with human immunodeficiency virus (HIV) living in Eastern Cape, South Africa. A cross-sectional data were collected using the Beck Depression Inventory and Strength and Difficulties Questionnaire in a sample of 152 caregiver/child dyads. The results revealed that poorer psychological functioning in children was significantly associated with depressive symptoms in caregivers. This relationship existed whether or not the child was raised by a biological or non-biological caregiver as well as for both genders. Younger children's psychological functioning was more negatively influenced than that of older children raised by a caregiver with depressive symptoms. In the context of a large treatment gap for common mental disorders in South Africa, there is a need for interventions to address maternal mental health in families infected and affected by the HIV/AIDS pandemic as a mental health promotion strategy given that HIV-infected children are a particularly vulnerable population for poor mental and behavioural health outcomes.

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## Introduction

Worldwide HIV/AIDS disproportionately affects women of childbearing age and children from resource-limited backgrounds. South Africa is estimated to be home to 6.1 million people infected with HIV of which approximately 410,000 are children between the age 0 and 14 years (WHO/UNAIDS/UNICEF, 2013). Furthermore, approximately 250,000–300,000 newborns are exposed annually to HIV and thus at risk of being infected through mother-to-child transmission (WHO/UNAIDS/UNICEF, 2013). While progress has been made to identify infants who became infected through mother-to-child transmission, many children with HIV still go undiagnosed (WHO/UNAIDS/UNICEF, 2013). Those children who are diagnosed early gain early access to antiretroviral treatment and have a better chance for survival deep into adolescence and adulthood (Jeremy et al., 2005).

However, while it is encouraging to note that with the improvement of medical treatment and dissemination of antiretroviral medication, HIV/AIDS-infected children have a chance for a prolonged and better life expectancy; the emerging associated psychopathology, neuropathology

and psychosocial complication nevertheless pose serious implications (Antinori et al., 2007; Lentoor, 2006). Paediatric HIV is now viewed as a chronic illness characterised by a progressive course of symptomatic periods of acute illness and possible developmental and psychological disabilities (Bachanas et al., 2001b).

Research has shown that children living with a HIV-positive caregiver are at increased risk for a wide range of emotional and behavioural problems that impact on school readiness and success of these children (Bauman, Silver, Draimin, & Hudis, 2007; Brackis-Cott, Kang, Dolezal, Abrams, & Mellins, 2009; Knitzer, Theberge, & Johnson, 2008; Puthanakit et al., 2010). There is evidence to show that children raised by depressed caregivers display a spectrum of cognitive and socio-emotional problems (Gagliardi & Honigfeld, 2008; Patcher, Auinger, Palmer, & Weitzman, 2006). In a recent study in Uganda, researchers found out that caregivers with greater depressive symptoms reported their HIV-infected children as having more behavioural problems related to executive functioning (Familiar et al., 2015).

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Despite evidence for the association between parental health status (physical and mental health) and HIV-positive child psychological well-being, the observed evidence of this association is not only limited but mostly located within the developed countries, and not directly comparable to a diverse socio-economic-and-cultural context such as South Africa. Given that South Africa has one of the largest HIV epidemics in the world (UNAIDS, 2014), it is thus imperative that the relationship between the mental well-being of caregivers and the psychosocial functioning of infected children be investigated to assess the extent of the problem locally. This is critical to inform appropriate mental health policy and services in order to reduce the associated vulnerability and enhance the psychosocial functioning of this population. The aims and objectives were in threefolds: (1) to ascertain the prevalence of depressive symptoms among caregivers of HIV+ children; (2) to ascertain psychosocial functioning among HIV-positive children and (3) to examine the relationship between depressive symptoms in caregivers and psychosocial functioning among HIV-infected children.

## Method

### Setting and study participants

The research was conducted within the Buffalo City Metropolitan Municipality, Eastern Cape, South Africa. The Eastern Cape is also one of the poorest provinces in South Africa, with high levels of under development and an unemployment rate of about 24.3% (Stats SA, 2012). A sample of 152 child/caregiver dyads were conveniently recruited through an invitation to both biological and non-biological caregivers of children infected with HIV perinatally and treated on antiretroviral drugs (ARVs). The sample of children was made up of both girls ( $n = 87$ ) and boys ( $n = 65$ ). Only caregivers 18 years and older, whose children were HIV-positive and were in the age range of 31.38–92.78 months ( $M = 63.13$ ), were included in the study.

### Procedure and data collection

Participants of the study were approached in the Paediatric Department after formal access was granted by the Head of the Department and written informed consent was obtained from the children's caregivers, while assent was directly requested from the child. The research was explained to the caregivers in English and isiXhosa by a clinical psychologist and an isiXhosa-speaking clinical social worker who had prior experience of working with HIV/AIDS-infected children and parents. With the

children, the measures were administered in the hospital in the presence of the caregiver.

### Ethical consideration

Ethical approval was given by both the University of KwaZulu Natal's Biomedical Research Ethics Committee (Protocol Number: BE252/11) and Ethics Committee of East London Hospital Complex. Each caregiver was informed about the purpose of the study, and it was emphasised that their participation or otherwise would not affect their child's treatment or quality of care at the health facility. Caregivers gave written informed consent, and assent from the children was obtained through verbally informing them of the study using child-friendly and age appropriate language. All other ethical principles (informed consent, anonymity, confidentiality and voluntary participation) were completely followed. Participants were informed of the availability of counselling and social-welfare services should the need for these arise.

## Measures

### Beck Depression Inventory (BDI) (caregiver variable)

The 21-items Beck Depression Inventory (BDI-II) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) was used to assess the presence and severity of depression among psychiatric and normal populations across cognitive, affective, somatic, neurovegetative and endogenous domains of depression. The self-report assessment is rated on a four-point scale of varying degrees of symptoms severity – ranging from 0 (no symptom) to 3 (severe symptom). The reliability of the BDI is well established within the South African context (Govender & Schlebusch, 2012; Kagee, 2008; Kagee, Nel, & Saal, 2014), and a Cronbach's alpha value 0.89 was found in this study.

### Strength and Difficulties Questionnaire (SDQ) (child variable)

The Strength and Difficulties Questionnaire (Goodman, Meltzer, & Bailey, 1998) was used to assess psychological, emotional and behavioural development problems in children. The questionnaire consists of 25 items and has been locally validated (Cluver & Gardner, 2006; Cluver, Gardner, & Operario, 2009). Selected items can also be used to form subscales for pro-social behaviour, hyperactivity, emotional symptoms, conduct and peer problems (Goodman, 1997), which give an indication

of whether a child/young person is likely to have a significant emotional or behavioural problem/disorder, and type of disorder. The SDQ demonstrated good reliability in this study, with a Cronbach's internal consistency reliability coefficient of 0.73.

### Statistical analysis

The statistical package IBM SPSS (21.0) was used to analyse the data. Pearson's  $r$  was performed to determine the associations between the caregivers' depressive symptoms and their children's psychological and emotional functioning. Group comparisons between biological and non-biological caregivers; and the depressed and non-depressed caregivers were conducted by using independent sample  $t$ -tests. Differences between groups (depressed and non-depressed) and child's psychological functioning were assessed using the one-way analysis of variance test (ANOVA). All test conducted were two-tailed and held statistical significance at  $p < .05$ .

## Results

### Socio-demographics of participants

The demographic characteristics of the participants are presented in Table 1. All the children ( $n = 152$ ) were HIV-infected and on ARVs, with an age range of 31.38–92.78 months (mean age = 63.13) and over half (57.2%,  $n = 87$ ) were girls. The majority (63%,  $n = 96$ ) of the HIV-infected children were living under the care of an adult relative, and over 70% were schooling. The average age of the caregiver was 45 years, and 65% had high school education and approximately 89% were unemployed and had government social grant as their main source of income. About 63% of the caregivers were non-biological mothers, and 65% were 36 years and above.

### Caregiver's and child's psychological functioning

The overall mean of the sample of caregivers on the BDI-III was  $M = 4.41$  ( $SD = 6.69$ ) with score ranging from "no symptoms" to "severe symptoms" (range: 0–38). Overall 48% ( $n = 73$ ) the sample of caregivers (both HIV-positive and negative; biological and non-biological) presented with some depressive symptoms, while 52% ( $n = 79$ ) reported having no symptoms of depression. Forty-eight per cent of caregivers reported low to mild depressive symptoms, while 6.5% reported to have moderate and 0.7% severe symptoms of depression. Biological caregivers reported higher depressive symptoms ( $M = 5.00$ ,  $SD = 6.88$ ) compared to non-biological caregivers ( $M = 4.10$ ,  $SD = 6.60$ ).

Overall psychosocial difficulties mean score was 16.9 ( $SD = 5.05$ ), an indication of significant presence of psychological symptoms. Overall 49.3% the children in the study demonstrated moderate to severe levels of psychosocial difficulties ( $M = 16.9$ ,  $SD = 5.05$ ), with 50.7% of the children having at least mild psychosocial difficulties. Hyperactivity problems were reported in 40.1% ( $M = 5.27$ ,  $SD = 1.72$ ), emotional problems in 29.6% ( $M = 4.31$ ,  $SD = 2.34$ ), conduct in 41.4% ( $M = 3.13$ ,  $SD = 2.18$ ) and peer-related problems in 51.3% ( $M = 3.49$ ,  $SD = 1.46$ ) of their children.

### Caregiver's depressive symptoms and HIV-infected children psychosocial functioning

Pearson product moment correlation coefficient showed that caregiver depressive symptoms were significantly associated with the outcome variable, child psychological function (SDQ) ( $r = 0.31$ ,  $p < .01$ ). A positive association was found between the child's psychological well-being and that of their non-biological caregivers ( $r = 0.27$ ,  $p < .01$ ). However, this association was not as strong as compared to when children are raised by their biological caregivers ( $r = 0.41$ ,  $p < .01$ ). The one-way ANOVA results revealed age group differences on children's psychological and socio-emotional function,  $F(2, 149) = 3.69$ ,  $p = .027$ . The results showed that the 3–4-year-old group of children ( $M = 23.45$ ) scored higher than the 5-year-olds ( $M = 20.17$ ) and the 6 year and above group ( $M = 23.17$ ), suggesting that the younger age group had more psychological difficulties compared to the older children in the study.

The results as presented in Table 2 showed that caregiver depression influenced the child's overall psychosocial functioning,  $F(2, 149) = 6.44$ ;  $p = .002$ . This suggests that the children's psychosocial functioning decreases with higher parental depressive symptoms. Multiple comparison post hoc showed that there was a difference in psychosocial symptoms in children of parents with no depressive symptoms ( $M = 15.18$ ) compared to those with high levels of depressive symptoms ( $M = 20.55$ ,  $p = .002$ ), and also between those with low-to-moderate depressive symptoms ( $M = 16.71$ ) compared to those with high depressive symptoms ( $M = 20.55$ ,  $p = .046$ ). Only the emotional subscale was significantly associated with parental depression,  $F(2, 149) = 8.67$ ;  $p < .001$ . Multiple comparison using post hoc analysis revealed that a statistical difference in depressive symptoms in children of parents with no depressive symptoms ( $M = 3.72$ ) and both low-to-mild ( $M = 4.68$ ),  $p = .034$  and high levels of depressive symptoms ( $M = 6.45$ ),  $p = .001$  exist. Differences in depressive symptoms in children were also

**Table 1.** Socio-demographics of participants ( $N = 152$ ).

	<i>N</i>	%
<i>Child variables</i>		
<i>Gender</i>		
Male	65	42.8
Female	87	57.2
<i>Age in months</i>		
Mean age	63.13	
Age range	31.38–92.78	
<i>Current school grade</i>		
N/A	46	30.3
Crèche	13	8.6
Grade R	46	30.3
Grade 1	33	21.7
Grade 2	12	7.9
Grade 3	2	1.3
<i>Primary caregiver variables</i>		
<i>Caregiver (<math>N = 152</math>) relationship to the child</i>		
Biological mother	56	36.8
Non-biological mother	96	63.1
<i>Age in years of primary caregiver</i>		
Mean age	45	
Age range	18–79	
<i>Education of primary caregiver</i>		
None	2	1.3
Primary	45	29.6
Standard 6–8	47	30.9
Standard 9–10	52	34.2
Tertiary level	3	2.0
Don't know	3	2.0
<i>Socio-economic variables</i>		
<i>Caregivers' employment status</i>		
Unemployed	5	3.3
Employed (piece jobs/minimal skills)	11	7.2
Grant (child support grant)	113	74.3
Disability/old age pension grant	22	14.5
Self-employed	1	0.7

found between those children whose parents had low-to-mild and high levels of depressive symptoms,  $p = .042$ .

Parental depressive symptoms were not found to have any significant association with the gender of the child,  $t(151) = 0.13$ ;  $p > .05$  (Table 3). Although girls ( $M = 23.00$ ,  $SD = 5.24$ ) showed higher levels of psychological symptoms than boys ( $M = 22.63$ ,  $SD = 5.26$ ), this difference was not strong enough to yield a statistical significance,  $t(151) = 0.43$ ;  $p > .05$ .

## Discussion

In this study high levels of depressive symptoms were reported by caregivers of children infected with HIV.

Furthermore, the results indicated that biological caregivers reported higher depressive symptoms compared to non-biological caregivers. While no distinctions were made with regards to the caregivers HIV status; the assumption is that the biological caregivers would also be HIV positive, given the inclusion criteria of the study that they are women. This result perhaps alludes to the biological caregiver's underlying feelings of guilt and self-blame associated with knowing that she is responsible for the child HIV infection. This is most likely to influence the nature of caregiving between the biological caregiver and the HIV-infected child (Murphy, Marelich, Stritto, Swendeman, & Witkin, 2002; New, Lee, & Elliott, 2007), since HIV-positive people are also more likely to be depressed. Children were, however, equally affected by the caregiver's depression irrespective of parental status of the caregiver. This suggests that a child who is raised by a caregiver, who is depressed, irrespective of caregiver status, will adversely be affected. The HIV-positive child's psychological function cannot be removed from the ecological context. Research has consistently demonstrated that children's emotional functioning is affected by caregiver depression irrespective of whether the caregiver is biological (and by inference HIV infected) or non-biological; and most often the biological mothers who is infected with the HIV is also at greater risk of having depressive symptoms (Murphy et al., 2002; Sipsma et al., 2013).

This emerging result is noteworthy, given that mothers (biological or non-biological) as primary caregiver play an important role in the management of child HIV (Mudavanhu, 2008). The presence of depressive symptoms may impair a mother's ability to adhere to treatment and prevent her from making appropriate decisions about seeking health care which may negatively impact on the HIV child's psychological functioning (Murphy et al., 2002). Thus, the struggle of these caregivers to match the social norm and value of a "perfect mother" while confronting feelings of guilt, blame and shame can be extremely burdensome, especially in the

**Table 2.** Psychological functioning of HIV children according to parental depressive state ( $N = 149$ ).

Variable	No symptoms		Low-to-mild symptoms		High-to-severe symptoms		<i>F</i> values	Post hoc comparisons
	[1]		[2]		[3]			
	Mean	SD	Mean	SD	Mean	SD		
Total SDQ	21.66	4.14	23.60	6.15	27.09	3.86	6.44**	[1 < 3]**, [2 > 3]**
Emotional	3.72	1.85	4.68	2.65	6.45	2.12	8.67***	[1 < 2]*, [3 > 1]***
Hyperactive	5.09	1.57	5.35	1.91	6.09	1.45	1.79	N/A
Conduct	2.96	2.18	3.15	2.15	4.18	2.27	1.52	N/A
Peer relation	3.41	1.40	3.53	1.56	3.82	1.33	0.44	N/A

\* $p < .05$ .

\*\* $p < .01$ .

\*\*\* $p < .001$ .

**Table 3.** Psychological functioning of HIV children and their caregivers according to type of caregivers, age and gender.

Dimensions	Non-biological caregivers		Biological caregivers		t-Values
	Mean	SD	Mean	SD	
SDQ	22.80	5.53	22.91	4.74	.13
BDI	4.05	6.58	5.00	6.88	.85
Dimensions	Younger Caregiver (18–35 years)		Older Caregiver (36 and above)		t-Values
	Mean	SD	Mean	SD	
SDQ	23.15	4.55	22.68	5.58	.53
BDI	4.81	6.91	4.19	6.59	.54
Dimensions	Boys		Girls		t-Values
	Mean	SD	Mean	SD	
SDQ	22.63	5.26	23.00	5.24	.43
BDI	4.20	5.96	4.56	7.21	.33

presence of such a ravaging illness as HIV/AIDS (Tompkins & Wyatt, 2008). Clearly, the interconnectedness of the HIV illness and depression of caregivers complicates the experience of caregiving (Nelms, 2005; Tompkins & Wyatt, 2008). Thus, maternal depressive symptoms among caregivers of children with HIV should be considered when discussing HIV management among these at risk children.

The findings also indicate that HIV-positive children struggle with HIV-associated psychological problems. This finding is consistent with other studies elsewhere, mainly international (Bachanas et al., 2001a; Drotar, Agle, Eckl, & Thompson, 1995; Forehand et al., 2002; Havens, Whitaker, Feldman, & Ehrhardt, 1994). It is therefore not surprising that these children are more likely to be negatively affected in their daily functioning, have more school absenteeism and poor school performances compared to uninfected children. These children are also at risk to engage in early unprotected sexual behaviour as adolescence due to associated mental health problems and lack of interpersonal skills (Pengpid, Peltzer, & Skaal, 2013). Albeit the sample demographics varied in age and social context across the bulk of research literature, the importance is the consistency that children infected with HIV display associated psychological problems, and it is therefore important not only to focus on the physical health needs of these children but also their mental health if we want to optimise their quality of life (Brown, Lourie, & Pao, 2000; Fawzi Smith et al., 2010). The significance in highlighting these symptoms presentation amongst these children is important, as it has not yet been addressed in the current paediatric and child HIV managing programmes, especially in this poor-resource context, such as the Eastern Cape.

There are several limitations entrenched in the present study that needs to be mentioned. Firstly, the data are cross-sectional, correlational and descriptive in nature; therefore as consequence, it precludes drawing any conclusion based on causality. Secondly, the

generalizability of the present findings is limited and cannot be assumed for the entire population of children and caregivers living with HIV/AIDS in South Africa. Thirdly, data were collected through caregiver self-report measures, as such can be argued to have inherent bias. It can be argued, given the fact of high levels of caregiver depression and HIV illness that there could possibly be some discrepancies in the caregiver reports, as demonstrated in previous research on other illness and HIV-related illness (e.g. Brown et al., 2000). Future research exploring children's own perception of their HIV illness and how they understand the associated effects of their illness, especially the psychological sequelae of it, in relation to the knowledge of their caregiver's illness and in case of orphans-in relations to the death of a biological caregiver.

In conclusion, the major policy and service implications from this study is that it provides evidence that caregiver depression is associated with child psychological problems, especially significantly with child emotional difficulties. This alludes to the fact that intervention efforts should not only be directed to the management of the physical aspect of HIV/AIDS, but importantly also focus attention on the associated mental health problems. Prevention efforts should be directed at caregivers infected and affected by HIV in order to prevent child depression or other mental health problems. Special attention should be directed towards biological mothers who are likely to be HIV-infected as well as having higher prevalence of depressive symptoms. The study provides some understanding to what extent the mental health needs of HIV-positive children and their caregivers are; and this holds promise as to what response is needed to reduce the burden of care on the infected and their families. Strengthening the caregiver's capacity could well be the first step towards curbing child depression, as such more and robust attention should be directed at mental health intervention.

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