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Caregiver socioemotional health as a determinant of child well-being in school-aged and adolescent Ugandan children with and without perinatal HIV exposure

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Abstract

OBJECTIVE Caregiver socio-emotional attributes are major determinants of child well-being. This investigation in vulnerable school-aged Ugandan children estimates relationships between children's well-being and their caregiver's anxiety, depression and social support.

METHODS Perinatally HIV-infected, HIV-exposed uninfected and HIV-unexposed Ugandan children and their caregivers were enrolled. Perinatal HIV status was determined by 18 months of age using DNA-polymerase chain-reaction test; status was confirmed via HIV rapid diagnostic test when children were 6–18 years old. Five indicators of child well-being (distress, hopelessness, positive future orientation, esteem and quality of life (QOL)) and caregivers' socioemotional status (depressive symptoms, anxiety and social support) were measured using validated, culturally adapted and translated instruments. Categories based on tertiles of each caregiver psychosocial indicator were defined. Linear regression analyses estimated percent differences (β) and corresponding 95% confidence intervals (CI) for child well-being in relation to caregiver's psychosocial status.

RESULTS As per tertile increment, caregiver anxiety was associated with 2.7% higher distress (95% CI:0.2%, 5.3%) and lower self-esteem/QOL (β = −1.3%/−2.6%; 95%CI: −5.0%,-0.2%) in their children. Child distress/hopelessness increased (β = 3.3%/7.6%; 95%CI:0.4%, 14.7%) and self-esteem/QOL decreased 2.3% (β = −2.3%/−4.4%; 95%CI: −7.2%, −1.3%) as per tertile increment in caregiver depression. Higher caregiver social support was associated with lower distress and higher positive outlook (β = 3%; 95%CI:1.4%, 4.5%) in their children. HIV-infected/exposed children had most caregiver depression-related QOL deficit (β = −5.2%/−6.8%; 95%CI: −12.4%, −0.2%) and HIV-unexposed children had most caregiver social support-related enhancements in positive outlook (β=4.5%; 95%CI:1.9%, 7.1%).

CONCLUSIONS Caregiver anxiety, depressive symptoms and low social support were associated with worse well-being in school-aged and adolescent children. Improvement of caregiver mental health and strengthening caregiver social support systems may be a viable strategy for improving well-being of vulnerable children and adolescents in this setting.

keywords psychosocial adjustment, depressive symptoms, distress, positive outlook, HIV, caregiver mental health

Introduction

With the rapid scale-up in access to highly active antiretroviral therapy (HAART) for HIV-infected children [1], those perinatally infected with HIV (PHIV) are reaching adolescence in large numbers [2, 3]. The quality of life (QOL) and psychosocial adjustment (PA) of PHIV and the larger group of PHIV-exposed uninfected (PHEU) children are poorly understood [3–5]. HIV-affected children face the normative stressors of childhood and adolescence along with stressors from increased stigma/discrimination, a higher burden of HIV-related familial loss [6] and other HIV-centred emotional problems [2, 3, 7]. PHIV children bear the specific burden of understanding/managing lifelong HAART, if/when to disclose their own HIV status in relationships, and the high risk of peer discrimination [6].

As many as 34 million HIV-affected children have been orphaned, lost a parent or changed guardianship due to HIV-related adversity or death [3, 7, 8]. AIDS orphans are often left in the care of surviving female relatives, typically grandmothers and aunties [9–12]. The strain on family cohesion and adverse psychological sequelae of high grief and familial loss impose burdens in this population to a level expected to exceed coping resources [2, 13, 14]. Emerging data suggest that psychological and neuropsychological challenges may be larger than previously thought [2, 4, 5, 8, 14, 15]. Even in children who are clinically stable, HAART alone is not sufficient to reverse the neurodevelopmental and cognitive consequences of HIV [16]. Caregiver psychiatric conditions, stressful life experiences, socioeconomic adversity and HIV-related stigmatisation all have been associated with behavioural problems in children from HIV-affected families [2, 4, 5, 13–15]. HIV-affected status may adversely affect child well-being through direct effects on quality of caregiving [17] and/or depression resulting from prolonged coping with chronic illness [7, 13, 18]. Possible indirect environmental effects on QOL in HIV-affected children include behavioural maladaptation to HIV stigma, AIDS-related deaths of community supports and material deprivation [3, 8, 15, 18–21].

Specific investigations of caregiver mental health and its impact on psychosocial adjustment, QOL or overall well-being of HIV-affected school-aged adolescents from sub-Saharan Africa are few [17, 18, 21, 22]. A recent qualitative study among Ugandan caregivers and their young children highlighted the potentially adverse impact of impaired caregiver mental health on child well-being [22]. We have previously reported on worse PA for Ugandan PHIV children compared to community controls [1], but the impact of caregiver psychosocial/mental health factors – depression, anxiety and social support, on child well-being was not explored. The present study informs current knowledge gaps by quantifying the relationships between (i) caregiver psychosocial/mental health factors and (ii) caregiver HIV status and five indices of child well-being during school age and adolescence. We further determine whether the impact of caregiver factors on child well-being differs according to the HIV status of their children. We hypothesised that poor caregiver psychosocial/mental health would be associated with lower well-being and QOL in their children.

Methods

Study population, enrolment and consent

Participants were enrolled as child–caregiver pairs from a single community clinic in Kampala, Uganda. The clinic is a primary care facility that delivers the full range of antenatal care services, including deliveries, outpatient consulting for the general population and the entire range of HIV/AIDS treatment and preventive services. Eligible adult caregivers, who could be non-biological parents, must have resided with the index child for at least 6 months prior to enrolment. Eligibility criteria for children included: (i) documented delivery of index child in a hospital in Kampala or its surrounding rural areas between 1996 and 2008, (ii) determinable HIV status of the birth mother and child pair during the index pregnancy, delivery or breastfeeding and (iii) current HIV testing for all HIV-negative children. Children were excluded if birth record was lacking or perinatal HIV status could not be reliably established via objective medical records. Additional exclusions resulted from lack of child well-being or caregiver psychosocial status/mental health data.

PHIV were recruited from children actively enrolled in HIV care at the clinic. PHEU were identified through antiretroviral therapy cards of HIV-infected adult women currently or previously cared for at same clinic. In addition, the Early Infant Diagnosis registers was used to identify age eligible PHEU children born to HIV-infected women at discharge from the early infant diagnosis programme. Age eligible PHEU and HIV-unexposed uninfected children were also enrolled from the clinic's outpatient department. All participants were recruited on a first-come first-enrolled basis between 20 March 2014 and 30 July 2014. Enrolment period was determined by resources available for the pilot study. Data were collected via face-to-face interviews with different research assistants interviewing each member of the caregiver–child pair.

The parent study was ethically reviewed and approved by the institutional review boards at the University of Georgia (IRB protocol # 0196) and the Makerere University School of Public Health (Protocol #010). Further approval was granted by the Uganda National Council for Science and Technology (Protocol # HS 1613). Caregivers provided written informed consent and children provided assent to participate in this study.

Consent was administered in the local language of Luganda by research assistants proficient in Luganda. Outright refusals were uncommon although at least one child–caregiver pair refused blood draw for complete blood count.

Measures of child well-being

Four indicators of child psychosocial adjustment (distress, hopelessness, self-esteem and positive outlook) were measured using child self-reported developmentally appropriate questionnaires translated and adapted for use in the Ugandan setting. Our process for adapting, translating and validating these instruments for use in this setting and for children within this age range has been reported elsewhere [1]. Distress was measured using a summed score of 12 questions from the Distress Weinberger Adjustment Inventory [23]. Hopelessness about the future was measured using the Children's Hopelessness Scale [24]. Positive outlook measured child's expectation of future positive occurrences via Positive Outlook-Individual Protective Factors Index [25]. Esteem was measured using the Hare Area-specific self-esteem scale to quantify children's subjective sense of being valued by people around them [26]. QOL was composite score of well-being in four domains – school, physical health, emotional health and social health – using child self-reported versions of the paediatric QOL inventory (PedsQL^{TM} 4.0) [27]. Children's scores on respective well-being measures were converted into a percentage (child's score/maximum score)*100.

Child and caregiver HIV status

Children were classified based on their perinatal HIV status as PHIV, PHEU or community controls (i.e. perinatally HIV unexposed uninfected). PHIV and PHEU status were determined by DNA-PCR by the 18th month of the child's life. Current HIV status for HIV-negative children was confirmed using an HIV rapid diagnostic test.

A caregiver in this study is a biological parent or other adult with whom index child resided for ≥ 6 months. For all children, perinatal HIV status was objectively determined by abstraction of relevant data from the following primary medical record sources: antenatal registry, labour and delivery forms or ART card. All caregivers self-reported their current HIV status based on clinical diagnosis indicated whether they were on antiretroviral therapy and estimated duration lived with HIV in direct response to specific questions as part of clinical interview.

Measurement of key caregiver factors: mental health and social support

Caregiver depressive symptoms, anxiety and social support, were each defined as a composite variable in participant Likert-scaled response to several questions using a structured questionnaire [28]. Caregiver depressive symptom score was defined as sum of responses to 15 questions where feelings associated with depression were presented. Caregiver anxiety was measured by summing responses to 10 questions describing persistent fears and worries. Social support was measured as the summed score of eight questions where caregivers were presented with statements about their ability to receive wanted emotional, monetary and physical support. In the absence of definite cut-offs for the measures of caregiver depression empirical thresholds based on the tertiles of each variable's distribution in our sample, we created low, medium or high categories for each measure. For analytic purposes, we primarily compared the two higher *vs*. lowest tertile of each variable.

Other measures

Data on the following potential confounders were measured using a structured questionnaire: caregiver demographic (age, sex, marital status) and socioeconomic factors (education status, income and material possessions), weight, height and self-rated health. Child factors included age, sex, weight, height and whether or not child was on HAART (if HIV positive).

Statistical analyses

A series of descriptive and multivariable analyses was designed to quantify the relationships between five measures of child well-being (distress, hopelessness, positive outlook, esteem and quality of life) and (i) caregiver psychosocial/mental health factors (depression, anxiety and social support) and (ii) caregiver HIV status. Secondary analyses stratified by child perinatal HIV status were implemented to determine whether the association between caregiver psychosocial/mental health factors and child well-being differed according to the HIV status of their dependent children.

Descriptive analyses included whole sample univariate and by caregiver HIV status bivariate description of the caregivers/dependent children with respect to demographic, socioeconomic and health variables using counts/percentages and means/standard deviations (SD) as appropriate. Across caregiver HIV groups, differences in means and proportions for continuous and categorical variables were evaluated using Chi-squared/Fisher's exact tests and *t*-tests respectively. Generalised estimating equation models with child well-being indicators as outcomes were used to account for clustering of children within caregivers at the household level. Crude and confounder adjusted models were built to examine relationships between caregiver factors and each indicator of child well-being. Potential confounders of child well-being were identified in light of the literature and included birth mother deceased status, caregiver factors (age, educational status, HIV status, marital status, household wealth and BMI) and child factors (age, sex, perinatal HIV status and stunting).

For each caregiver mental health/social support indicator, differences in child well-being measures and corresponding 95% confidence interval were calculated. The possibility that associations between caregiver mental health/social support and respective child well-being measures could vary by child and caregiver HIV status was evaluated by introducing the interaction term for HIV status and caregiver mental health/social support variables (HIV*caregiver psychosocial factor) in multivariable models including separate main effects for these factors. Where the *P*-value associated with the interaction term was ≤ 0.10, additional analyses for the association between caregiver mental health/social support and respective child well-being measures were implemented within each of the three perinatal HIV strata.

For each primary determinant, we calculated two effect sizes (ES) corresponding to differences in means of respective child outcomes for the second and third tertiles relative to the first tertile, expressed in pooled SD units. ES values were interpreted per threshold described by Cohen [29] as follows: 'trivial' (<|0.20|), 'small' (≥|0.20| to <|0.50|), 'moderate' (≥|50| to <|0.80|) and 'large' (≥|0.80|) effects. Given the available sample sizes of 139–151 (depending on the outcome), statistically significant effect sizes of 0.57–0.59 (power ≥ 0.8, $\alpha = 0.05$) were detectable in the comparisons of child outcomes according to tertiles of caregiver mental health and social support.

Ethical aspects

Ethical approval was provided by the institutional review boards of the University of Georgia (IRB Protocol # 0196), the Makerere University School of Public Health (IRB Protocol # 010) and the Uganda National Council for Science and Technology (Protocol # HS 1613). Caregivers provided written informed consent and all children provided assent for study participation.

Results

The parent study enrolled 168 children of 108 unique caregivers. Exclusions by child well-being and caregiver factors resulted in the availability of 128–151 children of 85–97 caregivers for analyses depending on the outcome and primary determinant under investigation (Figure S1). Caregivers were 37.7 years old on average. The majority of caregivers were female and 79% were biological mothers of enrolled child. Nearly 42% had less than primary school education, 40% self-rated their current health as good/very good/excellent and the majority were HIV positive ($n = 57$). HIV-positive caregivers had lived with the infection for an average of 10 years (SD = 5.5) and the majority were on HAART ($n = 54$). HIV-positive and HIV-negative caregivers were similar with respect to sex, age, alcohol use, marital status and BMI. HIV-positive caregivers had lower material wealth scores and were more likely to be the birth mothers of study children. Children cared for by HIV-positive caregivers were more likely to be HIV positive, had lower average esteem and positive outlook scores. Enrolled children of HIV+ caregivers were similar to those cared for by HIV caregivers in terms of age, sex and nutritional status (Table 1). The majority of children ($n = 133$, 80.1%) were biological parents as primary caregivers. HIV-infected children ($n = 18$, 32.2%) were more likely than HIV-exposed uninfected ($n = 4$, 7.1%) and HIV unexposed uninfected ($n = 11$, 20.4%) children to have non-biological parent as primary caregiver ([=0.0219, data not shown).

Caregiver anxiety and child well-being

Relative to children of least anxious caregivers, the children of caregivers in the second or third tertile of anxiety reported up to 7.4%(95% CI: 1.4%,13.4%) higher distress, had up to 3.9% (95% CI: −6.2%, −1.7%) lower self-esteem scores and as much as 6.4% (95% CI: −11.6%, −1.2%) lower QOL scores. Higher levels of caregiver anxiety –that is, second and third relative to first tertile – were associated with comparable increases in child distress and similar magnitude of declines in child QOL. There was no association between child hopelessness or positive outlook and caregiver anxiety (Table 2). As per Cohen's ES estimates, observed caregiver anxiety-related elevation in child distress was small (ES = 0.34–0.42), whereas estimated deficits in child self-esteem (ES = −0.40 to −0.53) and QOL (ES = −0.53 to −0.58) were small to moderate respectively (Table 3).

Table 1 Sociodemographic characteristics by caregiver HIV status

	Overall *n* = 97	HIV-negative caregiver (*n* = 40)	HIV-positive caregiver (*n* = 57)	*P*-value
Caregiver demographic factors (*n* = 97 unique caregivers)	***n* (%)**	***n* (%)**	***n* (%)**	
Respondent sex (female) *n* (%)	89 (92.7)	38 (95.0)	51 (91.1)	0.47
Currently use alcohol *n* (%)*	8 (10.2)	2 (5.0)	6 (10.5)	0.46
Married or living with a sexual partner	51 (52.6)	24 (60)	27 (47.3)	0.22
Respondent is mother of study child	77 (79.4)	26 (65)	51 (89.5)	<0.01
Deceased birth mother*	11 (11.3)	9 (22.5)	2 (3.5)	<0.01
Caregiver age categories (in years)				
<30	21 (21.7)	10 (21.3)	15 (24.5)	0.92
30–40	46 (47.4)	21 (44.7)	28 (45.9)	
>40	30 (30.9)	14 (29.8)	18 (29.5)	
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	
Age (in years)	37.7 (12.5)	39.1 (13.3)	36.8 (7.7)	0.11
Years of marriage (if caregiver is married)	13.8 (4.6)	13.8 (4.8)	11.0 (6.4)	0.19
Years lived with HIV (if HIV+)	-	-	10.0 (5.5)	-
Material score	2.6 (2.1)	3.7 (2.2)	1.9 (1.7)	<0.01
Social support score	22.7 (6.3)	23.5 (6.6)	22.1 (8.8)	0.98
Depressive symptoms score	30.0 (9.9)	29.3 (10.4)	30.5 (9.6)	0.56
Anxiety score	21.2 (8.0)	21.2 (8.0)	21.2 (8.0)	0.94
Body mass index (kg/m^2)	24.6 (4.4)	25.7 (4.5)	23.8 (4.2)	0.08
	***n* (%)**	***n* (%)**	***n* (%)**	
BMI categories				
<25	55 (60.4)	21 (56.8)	34 (63.0)	0.25
25–29.99	25 (27.5)	9 (24.3)	16 (29.6)	
≥30.0	11 (12.1)	7 (18.9)	4 (7.4)	
Self-rated current health is good, very good or excellent	39 (40.2)	17 (42.5)	22 (38.6)	0.70
On highly active retroviral therapy	54 (55.7)	0 (0)	54 (94.7)	-
Educational attainment				
<Primary education	40 (41.7)	13 (32.5)	27 (48.2)	0.11
Primary education completed	22 (22.9)	8 (20.0)	14 (25.0)	
O'levels or higher education	34 (35.4)	19 (47.5)	15 (26.8)	
Caregiver has own income	65 (67.0)	26 (65.0)	39 (68.4)	0.48
Child health and demographic factors (*n* = 151 unique children)	***n* = 151**	***n* = 67**	***n* = 84**	
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	
Height-for-age *Z*-score	−0.86 (1.66)	−0.96 (1.95)	−0.77 (1.6)	0.51
BMI *Z*-score	−0.93 (1.63)	−0.76 (1.57)	−1.1 (1.6)	0.28
Distress score	43.5 (15.9)	41.6 (14.4)	45.0 (16.9)	0.19
Hopelessness score	26.4 (29.7)	28.8 (33.2)	24.4 (26.7)	0.37
Positive outlook score	83.1 (9.1)	85.4 (9.4)	81.5(8.6)	<0.01
Esteem score	75.5 (6.2)	76.6 (7.2)	74.7(5.1)	0.06
Quality of life score	87.2 (13.6)	87.8 (12.6)	86.8 (14.4)	0.67
Age (years)	10.9 (3.5)	11.1 (3.6)	10.5 (3.4)	0.50
	***n* (%)**	***n* (%)**	***n* (%)**	
Age categories				
<7	41 (27.2)	18 (26.9)	23 (27.4)	0.52
7–9	44 (29.1)	16 (23.9)	28 (33.3)	
10–12	20 (13.3)	11 (16.4)	9 (10.7)	
13–18	46 (30.5)	22 (32.8)	24 (28.6)	
Child sex (Female)	71 (47.0)	33 (49.2)	38 (45.2)	0.62
HIV status*				
HIV-exposed uninfected	52 (34.7)	1 (1.5)	51 (61.5)	<0.01
HIV-exposed infected	46 (30.7)	17 (25.4)	29 (34.9)	

Table 1 (*Continued*)

	Overall *n* = 97	HIV-negative caregiver (*n* = 40)	HIV-positive caregiver (*n* = 57)	*P*-value
HIV-unexposed uninfected	52 (34.7)	49 (73.1)	3 (3.6)	
On antiretroviral regimen (if child HIV+)	35 (77.8)	14 (82.3)	21 (75.0)	0.69
Stunted	40 (25.6)	22 (31.6)	18 (20.7)	0.11
Underweight	39 [25]	14 (20.9)	25 (29.8)	0.22

**P*-value is based on Fisher's exact test. Except where indicated otherwise, *P*-values for test of differences in proportion are derived from Chi-square tests and *P*-value for mean differences in linear measures according to caregiver HIV status are based on *t*-tests calculated from analyses of variance.

Caregiver depression and child well-being

There was no association between caregiver depression and child positive outlook (Table 2). However, distress and hopelessness were, respectively, higher up to 6.7% (95% CI: 1.6%, 11.7%) and 14.7% (95% CI: 0.5%, 29%), for children of caregivers with moderate or higher *vs*. least number of depressive symptoms (Table 2). Self-esteem and overall QOL were, respectively, lower by as much as 4.9% (95% CI: −6.6%, −2.7%) and 8.7% (95%CI: −14.4%, −3.1%), for children of caregivers who reported the most *vs*. least depressive symptoms (Table 2). The moderate or high *vs*. least caregiver depressive symptom-associated differences in child distress, hopelessness, self-esteem and QOL were directionally consistent with worse well-being, but relationship was only statistically robust for children whose mothers had most *vs*. least depressive symptoms (Table 2). Cohen's classification observed small ES for caregiver depression-associated elevations in distress (ES = 0.25) and hopelessness (ES = 0.38) whereas the deficits in child QOL (ES = −0.70) and child esteem (ES = −0.80) were, respectively, moderate and large for children whose caregivers were in the third *vs*. first tertile of depressive symptoms (Table 3).

Caregiver social support and child well-being

Child distress was as much as 5.8% (95% CI: −11.5%, −0.1%) lower whereas child positive outlook was up to 6.4% (95% CI: 3.3%, 9.5%) higher for children of caregivers who received the moderate or highest *vs*. least social support. These associations were dose dependent but statistically robust only for children of caregivers in the third *vs*. first tertile of social support (Table 2).

There was no association between caregiver social support and child self-esteem or QOL. However, child hopelessness was 15% (95%CI: 2.4%, 27.8%) elevated for children of caregivers in the second *vs*. lowest tertile of social support, but there was no difference in hopelessness scores when comparing children whose caregivers were in the highest (difference = 3.1%, 95%CI: −9.7%, 15.8%) *vs*. lowest tertile of social support (Table 2). Estimated ES for most *vs*. least caregiver social support-associated decline in child distress (ES = −0.34) was small. Most *vs*. least caregiver social support-related elevation in child self-esteem (ES = 0.46) and overall QOL (ES = 0.22) were each small; elevation of positive outlook (ES = 0.57) of children with most *vs*. least social support was moderate (Table 3).

Interaction analyses

Caregiver HIV status was not associated with any measure of child well-being, but child HIV status was associated with higher levels of distress and lower QOL (Table S1). The relationship of caregiver psychosocial status and all measures of child well-being did not vary according to the caregiver's HIV status. There were child HIV-status-related variations in the association between caregiver social support and child positive outlook (Perinatal HIV status*Caregiver Social support, *P* = 0.04). The positive association between caregiver social support and child positive outlook was only evident and statistically robust among PHEU (difference = 2.8%, 95% CI: 0.4%, 5.2%) and community controls (difference = 4.5%, 95% CI: 1.9%, 7.1%) but not among PHIV children (difference = 0.8, 95% CI: −1.2%, 2.7%; Figure 1; Table S2).

The relationship between caregiver depression and child QOL also varied by child HIV status (Perinatal HIV status*Caregiver Depression, *P* = 0.01). The inverse association between caregiver depressive symptoms and child QOL was evident in HIV-affected children with consistent evidence of dose response as noted in the entire sample. Among HIV-negative community controls, there was no association between caregiver depression and child QOL (Figure 2, Table S3).

Table 2 Children's psychosocial adjustment and well-being in relationship to their caregiver's depression, anxiety and social support in Kampala, Uganda

	Child distress Risk difference (95% CI)	Hopelessness Risk difference (95% CI)	Positive outlook Risk difference (95% CI)	Self-esteem Risk difference (95% CI)	Quality of life Risk difference (95% CI)
Caregiver anxiety	*n* = 148	*n* = 151	*n* = 149	*n* = 151	*n* = 135
Per tertile increment	**2.7 (0.2, 5.3)**	2.3 (−4.9, 9.6)	−0.2 (−1.9, 1.6)	**−1.3 (−2.3, −0.2)**	**−2.6 (−5.0, −0.3)**
Tertile 1	Ref	Ref	Ref	Ref	Ref
Tertile 2	**7.4 (1.4, 13.4)**	5.4 (−8.1, 18.8)	−0.8(−4.9, 2.8)	**−3.9 (−6.2, −1.7)**	**−6.4 (−11.6, −1.2)**
Tertile 3	**5.8 (0.7, 11.0)**	4.9 (−9.5, 19.3)	−0.3 (−4.1, 3.6)	−1.9 (−4.1, 0.2)	**−5.8 (−10.4, −1.1)**
Caregiver depression	*n* = 139	*n* = 142	*n* = 140	*n* = 142	*n* = 128
Per tertile increment	**3.3 (0.8, 5.8)**	**7.6 (0.4, 14.7)**	−0.5 (−2.3, 1.3)	**−2.3 (−3.3, −1.3)**	**−4.4 (−7.2, −1.5)**
Tertile 1	Ref	Ref	Ref	Ref	Ref
Tertile 2	4.0 (−1.4, 9.5)	3.8 (−8.3, 15.8)	−0.5 (−4.4, 3.3)	−0.9 (−3.1, 1.4)	−3.7 (−9.0, 1.6)
Tertile 3	**6.7 (1.6, 11.7)**	**14.7 (0.5, 29.0)**	−1.0 (−4.7, 2.7)	**−4.9 (−6.6, −2.7)**	**−8.7 (−14.4, −3.1)**
Caregiver social support	*n* = 148	*n* = 151	*n* = 149	(*n* = 151)	*n* = 135
Per tertile increment	**−2.8 (−5.5, −0.02)**	2.6 (−4.1, 9.3)	**3.0 (1.4, 4.5)**	1.1 (−0.2, 2.4)	1.0 (−1.91, 2.8)
Tertile 1	Ref	Ref	Ref	Ref	Ref
Tertile 2	−1.3 (−7.8, 5.2)	**15.1 (2.4, 27.8)**	1.8 (−1.2, 4.8)	2.0 (−0.3, 4.1)	−1.6 (−5.0, 7.0)
Tertile 3	**−5.8 (−11.5, −0.1)**	3.1 (−9.7, 15.8)	**6.4 (3.3, 9.5)**	2.2 (−0.3, 4.8)	1.2 (−3.9, 7.4)

All estimates are derived from a GEE model with the child's psychosocial health indicator as outcome variable. Models are not mutually adjusted for caregiver depression, anxiety and social support.

Bolded number denotes statistically significant associations.

Discussion

Our investigation included three perinatal HIV groups, including community control children, confirmation of current HIV status among children HIV-negative at birth and rigorous analytic strategy including multivariable adjustment for important socio-demographic and economic confounders. There was no evidence that caregiver HIV sero-status was associated with child psychosocial adjustment and QOL. We identified 'small' elevations in child distress, 'moderate' deficits in child global esteem and 'large' deficits in overall QOL for caregivers with highest *vs.* lowest anxiety and depression levels as per Cohen's criteria. Conversely, we found small declines in child distress and small to moderate improvements in child positive outlook, esteem and overall QOL for children of caregivers reporting highest *vs.* lowest levels of social support. The findings that high caregiver depression and anxiety were associated with worse distress, hopelessness and positive outlook in their children are in-line with our hypothesis and similar to findings among PHIV South African children [20]. Our findings further support observations in HIV-unaffected contexts of caregiver depression-related increases in childhood anxiety and distress [30], evidence of substantial decline in children's internalising and externalising behavioural problems with resolution of maternal depression and the previously reported lower child-self-esteem [31] and higher incidence of childhood depression among children whose mothers had a history of major depressive disorder [32].

These data highlight the possible contribution of caregiver depression and anxiety to compromised caregiving quality [33] and contribute to the limited body of information regarding determinants of child psychosocial adjustment in SSA settings. Small deficits (as per Cohen's classification) may significantly underestimate the clinical significance of interventions to reduce caregiver depression and distress for PA and mental well-being of their children, as caregiver depression/anxiety is common conditions affecting millions of HIV-affected and HIV-unaffected caregivers. We expect that these small/moderate deficits at the individual level may amount to important differences in disease burden at the population level.

The no-difference finding in child psychosocial adjustment and QOL in relationship to caregiver HIV status is noteworthy, and we believe refreshing in its implication for safe parenting by HIV-positive adults stable on long-term HAART who desire to be caregivers/parents. It indicates the possible absence of deficits in children's QOL and psychosocial adjustment with an HIV-positive

Table 3 Estimated effect sizes for mean differences in child psychosocial adjustment indicators in relationship to caregiver's anxiety, depression and social support

	Distress Effect size	Hopelessness Effect size	Positive outlook Effect size	Esteem Effect size	Quality of Life Effect size
Caregiver anxiety					
Tertile 1	Ref	Ref	Ref	Ref	Ref
Tertile 2	0.42	0.12	−0.04	−0.53	−0.53
Tertile 3	0.34	0.16	−0.09	−0.40	−0.58
Caregiver depression					
Tertile 1	Ref	Ref	Ref	Ref	Ref
Tertile 2	0.20	0.03	−0.15	−0.08	−0.40
Tertile 3	0.25	0.38	−0.11	−0.79	−0.70
Caregiver social support					
Tertile 1	Ref	Ref	Ref	Ref	Ref
Tertile 2	−0.04	0.42	0.19	0.35	−0.15
Tertile 3	−0.34	0.06	0.57	0.46	0.22

Estimation of effect sizes are based on unadjusted means for respective endpoints. Interpretation of ES is per Cohen's Classification as follows: 'trivial' (<|0.20|), 'small' (≥|0.20| to <|0.50|), 'moderate' (≥|50| to <|0.80|) and 'large' (≥|0.80|) effects.

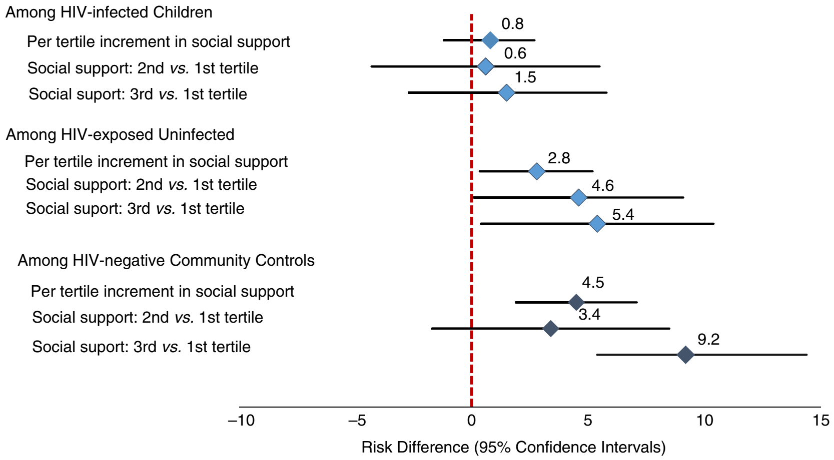

Figure 1 Caregiver social support-related differences in child positive outlook within perinatal HIV groups. [Colour figure can be viewed at wileyonlinelibrary.com]

caregiver. Related studies from SSA rarely include community controls (i.e. HIV-unaffected children/caregivers) and most reported comparisons are among HIV-affected children (i.e. children/adolescents orphaned due to HIV/AIDS *vs*. children with HIV-infected caregivers) [34, 35]. From these studies, caregiver illness appears to contribute to impaired child psychosocial adjustment [35, 36]. Whether caregiver HIV-positive status in the post-HAART era continues to confer substantial psychosocial adjustment and mental health deficits in their children remains unclear. Data from this investigation suggest substantial caregiver HIV status-related deficits in these parameters may be small for most endpoints. Of note, virtually all HIV-infected caregivers in this study were already stably connected to HIV care and routine monitoring for HIV and general health. Given these critical preconditions, child QOL and psychosocial indices being comparable for HIV affected and unaffected caregivers may partly reflect a tangible benefit of HAART, access to routine health monitoring and possibly additional HIV-related support services – for example, spiritual care [37], mental health counselling [38] and nutritional supplementation [39] that may be more common for HIV-infected compared to HIV-uninfected caregivers. Specific studies in the African setting – preferably prospective in design with larger sample size, are needed to clarify these findings including the suggestive evidence of caregiver HIV-positive status-associated deficits in QOL and positive outlook observed only among community control children.

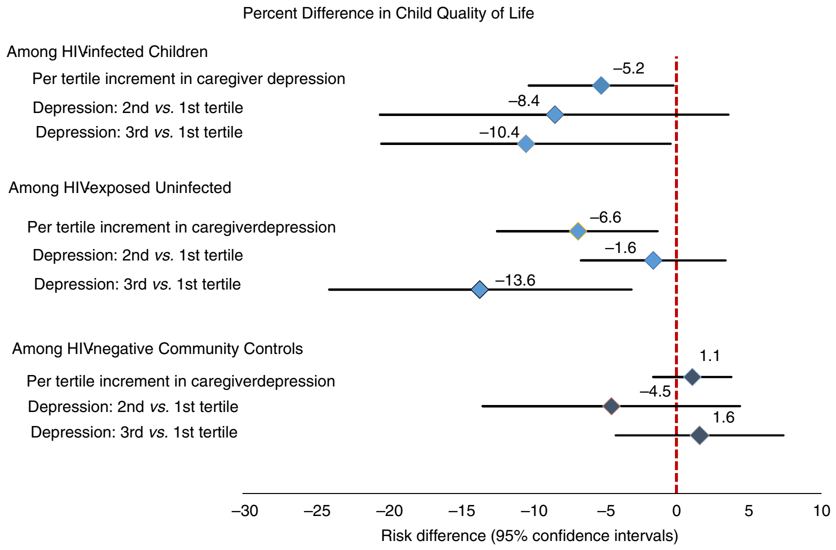

Figure 2 Caregiver depressive symptoms related differences in child quality of life by perinatal HIV status. [Colour figure can be viewed at wileyonlinelibrary.com]

Higher levels of parental support and/or caregiver emotional well-being are known resilience enhancing factors in children with or without HIV [2, 7, 14]. Our observation that higher levels of caregiver social support are associated with superior QOL, positive outlook and lower levels of distress in children is evidence that given HIV-related adversity, enhancement of caregiver social support may be an effective strategy for buffering against poor psychosocial adjustment outcomes in dependent children [40–42]. Our findings corroborate observations among Ugandan and South African adolescents that are singly or doubly orphaned due to HIV/AIDS [40, 41]. In these studies, children reported higher social support measures when paired with a mentor – that is, a non-parent adult for support and guidance. The presence of a mentor was in turn associated with lower distress levels [40, 41]. Similarly, among Chinese adolescents, including HIV orphans, other vulnerable children and community controls, high levels of adolescent perceived social support were associated with lower psychological distress and greater future expectation scores [42]. However, the finding of elevated hopelessness for children with moderately supported caregivers was surprising. It was inconsistent with our hypothesis and requires further elucidation in the context of larger prospective investigations including HIV-affected and -unaffected African children.

The heterogeneity in the association of caregiver social support and depression noted for positive outlook and QOL taken together emphasise the vulnerability of PHIV and PHEU. Our data suggest that the benefit of higher caregiver social support and lower caregiver depression on positive outlook and QOL is not equal between cohorts. Observations of stronger statistically robust associations between caregiver social support and child positive outlook among PHEU and community controls suggest that interventions to improve caregiver social support will accrue the largest benefit for improving positive outlook in HIV-negative children. Similar positive outlook improvement in PHIV children, on the other hand, will likely require additional interventions beyond caregiver social support. Subgroup analyses further suggest that caregiver depression may have most pronounced adverse effect on QOL among HIV-affected children and that interventions to reduce caregiver depression may accrue greater QOL benefits for PHEU and PHIV children.

Previous work in Ugandan school-aged and adolescent children [1, 19, 43] and children from other Sub-Saharan African settings [20] has demonstrated a range of neurocognitive, QOL and behavioural deficits for PHIV and HIV/AIDS orphaned children compared to community controls. Studies of the independent or contributory role of caregiver mental health parameters remain poorly elucidated. The importance of instrumental support of caregivers through the treatment of depression, alleviation of caregiving stress by means of cash transfer programmes to meet material caregiving needs and through specific training to enhance caregiving quality has been described among HIV-affected caregivers [17, 33, 44–48]. By delineating these specific child psychosocial adjustment indices that are negatively impacted by poor caregiver social support, depression and anxiety, we provide additional data on the importance of caregiver mental health as a modifiable risk factor for improving the well-being of vulnerable children. Limitations of the present study include the absence of data on children's knowledge of their HIV status, cross-sectional nature of the study and relatively small sample size that limits inferential power. Awareness of one's own HIV status may affect PA; in particular, older age at HIV status disclosure has been associated with worse adjustment in African children [3].

In summary, we demonstrate that independent of primary caregiver's HIV status, higher levels of caregiver depression, anxiety and decreased social support are associated with higher levels of child distress, hopelessness and lower levels of self-esteem and positive outlook. Future interventions to mitigate depression and anxiety and improve social support in primary caregivers will likely benefit all children, regardless of HIV status. However, HIV-affected households may require more intense or multifaceted interventions to mitigate HIV-related disadvantages for some psychosocial adjustment outcomes – maintenance of positive outlook, hopefulness and future aspirations. Future research to determine the extent to which PA deficits in vulnerable children reach the threshold of psychiatric disorders is needed to properly guide interventions and holistic management of mental health in vulnerable African children.

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Supporting Information

Additional Supporting Information may be found online in the Supporting Information section at the end of the article:

Figure S1 Study sample for respective analyses.

Table S1 Association between select child/caregiver factors and respective outcomes – results from multivariable analyses.

Table S2 Correlates of child outlook during school age and adolescence by perinatal HIV status.

Table S3 Correlates of child quality of life during school age and adolescence by perinatal HIV status.

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