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The effects of caregiver and household HIV on child development: a community-based longitudinal study of young children

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Abstract

Objective Many studies that document child outcomes in the context of parental HIV – which has been established as a risk factor for child development – focus on older children/adolescents. Studies also concentrate on the status of the primary caregiver, not other household members who might be infected.

Design This study examined the effects of caregiver and household HIV on child development (4–13 years) in South Africa and Malawi (2011–2014).

Methods Data were gathered from 989 children and their primary caregivers at baseline and repeated at 12–15 months follow-up (86.5% follow-up rate). Only caregivers of a single child and caregiver/child dyads without missing data were included, providing a sample of 808 dyads for analysis. Children were divided into three groups according to caregiver-reported HIV burden: having an HIV-positive primary caregiver (19.8%), having HIV in the household (14.2%) or no HIV (66%).

Results The HIV burden was positively associated with an array of negative child outcomes, often mediated by caregiver depression levels. Family HIV burden at baseline affected child behavioural problems at follow-up indirectly through carer depression ($B = 0.02$; CI = 0.003, 0.06). Internalizing ($B = 0.02$; CI = 0.002, 0.05) and externalizing problems at follow-up ($B = 0.01$; CI = 0.0002, 0.03) were also indirectly affected by family HIV burden through caregiver depression.

Conclusions The data suggest that family HIV can affect child development, emphasizing the important role of depression in the pathway to such an effect. Community-based interventions directed at alleviating parental depression in the presence of HIV may help to interrupt the cycle of family HIV and adverse child outcomes.

Keywords
caregivers, child development, depression, HIV, violence

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Introduction

Quality caregiving plays an important role in child development (Engle *et al.* 2007). Caregiving ensures a safe and secure environment for young children and provides access to basic necessities such as food and shelter and stimulation and love to promote optimal development and protection from harm. Children's early life experience is shaped by such family contexts (Richter *et al.* 2008), and caregiving under challenging situations can place a child at risk, thus jeopardizing this experience (Engle and Black, 2008).

Caregiver HIV infection is a risk factor for poor child development outcomes (Sherr *et al.* 2014; Stein *et al.* 2014). In the early days of the epidemic, efforts to address the needs of

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children with HIV-positive parents were focused on preventing the transmission of the virus to children, and these have borne fruit (Kellerman *et al.* 2013). However, HIV has been shown to have dramatic effects on social and emotional adjustment for adults. When these adults are also the primary caregivers of children, it is important to understand what the nature of parenting challenges are and how best to deal with them. For many, HIV diagnosis may occur during pregnancy, diverting emotions and overlaying the pregnancy experience with the challenges of adapting to both HIV infection and antiretroviral treatment (Rochat *et al.* 2006). Ongoing adult infection poses a series of indirect risks for child development and upbringing (Oswalt and Biasini, 2012). Indirect risks include illness and hospitalization, mental health reactions to diagnosis (Joseph and Bhatti, 2004) or the need for children to shoulder household burdens in the face of reduced parental attention, availability, resources or income (Sherr *et al.* 2014).

Children of parents with HIV have been shown to face a number of challenges (Kourtis *et al.* 2013). Previous studies have shown that parental HIV is associated with poor educational outcomes in children (Guo *et al.* 2012), as well as psychological and sexual risk (Cluver *et al.* 2013). Studies have also shown that children may drop out of school, experience exacerbated mental health difficulties and abuse that persists over time (Bauman *et al.* 2007; Cluver *et al.* 2007; Xu *et al.* 2010; Cluver, 2011; Cluver *et al.* 2012). Some studies have recorded inconsistent parental care (Walker *et al.* 2011). At the extreme, parental death has many implications for child outcomes (Chuong and Operario, 2011; Operario *et al.* 2011). The effects are widespread, including multiple separations, movements to new households, educational challenges and an increased risk for internalizing disorders and post-traumatic stress (Cluver *et al.* 2007; Kuo *et al.* 2014).

Many studies exploring psychosocial outcomes focus on adolescents (Cluver *et al.* 2013). The effects on younger children need documenting. Furthermore, the literature now needs updating in order to understand the effects of HIV in caregivers in the presence of treatment, where illness and death are less common and caregivers have a good life expectancy. It is also unclear whether the burdens are directly or indirectly related to HIV. So the HIV status of the caregiver may not be the sole source of challenge, but HIV in the family, home or household may also affect child development and adaptation. This is especially true in sub-Saharan Africa for younger children where the care input comes from the wider extended household and may not be vested exclusively in a single caregiver. For the most part, global studies concentrate on the primary caregiver, they generate clinic-based samples and they do not look at compound effects of HIV within the household irrespective of household member roles. This study sets out to examine the effects of both primary caregiver HIV and household HIV on child development outcomes for younger children drawn from a community-based, rather than a clinic-based, sample residing in Malawi and South Africa.

Methods

Participants

Participants were drawn from the Child Community Care study, which at baseline included 952 carers who, with their children, attended community-based organizations (CBOs) in South Africa and Malawi. The CBOs were recruited with the collaboration of 11 funding partners who provided comprehensive total lists of all 588 funded CBOs, which were stratified by funder and geographical region, and 28 were randomly generated for inclusion (24 South Africa 4 Malawi – prorated to country population size). Consecutive CBO attending children aged 4 to 13 years and their primary caregivers were interviewed with a 99.2% response rate. Interviews were conducted by trained data collectors utilizing mobile phone technology (Tomlinson *et al.* 2009). Questionnaires were constructed to examine broad domains of child functioning. Baseline data were collected in 2011–2012 with follow-up 12–15 months later. Ethical approval was granted from the University College London (reference 1478/002) and Stellenbosch University (reference N10/04/112). All caregivers were provided with detailed information and provided written consent. Caregivers and children were not paid, but received a grocery or food item, a drink and a certificate of participation. At baseline, 952 caregivers were interviewed. Those with a study child, fully completed child data at baseline and follow-up were retained in this analysis – 808 child/carer dyads. Carers were aged 17–87 years (M = 44.17, SD = 14.94) and children 4–13 years (M = 8.99, SD = 2.81). Ninety-five percent of the caregivers ($n = 768$) and 51.9% children ($n = 419$) were female. Three groups of caregivers were generated: (i) HIV positive, (ii) HIV-negative primary caregivers (but living in a home with someone HIV-positive) and (iii) HIV-unaffected HIV-negative caregivers living in a home with no HIV infection.

Measures

Demographics were collected for both child and caregiver including age, gender, education, employment, living arrangements, type of housing, reported HIV status and household size. *Food security* was measured by the Food and Nutrition domain of the Child Status Index (Nyangara *et al.* 2009) and children reported going to bed hungry the previous night. *Child work* was monitored with questions from the Survey of Activities of Young People (Statistics South Africa, 1999). *Family HIV burden* was ascertained using caregiver self-report. *Separation and bereavement* were listed by carer and child reports for recent deaths, illness and separation.

Child cognitive functioning was measured with the digit span task for working memory (Wechsler, 2004) and a draw-a-person task for general cognitive abilities (Goodenough, 1926; Harris, 1963). *Child delinquency* was measured using three items reported by children on a 4-point scale relating to experience of police arrest, being drunk or high or beating someone up from the externalizing and risk behaviour domain (Snider and Dawes, 2006), generating a 0–12 score. *Child trauma* was measured with the brief Trauma Symptom Checklist for Children (Briere, 1996), consisting of 10 items (scored 0–3; $\alpha = 0.74$).

Child physical functioning and quality of life used carer report on the Paediatric Quality of Life Inventory (Varni *et al.* 2001) with five items (0 = never to 4 = almost always; $\alpha = 0.83$). The quality of life score summed the subscales of the PedsQL. *Child social and emotional functioning* used the short version of the Strengths and Difficulties Questionnaire (Goodman, 1997) comprising six subscales: emotional problems (three items); peer problems (two items); hyperactivity (one item); conduct problems (three items); externalizing problems (average of the conduct and hyperactivity items); and internalizing problems (average of the emotional and peer problem items). *Child depression* used child report on an adapted version of the Children's Depression Inventory (Kovacs, 1992), consisting of 10 items ($\alpha = 0.62$) (scored 0–2 with a summed total score). *Child self-esteem* used child report on a short version of the Rosenberg self-esteem scale (Rosenberg, 1965), consisting of nine items ($\alpha = 0.60$) generating a self-esteem score between 0 and 36.

Child education status and progress. Three educational measures documented school enrolment (0 = no, 1 = yes), attendance (0 = no, 1 = not a lot, 2 = sometimes, 3 = regularly) and correct class for age (0 = no, 1 = yes, or above). *Caregiver mental health* used the Shona Symptom Questionnaire (Patel *et al.* 1997), consisting of 14 binary items ($\alpha = 0.86$) with total scores 0–14. Anxiety was measured using five binary, individual items of the Brief Patient Health Questionnaire (Kroenke *et al.* 2001).

Experience of stigma and community belonging. Child and carer reported on the experience of stigma, discrimination and social exclusion scale ($\alpha = 0.66$) (Snider and Dawes, 2006), consisting of five binary items for the child and three binary items for the carer.

Domestic violence. Two individual child-report questions adapted from the conflict tactics scales (Straus, 1997), namely, how often adults in their household shout and hit each other (scored 0 = never, 1 = less often, 2 = monthly, 3 = weekly). Total scores ranged from 0 to 6. *Community violence* documented frequency of witnessing street attacks and personal attacks outside the home (scored 0 = never, 1 = less often, 2 = monthly, 3 = weekly). Total scores ranged from 0 to 6.

Household discipline and punishment. Individual carer report questions, adapted from parent–child conflict tactics scales (Straus *et al.* 1998), used to measure harsh psychological discipline (five items) and harsh physical discipline (two items). All items were scored 0 = never, 1 = less often, 2 = monthly and 3 = weekly. Psychological discipline scores ranged from 0 to 15 and physical discipline 0–6.

Data analysis

Statistical analyses utilized SPSS v23 (Corp, 2014). The analyses were controlled for caregiver age and gender, child age and gender, country of residence, caregiver education, child orphanhood, child HIV status and number of people in the household by adding these variables as covariates to all the models. Chi-squared tests (for categorical variables) and one-way analyses of variance (ANOVAs) (for continuous variables) were used to examine simple differences between the three groups of interest at baseline. Logistic (for binary outcomes) and linear (for continuous outcomes) regression analyses were undertaken to look at the effects of carer and household HIV on child outcomes at baseline. Repeated measures ANOVAs were carried out to examine direct influences of family HIV burden on the progression of these same child outcomes over time. The SPSS macro PROCESS (Hayes, 2013) was used to perform mediation analyses at baseline and at follow-up. In the mediation analyses, family HIV burden was the predictor of interest, and caregiver depression, caregiver experience of stigma, physical violence as a form of discipline, domestic violence and community violence were all added simultaneously as mediators. Mediation analyses were controlled for the same variable as the linear and logistic regression analyses. All mediation analyses on child outcomes at follow-up were controlled for the same outcome at baseline. All confidence intervals (CIs) reported are 95%.

Results

Baseline descriptives

Overall, family HIV burden was high. At baseline, 19.8% ($n = 160$) of primary caregivers were HIV positive and 14.2% ($n = 115$) were HIV negative but lived in a household with an HIV-positive person. These two groups were compared with HIV-negative carers living in HIV-unaffected households (66.0%, $n = 533$).

Country of residence differed significantly between the three groups ($\chi^2 = 11.53$, $P = 0.003$); Malawi had disproportionally many HIV-positive caregivers. Caregiver education was also significantly different ($\chi^2 = 22.68$, $P = 0.031$), as the group where no one was HIV positive tended to be slightly lower educated, and a higher proportion of this group had no education at all. Caregiver age ($F(2, 805) = 19.89$, $P < 0.001$) was also significantly different; the HIV-positive caregivers were youngest, followed by those where no one was HIV positive. On average, those living in an HIV-affected household were oldest. Child orphanhood was highest among those who had HIV-positive caregivers and lowest among those living in an HIV-affected household ($\chi^2 = 45.05$, $P < 0.001$). The number of people in the household was higher for the families in the HIV-affected household than for the other two groups ($F(2, 698) = 18.06$, $P < 0.001$). In total, 21.9% of the children of the HIV-positive carers were also HIV positive. In HIV-affected households, 30.4% of the children were HIV positive, compared with 0% in households free of HIV ($\chi^2 = 154.74$, $P < 0.001$). Because we were interested in outcomes affected by carer HIV status over and above child HIV status, and because child HIV status differed between the three groups, it was controlled for in the analyses. The other demographics that differed significantly between groups were also controlled for.

As can be seen in Table 1, the children with HIV-positive carers or living in HIV-affected households had a significantly different quality of life ($F(2, 805) = 7.21$, $P = 0.001$) and higher internalizing problems ($F(2, 805) = 8.86$, $P < 0.001$) and externalizing problems ($F(2, 805) = 5.34$, $P = 0.005$). They also had higher general problem scores ($F(2, 805) = 10.40$, $P < 0.001$). Delinquency ($F(2, 805) = 4.29$, $P = 0.014$) and experience of stigma also differed significantly between the three groups. Lastly, children with HIV-positive carers or living in HIV-affected households also suffered significantly higher educational risk ($F(2, 762) = 3.08$, $P = 0.046$). The other child outcomes were not significant. Only the outcomes that differed significantly at baseline were retained for further analysis.

Caregiver depression was higher in the two HIV-affected groups compared with the HIV-unaffected group ($F(2, 805) = 7.34$, $P = 0.001$). Child experience of stigma differed significantly by group; experience of stigma was much higher in the group with HIV-positive carers compared with the other two groups ($F(2, 696) = 4.75$, $P = 0.009$). Household HIV burden was associated with a significant difference in the physical violence experienced by children as a form of discipline ($F(2, 805) = 4.94$, $P < 0.007$), as harsh physical discipline occurred more frequently in the two HIV-affected groups. Children also differed significantly in the extent to which they experienced domestic violence ($F(2, 800) = 8.30$, $P < 0.001$) and community violence ($F(2, 800) = 6.06$, $P = 0.002$), both of which were higher in the two HIV-affected groups than in the HIV-unaffected group. These variables were used as potential mediators in the subsequent regression models.

Baseline effect of carer HIV status on child outcomes

Controlling for the covariates caregiver age and gender, child age and gender, country of residence, caregiver education, child orphanhood, child HIV status and number of people in the household, household HIV burden was not directly associated with children's general behavioural problems ($B = 0.005$, $t(678) = 0.04$, $P = 0.96$). However, a mediated effect of household HIV burden on behavioural problems was found through caregiver depression ($B = 0.08$; $\mathrm{CI} = 0.02, 0.17$), exposure to harsh physical discipline ($B = 0.05$; $\mathrm{CI} = 0.01, 0.10$), exposure to community violence ($B = 0.03$; $\mathrm{CI} = 0.002, 0.08$) and child stigma ($B = 0.03$; $\mathrm{CI} = 0.005, 0.09$). This signifies that household HIV burden influenced child problem behaviour by being positively associated with caregiver depression, community violence, harsh physical discipline and stigma, which all four were in turn positively associated with child behavioural problems.

Breaking down the behavioural problems into subcategories, there was no direct effect of household HIV burden on child internalizing problems ($B = 0.003$, $t(678) = 0.04$, $P = 0.97$). However, an indirect effect was found through caregiver depression ($B = 0.06$; $\mathrm{CI} = 0.01, 0.12$), harsh physical discipline ($B = 0.02$; $\mathrm{CI} = 0.01, 0.05$) and stigma ($B = 0.03$; $\mathrm{CI} = 0.01, 0.09$). This shows that family HIV burden was positively associated with caregiver depression, harsh physical discipline and stigma, which were positively associated with child internalizing problems. Externalizing problems were also not directly associated with family HIV burden ($B = 0.01$, $t(678) = 0.12$, $P = 0.90$), but indirectly through caregiver depression

Table 1. Sample characteristics at baseline according to family HIV burden

	Carer HIV-positive ***n* = 160**	**HIV in the household** ***n* = 115**	**No one HIV-positive** ***n* = 533**	**Difference statistic (*P*-value)**
Demographics				
Child age	**8.24 (2.81)**	**8.70 (2.73)**	**9.28 (2.79)**	**9.29 (<0.001)**
Child gender[†]	76 (47.5%)	61 (53.0%)	282 (52.9%)	1.52 (0.47)
Caregiver age	**38.29 (10.33)**	**49.00 (15.80)**	**44.89 (15.41)**	**19.89 (<0.001)**
Caregiver gender[†]	151 (94.4%)	110 (95.7%)	507 (95.1%)	0.25 (0.88)
Caregiver education				
No education	**15 (9.4%)**	**15 (13.0%)**	**113 (21.2%)**	**22.68 (0.031)**
Some primary education	**57 (35.6%)**	**38 (33.0%)**	**160 (30.0%)**	
Primary education completed	**28 (17.5%)**	**19 (16.5%)**	**82 (15.4%)**	
Grade 10	**34 (21.2%)**	**28 (24.3%)**	**112 (21.0%)**	
Matric completed	**22 (13.8%)**	**14 (12.2%)**	**60 (11.3%)**	
Some tertiary education	**4 (2.5%)**	**1 (0.9%)**	**2 (0.4%)**	
Tertiary education completed	**0 (0.0%)**	**0 (0.0%)**	**4 (0.8%)**	
Country				
South Africa	**125 (78.1%)**	**107 (93.0%)**	**432 (81.1%)**	**11.53 (0.003)**
Malawi	**35 (21.9%)**	**8 (7.0%)**	**101 (18.9%)**	
Socio-economic outcomes				
Comfortable home	89 (55.6%)	70 (60.9%)	325 (61.0%)	1.52 (0.47)
Own bed	36 (22.5%)	27 (23.5%)	156 (29.3%)	3.75 (0.15)
Went to bed hungry	23 (14.4%)	16 (13.9%)	66 (12.4%)	0.53 (0.77)
Household employment				
Yes, every day	14 (8.8%)	12 (10.4%)	34 (6.4%)	5.96 (0.20)
Yes, sometimes	14 (8.8%)	5 (4.3%)	53 (9.9%)	
No employment	132 (82.5%)	98 (85.2%)	446 (83.7%)	
Child food security				
Child is well fed	103 (64.4%)	90 (78.3%)	384 (72.0%)	9.25 (0.16)
Child has enough to eat most days	34 (21.2%)	14 (12.2%)	73 (13.7%)	
Child frequently has less food than needed	19 (11.9%)	10 (8.7%)	65 (12.2%)	
Child rarely has food to eat	4 (2.5%)	1 (0.9%)	11 (2.1%)	
Family care and health				
Child HIV-positive	**35 (21.9%)**	**35 (30.4%)**	**0 (0.0%)**	**154.74 (<0.001)**
Orphanhood				
Yes, mother died	**14 (10.3%)**	**26 (26.3%)**	**83 (17.8%)**	**45.05 (<0.001)**
Yes, father died	**34 (25.0%)**	**7 (7.1%)**	**89 (19.1%)**	
Yes, both died	**11 (8.1%)**	**32 (32.3%)**	**86 (18.5%)**	
No one died	**76 (55.9%)**	**32 (32.3%)**	**201 (43.1%)**	
I don't know	**1 (0.7%)**	**2 (2.0%)**	**7 (1.5%)**	
Moved homes	11 (6.9%)	7 (6.1%)	42 (7.9%)	0.53 (0.77)
Care for younger kids	83 (61.0%)	52 (52.5%)	240 (51.5%)	3.89 (0.14)
Care for sick people	84 (61.8%)	59 (59.6%)	263 (56.4%)	1.36 (0.51)
Missed school to attend household duties	14 (10.3%)	8 (8.1%)	45 (9.7%)	0.34 (0.84)
Number of people in the home	**6.21 (2.78)**	**8.06 (4.05)**	**6.21 (2.54)**	**18.06 (<0.001)**
Discipline: physical violence	**0.68 (0.76)**	**0.64 (0.73)**	**0.50 (0.64)**	**4.94 (0.007)**
Discipline: psychological violence	0.86 (1.10)	0.94 (1.24)	0.73 (1.08)	2.07 (0.13)
Domestic violence	**1.44 (1.85)**	**1.38 (1.83)**	**0.94 (1.44)**	**8.30 (<0.001)**
Community violence	**0.75 (1.11)**	**0.75 (0.98)**	**0.52 (0.80)**	**6.06 (0.002)**
Carer outcomes				
Panic disorder	19 (11.9%)	12 (10.4%)	43 (8.1%)	2.41 (0.30)
Depression/anxiety	**5.73 (4.01)**	**5.79 (3.91)**	**4.68 (3.69)**	**7.34 (0.001)**
Child outcomes				
Enrolled in school	155 (96.9%)	111 (96.5%)	516 (96.8%)	0.03 (0.99)
Educational risk	**0.91 (1.15)**	**0.92 (1.11)**	**0.71 (0.98)**	**3.08 (0.046)**
Delinquency	**0.69 (1.13)**	**0.91 (1.44)**	**0.58 (1.07)**	**4.29 (0.014)**
Depression	1.23 (1.89)	0.89 (1.47)	1.02 (1.56)	1.56 (0.21)
Self-esteem	20.99 (2.98)	21.15 (2.71)	21.11 (2.83)	0.13 (0.88)

Continues

Table 1. (Continued)

	Carer HIV-positive *n* = 160	**HIV in the household** *n* = 115	**No one HIV-positive** *n* = 533	**Difference statistic (*P*-value)**
Stigma score	**0.75 (1.23)**	**0.47 (0.85)**	**0.46 (0.93)**	**4.75 (0.009)**
Community belonging	3.71 (0.63)	3.77 (0.55)	3.81 (0.56)	1.91 (0.15)
Trauma	3.68 (3.15)	3.74 (3.17)	3.47 (3.23)	0.48 (0.62)
Digit span	8.47 (4.41)	9.32 (3.70)	8.79 (3.97)	1.39 (0.25)
Draw-a-person	82.55 (20.96)	88.10 (16.11)	86.29 (18.37)	2.95 (0.053)
General behavioural problems	**3.33 (2.41)**	**3.65 (2.62)**	**2.70 (2.32)**	**10.40 (<0.001)**
Internalizing problems	**2.10 (1.68)**	**2.23 (1.75)**	**1.68 (1.42)**	**8.86 (<0.001)**
Externalizing problems	**1.23 (1.36)**	**1.43 (1.48)**	**1.02 (1.25)**	**5.34 (0.005)**
Quality of life	**89.34 (9.36)**	**89.48 (10.33)**	**92.16 (9.80)**	**7.21 (0.001)**
Physical functioning	96.09 (9.82)	97.39 (6.96)	96.66 (10.66)	0.56 (0.57)

Data are *n* (%) with difference statistic χ^2 or M (SD) with difference statistic *F*.
Bolded variables differed significantly between the three groups.
† Number of females.

($B = 0.02$; CI = 0.006, 0.06), harsh physical discipline ($B = 0.03$; CI = 0.005, 0.06) and community violence ($B = 0.02$; CI = 0.002, 0.05). Family HIV burden was positively associated with all three mediators, which were positively associated with externalizing problems.

Similar results were found using the same model to predict child delinquency at baseline. While there was no direct effect of family HIV burden on delinquency ($B = 0.01$, $t(678) = 0.24$, $P = 0.81$), a mediated effect was found through domestic violence ($B = 0.02$; CI = 0.005, 0.05) and community violence ($B = 0.02$; CI = 0.01, 0.05). Household HIV burden was positively associated with both types of violence, which were in turn positively associated with child delinquency. Similarly, no direct effect ($B = -0.34$, $t(678) = 0.79$, $P = 0.43$), but an indirect effect of family HIV burden on quality of life through caregiver depression ($B = -0.37$; CI = −0.74, −0.07) and domestic violence ($B = -0.10$; CI = −0.32, −0.0004) was found. Household HIV burden was positively associated with both mediators, which were in turn negatively associated with child quality of life. Finally, an indirect effect, but no direct effect ($B = 0.002$, $t(648) = 0.04$, $P = 0.97$), of household HIV burden on school attendance was found through caregiver depression ($B = 0.02$; CI = 0.003, 0.04) and harsh physical violence ($B = 0.01$; CI = 0.001, 0.03), meaning that household HIV burden was positively associated with both mediators which in turn were positively associated with educational risk.

Follow-up descriptives

Overall, there were fewer differences between the three groups at follow-up. Of all the outcome variables that had been significantly different between groups at baseline, only domestic violence ($F(2, 798) = 3.30$, $P = 0.037$) and quality of life ($F(2, 805) = 3.50$, $P = 0.031$) were still significantly different at follow-up (Table 2).

Follow-up effect of carer HIV status on child outcomes

Using repeated measures ANOVA, no effects of household HIV burden on change over time in child outcomes were found. However, mediation analyses revealed several indirect effects of family HIV burden at baseline on child outcomes at follow-up. Family HIV burden affected child behavioural problems at follow-up indirectly through carer depression at baseline ($B = 0.05$; CI = 0.01, 0.11) and stigma ($B = 0.03$; CI = 0.003, 0.10). Internalizing problems was indirectly affected by family HIV burden through caregiver depression ($B = 0.03$; CI = 0.01, 0.07) and stigma ($B = 0.02$; CI = 0.001, 0.06). Externalizing problems was only indirectly affected by family HIV burden through caregiver depression ($B = 0.02$; CI = 0.004, 0.05).

CBO service access by family HIV burden

Access to CBO services differed between the three groups. Families with an HIV-positive caregiver were significantly more likely to receive or have access to medical services from the CBO – 25.0% of HIV-positive carers, 10.4% of HIV-affected households and 6.0% of HIV-unaffected families ($\chi^2 = 47.67$, $P < 0.001$). Access to material services also differed significantly by group. Overall, 53.8% of the HIV-positive carers, 70.4% of HIV-affected households and 58.2% of HIV-unaffected families received material supplies from the CBOs ($\chi^2 = 8.20$, $P = 0.017$). Lastly, there was a significant difference between the groups when measuring access to education services with 18.1% of the HIV-positive carers, 32.2% of the

Table 2. Simple differences at follow-up between family HIV burden groups on outcomes that also significantly differed between groups at baseline

	Carer HIV-positive *n* = 160	Carer HIV-negative but HIV in household *n* = 115	No one HIV-positive *n* = 533	Difference statistic (*P*-value)
Educational risk	0.79 (1.03)	0.75 (1.02)	0.83 (1.12)	0.36 (0.74)
Delinquency score	0.60 (1.12)	0.59 (1.13)	0.58 (1.18)	0.02 (0.98)
Domestic violence score	**1.11 (1.64)**	**0.80 (1.22)**	**0.80 (1.32)**	**3.30 (0.037)**
Community violence score	0.68 (0.81)	0.59 (0.78)	0.60 (0.80)	0.72 (0.49)
Harsh physical discipline	0.51 (0.76)	0.46 (0.64)	0.39 (0.57)	2.39 (0.093)
Quality of life	**91.92 (9.88)**	**93.84 (7.32)**	**93.70 (7.09)**	**3.50 (0.031)**
Internalizing problems	1.89 (1.84)	1.63 (1.79)	1.66 (1.58)	1.33 (0.26)
Externalizing problems	1.33 (1.59)	1.10 (1.31)	1.11 (1.30)	1.74 (0.18)
General problem score	3.23 (2.77)	2.73 (2.36)	2.77 (2.36)	2.32 (0.099)

Data are M (SD) with difference statistic *F*.
Bolded variables differed significantly between the three groups.

HIV-affected households and 25.7% of the HIV-unaffected households received extra educational support ($\chi^2 = 7.30$, $P = 0.026$). The three groups did not differ in the receipt of psychological services, child support, parenting interventions, home visits, referrals to social services or help with accessing grants (Fig. 1).

Discussion

Good caregiving is important for children to thrive, but adversity can affect the capacity of parents to provide optimal care (Cooper *et al.* 2009), and HIV in caregivers has been found to negatively affect child outcomes (Sherr *et al.* 2014; Stein *et al.* 2014). Much of the research on child outcomes in the presence of adult HIV assumes that caregiving is vested in the hands of a single individual, most often thought to be the biological mother. In this study, we found that both children with HIV-positive carers or living in HIV-affected households were significantly worse off than children living in homes that were HIV free.

When controlling for a number of factors at baseline, household HIV burden was associated with caregiver depression, community violence, harsh physical punishment and stigma, which in turn was indirectly associated with a range of

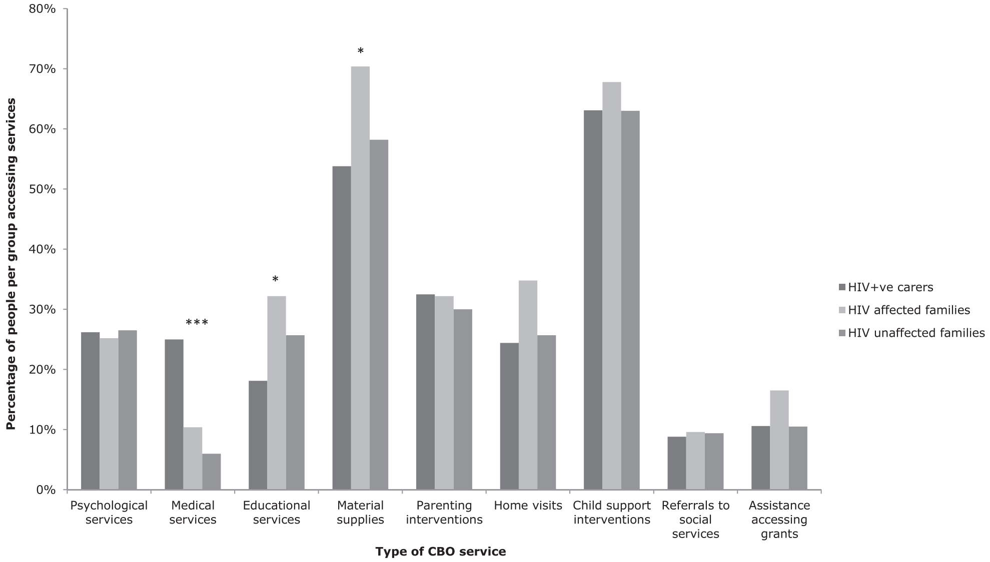

Figure 1. Percentage of people accessing different community-based organization (CBO) services broken down by family HIV burden. Significant differences in service access between groups were found for medical services, educational services and the reception of material supplies. Differences were assessed using chi-squared test. $^*P < 0.05$, $^{***}P < 0.001$.

poor child outcomes. At follow-up, caregiver depression was the major driver behind the link between family HIV burden and poorer child outcomes. Caregiver or household HIV predicted increased behavioural problems over time. School attendance was negatively affected by caregiver and household HIV. Furthermore, despite the need, children with a family HIV burden received less educational support from the CBO. HIV-infected and HIV-affected families received more support in terms of medical and material services yet few of the more psychosocial services that they could well benefit from. It may be that HIV diverts or distracts service provision or that the full array of needs is not comprehensively met, either through lack of availability or a perception that biomedical services are a higher priority for such families.

In southern African countries most affected by HIV, the complexity of family structures and models of caregiving matter. Children grow up in households where their needs may be met by a variety of individuals (Tomlinson *et al.* 2014). HIV clusters in families, and those families affected by the disease also live in adverse circumstances often exposed to several other risk factors (Skeen *et al.* 2016). This study shows that HIV status in other household members, including but not limited to the primary caregiver, is an important consideration in assessing a child's level of risk.

The role of different types of violence in predicting child outcomes in this sample has been explored in detail (Sherr *et al.* 2016; Skeen *et al.* 2016). In these analyses, the additional effect of poor caregiver mental health and its relationship with HIV was further explored. HIV and mental health problems are closely linked in a bidirectional relationship: HIV infection can lead to mental health problems (Patel *et al.* 2007; Kuo *et al.* 2014), while those who have mental health problems or abuse substances are at increased risk of contracting HIV (Stevens *et al.* 2003). This additional risk for poor mental health associated with HIV is particularly relevant for child development. People with HIV may suffer economic hardship, unemployment and stigma, which may result in them residing in more challenging, impoverished and violent neighbourhoods. There are mental health consequences of status disclosure. Research has shown a clear link between maternal/paternal mental health and poorer child outcomes (Tomlinson *et al.* 2014). Depressed adults may be more likely to use harsh physical punishments – perhaps driven by depression, challenges in managing children while focusing on their own health management or competing stressors associated with HIV (Kelley *et al.* 2015).

There is good evidence from a range of studies that interventions delivered by community health workers can reduce depression (Van Ginneken *et al.* 2013) and child outcomes can improve in the context of community-based delivery of support to caregivers (Tomlinson *et al.* 2014). There are also ongoing trials examining the impact of community-based treatment of maternal depression (Lund *et al.* 2015). CBOs are well placed to deliver such interventions. These should include interventions specifically focused on parenting and child behaviour problems. Provision of educational and psychological services either directly from the CBO or via a referral system may be warranted for children living with an HIV-positive caregiver or within a household with HIV-positive members.

The study was based in the community with a number of limitations to be considered before findings can be generalized. HIV status was based on caregiver report and not confirmed with biological testing. Such reports have been shown to be reliable, but unknown or unreported HIV is possible. Biological testing may have been an alternative strategy. Another limitation was that the response rate at follow-up was 86%, and thus, the findings may not generalize totally. For the analysis of household HIV, the sample size did not allow for a more fine-grained analysis on who in the household was affected by HIV. A more detailed study would be needed to explore various roles within extended households. Despite this, this is one of the largest community-based studies available to explore the effects of adult HIV on child outcomes.

Our data suggest that such effects are clearly visible in some areas and at times mediated by complex factors associated with HIV infection and perhaps environmental poverty and circumstance. The lack of specialized mental health provision was of note and the fact that CBO input seemed beneficial over time was also an important finding. CBO enhancement with parenting, mental health provision and addressing violence may be of specific utility in protecting vulnerable young children.

Key messages

- Family HIV burden has been found to adversely affect child outcomes.
- Caregiver depression was found to be a key driver in the association between household HIV burden and negative child outcomes.
- In settings that lack specialised mental health provision, community-based interventions, found to be beneficial over time, may be well placed to alleviate caregiver depression in the presence of HIV and may help to disrupt adverse child outcomes.

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Author contributions

L. S., M. T. and S. S. designed and carried out the study. The team conceptualized the paper. S. S., I. H. and A. M. lead the data analysis. L. S. primarily wrote up the manuscript, and all other authors contributed substantially to drafting, interpreting and writing. All authors have read through the manuscript and agreed to its submission.

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