

Policy Brief: Pathways from parental AIDS to psychological, educational and HIV risks for children.

Citation: Cluver, L, Orkin, M, Boyes, M, Sherr, L, Makhasi, D, Nikelo, J. (2013). Pathways from parental AIDS to child psychological, educational and sexual risk: developing an empirically-based theoretical model

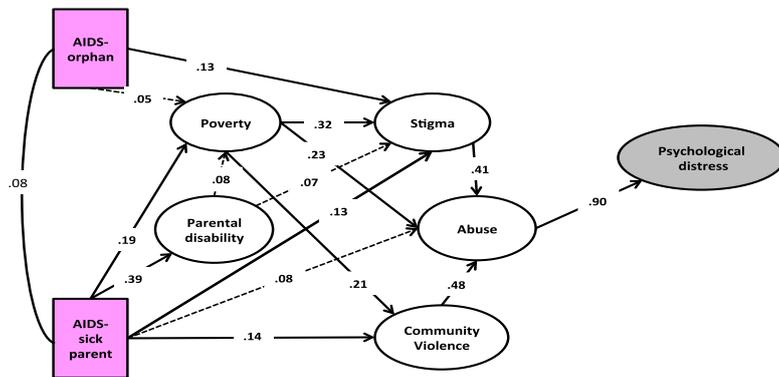
The Questions:

- Evidence shows that parental AIDS-illness and death have severe negative impacts on children. But we need to understand *why* AIDS has these effects.
- This study aims to identify these pathways, and thus identify important targets for interventions.
- 3 key outcomes are examined: psychological, HIV-infection risks and educational

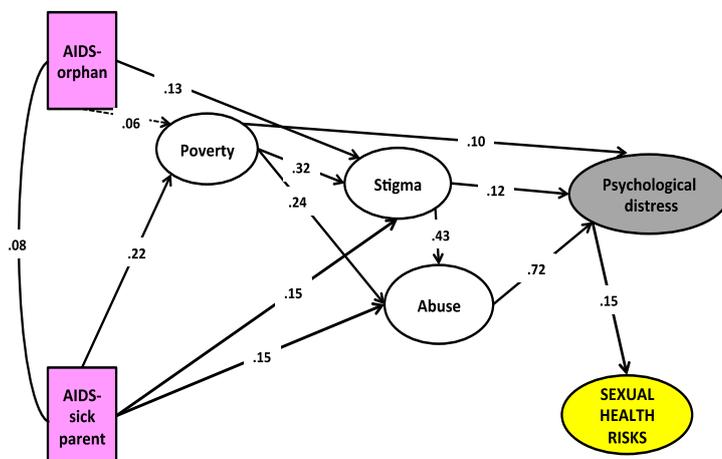
The Research:

- Cross-sectional survey of 6002 children aged 10-17
- Rural and urban sites in the Western Cape, Mpumalanga, and KwaZulu-Natal, South Africa.
- Validated scales and symptom checklists were used. Structural equation modelling in AMOS 19 identified pathways of risk.

Pathways to psychological risks



Pathways to HIV-infection risks



Key findings:

- AIDS orphanhood and parent AIDS-illness impact children through a set of linked factors. Family AIDS increases likelihood of parental disability, poverty, community violence, stigma and child abuse, and these in turn negatively impact children.
- These risk pathways work in chain effects – they link with each other to increase risks further
- We may not be able to reverse AIDS-orphanhood, or have a cure for HIV in the immediate future. But we *can* improve outcomes for AIDS-affected children by targeting interventions at these risk pathways.

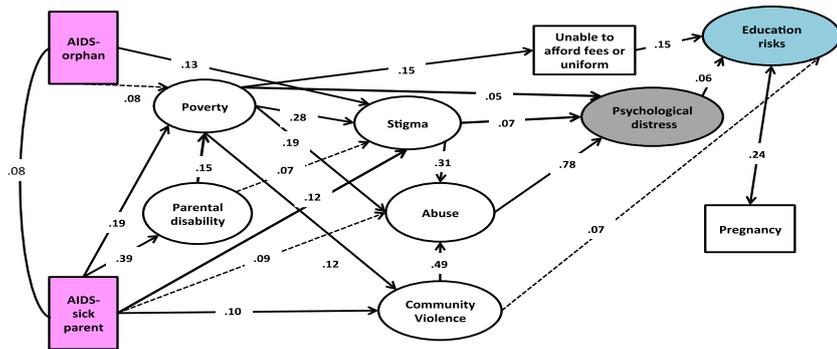
AIDS-orphanhood and parental AIDS-illness raise risks of poverty and parental disability.

Through these linkages, AIDS-affected children are more likely to be stigmatised outside the home, and exposed to physical, emotional and sexual abuse or rape.

It is these 'interlinking factors' that cause psychological distress such as depression, anxiety and suicidal behaviour.

And it is psychological distress that leads to higher rates of HIV infection risks (such as transactional sex, low condom use) amongst AIDS-affected adolescents.

Pathways to education risks



Education risks are also higher amongst AIDS-affected children. Parental AIDS raises levels of poverty, which leads directly to non-enrolment through inability to afford fees or uniforms.

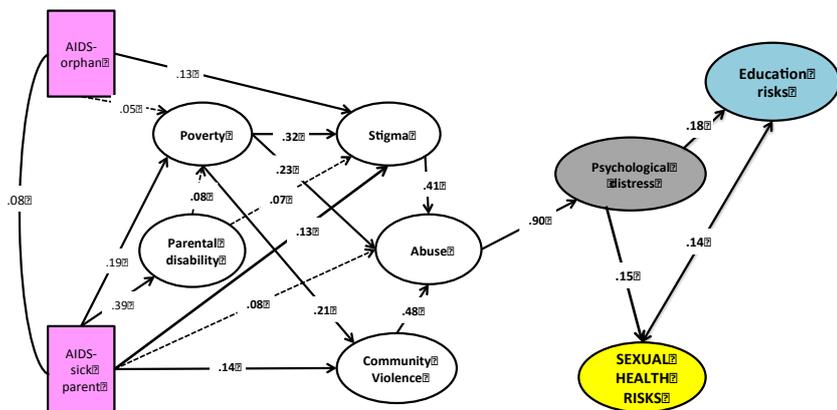
Children in AIDS-affected families also have more exposure to community violence (such as being robbed, seeing someone shot) – this is also linked to education risks such as non-attendance.

Parental AIDS also raises education risks such as grade failure through psychological distress.

Psychological, educational and HIV-infection risks are also linked with each other, causing multiple risks for AIDS-affected children.

In all models, living with an AIDS-unwell parent had stronger links to negative outcomes than AIDS-orphanhood, but both predicted negative child outcomes. Girls and older children were worst affected overall.

Combined pathways of risk



Implications for programming:

- Targeting programmes at these intervening factors such as hunger and abuse can interrupt pathways of risk for AIDS-affected children
- Many of these factors have good evidence of effective interventions, for example cash transfers to reduce poverty, and parenting support programmes to reduce abuse.

This research is a collaboration between the South African government, the National Action Committee for Children Affected by AIDS (NACCA), Oxford University, & the Universities of Oxford, KwaZulu-Natal, Cape Town and Witwatersrand.

This research was generously funded by:



Policy Brief: The Protective Role of Social Support for Caregiver Mental Health

Selected citations:

- Casale, M, Wild, L, Cluver, L, Sello, L and Kuo, C (In press). *The relationship between social support and anxiety among caregivers of children in HIV-endemic South Africa. Psychology, Health and Medicine.*
- Casale, M., Wild, L., & Kuo, C. (2013). "They give us hope": HIV-positive caregivers' perspectives on the role of social support for health. *AIDS Care*, doi:10.1080/09540121.2013.763893.

Primary caregivers of children in poor HIV-endemic communities represent a high risk population for mental health conditions, given the challenges associated with caring for biological and foster children in difficult social and financial conditions. This may be especially true if caregivers are living with HIV or other chronic illness. Studies from many parts of the world have shown social support (emotional and tangible support from friends, family and the broader community) to be a protective factor for health. However, no large studies have previously explored the relationship between social support and health with caregiver populations in HIV-endemic areas of southern Africa. Also, in southern Africa and beyond, there are gaps in our understanding of *how* social support may be positively influencing health. Yet this understanding is central to developing effective interventions. The mixed methods research described below aimed to determine whether more social support was associated with better caregiver mental health, and to explore caregivers' perceptions of how social support was affecting their health.

The Questions:

- Is more available social support associated with lower odds of depression and anxiety among caregivers of children in poor, HIV-endemic communities?
- What are the pathways and mechanisms through which caregivers perceive social support to be influencing their health?

The Research:

- Cross-sectional survey of 2477 adult caregivers of children aged 10-17 years in a rural and urban site in KwaZulu-Natal, South Africa (Young Carers KwaZulu-Natal Study)
- Qualitative follow-up study with 24 male and female caregivers (12 HIV-positive, 12 HIV-negative) who participated in the survey.

Finding 1: Living with HIV or other chronic illness was associated with worse caregiver mental health

Analysis of the survey data showed that:

- caregivers living with HIV were about **four times** more likely to be experiencing anxiety or depression than healthy caregivers
- caregivers living with other chronic illness were **about twice** as likely to be experiencing anxiety or depression than healthy caregivers

Finding 2: More social support was associated with better caregiver mental health

- Caregivers who reported having more available social support were less likely to be experiencing anxiety or depression than caregivers who reported having less support.

Finding 3: Pathways explaining the support – mental health relationship

The qualitative data showed that caregivers perceived social support to be positively influencing their mental health in various ways:

- By providing them with the opportunity to communicate their problems and receive advice
- By boosting their self-esteem, confidence and hope, which are factors associated with greater resilience
- By encouraging them to cope more proactively with stressors, e.g. by tackling problems more directly
- By reducing 'rumination', that is: by preventing caregivers from repetitively and negatively thinking about the causes of their illness and their imminent death.

Conclusions:

- Emotional and instrumental social support can be protective for the health of caregivers of children in HIV-endemic communities, whether or not they are living with HIV or other illness. Social support should be a key element of mental health interventions.
- Qualitative findings suggest that social support could be positively influencing caregiver mental health in various ways, for example by boosting psychological factors associated with resilience and encouraging them to cope with stress in ways that may be more beneficial for their health. It is important to instil hope among HIV-positive individuals in particular and to protect (particularly HIV-positive and/or female) caregivers from social isolation.

This research was generously funded by:

Policy Brief: Adolescent pregnancy among sexually-active South African girls

Citation: Toska, E, Cluver, L, Boyes, M, Pantelic, M, Kuo, C, Masiya, A. (under review). From Sugar Daddies to Sugar Babies – Quantitatively exploring the pathway between inequitable sexual relationships, condom use, and adolescent pregnancy in South Africa. Journal of Family Planning and Reproductive Health Care.

Adolescent pregnancy has been linked to negative outcomes for both mothers and children. Most studies exploring the risk factors contributing to adolescent pregnancy in South Africa are qualitative, with few quantitative studies exploring the pathways through which these factors result in pregnancy. Qualitative research suggest adolescent pregnancy is linked to unequal relationships and reduced condom use. This research project is a collaboration between the South African government, the National Action Committee for Children Affected by AIDS (NACCA), the Universities of Oxford, Cape Town and KwaZulu-Natal.

The Questions:

- What were the risk factors for adolescent pregnancy among sexually-active South African girls living in areas of high HIV prevalence?
- What was the relationship between adolescent pregnancy, unequal sexual relationships and condom use?

The Research:

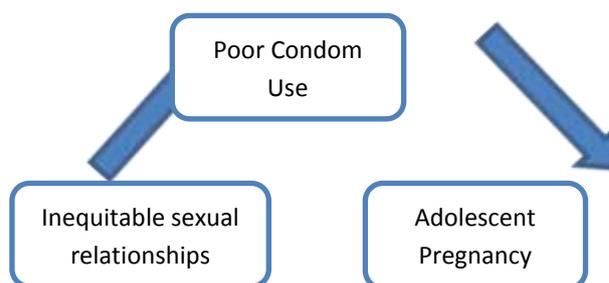
- Cross-sectional survey of 3,336 girls aged 10-19, 447 of whom were sexually active.
- Location: rural and urban sites in the Western Cape, Mpumalanga, and KwaZulu-Natal.
- Unequal (or *inequitable*) sex was measured as sex with an older partner (>5yrs) or transactional sex.

Finding 1: Risk factors for adolescents pregnancy among sexually-active South African girls

- 20.4% of sexually active girls were pregnant, though rates varied by province.
- Girls who reported inconsistent condom use were nearly **9 times** more likely to report pregnancy.
- Girls who engaged in inequitable sex – that is sex with an older partner or transactional sex – were **1.6 times** more likely to have been pregnant.
- Girls who reported long-term school absences were nearly **4 times** more likely to have been pregnant.
- Girls who were enrolled in schools were **75% less likely** to report pregnancy, while those enrolled in free schools were nearly **80% less likely** to report pregnancy.

Finding 2: Condom use mediates the relationship between inequitable sexual relationships and adolescent pregnancy

- Girls who engaged in inequitable sexual relationships fell pregnant primarily because of lower levels of condom use.
- Potential reasons for lower condom use in inequitable sexual relationships include inability to negotiate condom use, and lack of access to condoms when engaging in inequitable sexual relationships.



Conclusions:

- Unequal sexual relationships, inconsistent condom use and prolonged school absences were key risk factors for adolescent pregnancy among sexually-active girls.
- Girls who had inequitable sexual relationships were more likely to be pregnant, because in these relationships they reported lower condom use.
- Interventions must address adolescent girls' inability to negotiate condom use in inequitable relationships and increase their access to other family planning methods.

This research was generously funded by:

Policy Brief: PTSD among caregivers of orphaned and vulnerable children

Citation: Kuo, C, Reddy, M, Operario, D, Cluver, L, Ndlovu, L, Stein, D (2013) Posttraumatic stress symptoms amongst adults caring for orphaned children in HIV-endemic South Africa. AIDS and Behavior. 17(5):1755-63

PTSD is a psychiatric disorder that can occur to individuals exposed to traumatic events. Individuals with PTSD experience emotional and psychological reactions triggered by trauma-related stimuli that significantly impact their functioning in daily life. Our knowledge of PTSD among HIV affected populations is limited, especially among caregivers of orphaned and vulnerable children. These caregivers may be at high risk for PTSD since they are often grappling with potentially traumatic experiences of familial illness and death whilst also supporting orphaned children. This study aimed to establish rates of PTSD among caregivers of AIDS-orphaned and other vulnerable children and identify protective factors for PTSD.

The Questions:

- What are the types of traumatic events linked to PTSD among caregivers of children in HIV-endemic communities?
- What is the prevalence of PTSD among caregivers of AIDS-orphaned and other vulnerable children?
- What are the protective factors for PTSD?

The Research:

- Cross-sectional survey of 1599 adult caregivers in KwaZulu Natal Province
- Life Events Checklist was used to identify traumatic events
- Harvard Trauma Questionnaire was used to assess PTSD symptoms

Finding 1: Many caregivers experienced traumatic events

- 60% of caregivers reported experiencing, witnessing, or hearing of a traumatic or life threatening event happening to someone they know.
- The unexpected death of someone close (30%), life threatening injuries or illnesses (19%), and sudden or violent deaths (13%) were some of the most frequently reported traumatic events.
- Not everyone develops PTSD after a trauma. Among the caregivers who reported that the traumatic event was still bothering them (n=116), 22% reported PTSD.

Finding 2: Caregivers of orphaned children at higher risk for PTSD compared to caregivers of non-orphaned children

- Caregivers of AIDS-orphaned and other orphaned children (e.g., children orphaned through violence, etc.) were significantly more likely to report PTSD (28%) than caregivers of non-orphaned children (10%).

Finding 3: Grants protect against PTSD

- The old age pension is a potential protective factor for PTSD among caregivers.

Conclusions:

- Many caregivers of children in HIV-endemic communities experience traumatic events. Many of these events are related to death or illness.
- Rates of PTSD among caregivers are slightly lower than national averages, but still significant. Notable is that PTSD is much more likely to occur among caregivers of AIDS-orphaned and other-orphaned children.
- The old age pension may serve as a protective factor for PTSD among caregivers of orphaned children.

This research was generously funded by: US National Institute of Mental Health (F31MH081820 and K01 MH096646-01A1 to Dr. Caroline Kuo), the Leverhulme Trust (F08-599C to Dr. Don Operario), the Health Economics and HIV and AIDS Research Division at University of KwaZulu-Natal, the Economic and Social Research Council (ESRC), the Claude Leon Foundation, The John Fell Fund and the National Department of Social Development.

Policy Brief: Positive parenting in families affected by HIV and AIDS

Citation: Lachman, J.M., Cluver, L., Boyes, M., Kuo, C., Casale, M., Impact of HIV/AIDS on parenting behavior in South Africa: the mediating role of depression and poverty. AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 2013.

Families affected by HIV/AIDS in the developing world experience higher risks of psychosocial problems than non-affected families. Positive parenting behaviour – generally conceptualized as involved, nurturing, and accepting behaviour – may buffer against the negative impact of child AIDS-orphanhood and caregiver AIDS-sickness on child wellbeing. Although there is substantial literature regarding the predictors of parenting behaviour in Western populations, there is insufficient evidence on HIV/AIDS as a risk factor for poor parenting in low- and middle-income countries. This study examines the relationship between HIV/AIDS and positive parenting with poverty, caregiver depression, perceived social support, and child behaviour problems as potential mediating factors of this relationship.

The Questions:

- Do families with AIDS-ill caregivers or children orphaned by AIDS experience reduced positive parenting?
- What might be causing this?

The Research:

- Cross-sectional survey of 2477 caregiver-child dyads in KwaZulu-Natal Province
- Alabama Parenting Questionnaire was used to assess positive parenting
- Multiple mediation tests were conducted to using with poverty, caregiver depression, perceived social support, and child behaviour

Finding 1: Families with AIDS-ill caregivers and those with children orphaned by AIDS were associated with less positive parenting in comparison with non-affected families.

Finding 2: Familial HIV/AIDS's association to reduced positive parenting was mediated by poverty, caregiver depression and child behavior problems but not social support.

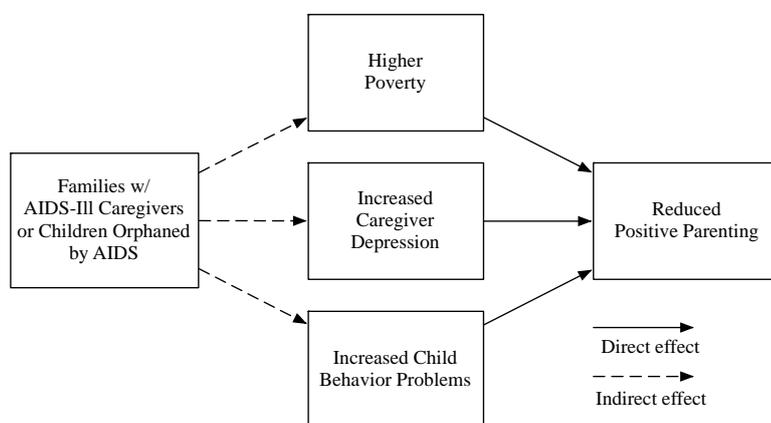


Figure 1. Multiple mediation model of familial HIV/AIDS's association with positive parenting.

Conclusions:

- Interventions targeted at strengthening child-caregiver relationships may require consideration of the broader social factors that influence parent behavior.
- Parenting interventions for HIV/AIDS affected families may need to incorporate cognitive behavioral or other strategies in order to adequately address parental depression.
- Parenting interventions may be more effective if integrated within a wider network of support services that address financial insecurity and family mental health.
- Parenting interventions may be more cost effective by targeting families living in high deprivation areas.

This research was generously funded by: the Health Economics and HIV and AIDS Research Division (HEARD) at the University of Kwazulu-Natal, the Economic and Social Research Council (UK), the National Research Foundation (SA), the National Department of Social Development (South Africa), the Claude Leon Foundation, the John Fell Fund, and the National Institute for Mental Health.

Policy Brief: Depression among caregivers of orphaned & vulnerable children

Citation: Kuo, C, Operario, D, Radebe, S & Cluver. L (2012) Depression among carers of AIDS-orphaned and other children in Umlazi Township, South Africa. Global Public Health. 7(3) 253-69

There is growing evidence of the mental health consequences faced by children orphaned and made vulnerable by HIV and AIDS. However, far fewer studies examine the mental health outcomes of adults caring for these children. We need a better understanding of the mental health outcomes of these caregivers. Depression is an especially important outcome to understand, given that HIV and depression are the leading causes of global burden of disease in low and middle income countries. This study examines the prevalence of depression among caregivers of AIDS-orphaned and other vulnerable children and identifies risk and protective factors for depression.

The Questions:

- What is the prevalence of depression among adults caring for children in HIV-endemic communities?
- Are caregivers of AIDS-orphaned and other vulnerable children at higher risk for depression?
- What are risk and protective factors for depression?

The Research:

- Cross-sectional survey of 1599 adult caregivers in KwaZulu Natal Province
- Sampling was based on a representative community sample
- The Center for Epidemiologic Studies Depression Scale was used to assess depressive symptomology

Finding 1: High rates of depression among adults caring for children

- 30% of adults caring for children in a HIV-endemic community reported depression.

Finding 2: Orphan caregivers at highest risk for depression

- Orphan caregivers – both those caring for AIDS-orphaned and other-orphaned children – were more likely to be depressed (35%) compared to non-orphaned caregivers (18%).
- Caregivers of AIDS-orphaned and other-orphaned children were at equally high risk for depression.

Finding 3: Risk and protective factors for depression

- Risk factors
 - Caregivers were 3.5x more likely to be depressed if their household was food insecure.
 - Caregivers were 2 times more likely to report depression if were female
- Protective factors
 - Caregivers had a 55% lower odds of depression if their household had steady salaried income.

Conclusions:

- Adults caring for children in HIV-endemic communities are at high risk for depression, with approximately 1/3 of all adult caregivers reporting depression.
- Orphan caregivers face an even higher risk for depression compared to caregivers of non-orphaned children. This elevated risk is not changed by the whether they are caring for an AIDS-orphaned other other-orphaned child, suggesting that the responsibilities of caring for an orphaned child, rather than cause of orphanhood, elevates risk for caregiver depression.
- Families in HIV-affected communities need mental health support.
- Given the level of need, we urgently need to generate evidence on efficacious and effective community-based interventions that can prevent and reduce risk depression among caregivers in HIV-affected communities.
- Interventions may want to consider a family-based approach, given the important dynamics of caregiving as a risk factor for caregiver depression.

This research was generously funded by: US National Institute of Mental Health (F31MH081820 and K01 MH096646-01A1 to Dr. Caroline Kuo), the Leverhulme Trust (F08-599C to Dr. Don Operario), the Health Economics and HIV and AIDS Research Division at University of KwaZulu-Natal, the Economic and Social Research Council (ESRC), the Claude Leon Foundation, The John Fell Fund and the National Department of Social Development

Policy Brief: Cumulative effects of HIV illness and caring for children orphaned by AIDS on caregiver anxiety

Citation: Kuo, C, Cluver, L, Casale, M, Lane, T, Radebe, S (Under Review) Cumulative effects of HIV illness and caring for children orphaned by AIDS on anxiety among adults caring for children in HIV-endemic South Africa

There is growing evidence that adults caring for children in HIV-endemic communities are at risk for poor psychological outcomes. However, we still have a limited understanding of how various HIV impacts – including a caregiver’s own HIV illness, responsibilities of caring for a child orphaned by AIDS, or both – affect psychological outcomes among caregivers. This study examined rates of anxiety among adults caring for children in HIV-endemic communities, and whether multiple simultaneous exposures to the impacts of HIV elevated risk for caregiver anxiety. This research is a collaboration between South African government, the National Action Committee for Children Affected by AIDS (NACCA), Oxford University, Brown University, and the University of KwaZulu-Natal.

The Questions:

- What are rates of anxiety among caregivers?
- Do multiple exposures to HIV elevate risk for caregiver anxiety?
- What role does stigma have on anxiety among caregivers affected simultaneously by HIV illness and caring for a child orphaned by AIDS?

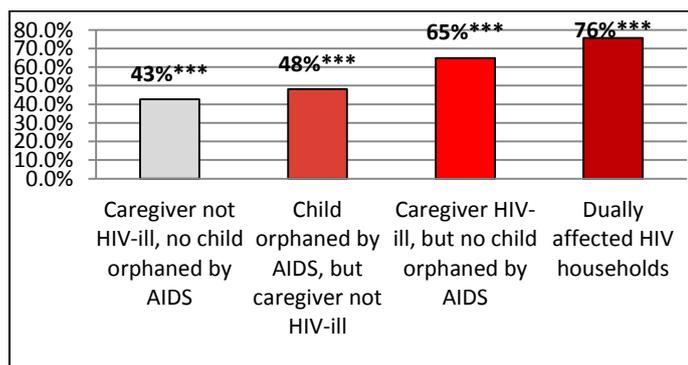
The Research:

- Cross-sectional survey of n=4954 caregivers and children aged 10-17 years in rural and urban sites in KwaZulu-Natal, South Africa
- Anxiety was measured using the Beck Anxiety Inventory

Finding 1: Caregivers affected by HIV are at high risk for anxiety

- 49% of caregivers reported anxiety.
- Dually affected caregivers were the most likely to report anxiety at 76%, followed by those caring for a child orphaned by AIDS but not living with HIV at 65%, followed by those living with HIV but not caring for a child orphaned by AIDS at 48%.

Figure 1: Rates of anxiety highest among dually affected caregivers



Finding 2: There is a cumulative effect of HIV exposure on caregiver risk for anxiety

- Simultaneous exposure to living with HIV and caring for a child orphaned by AIDS resulted in a cumulative risk for caregiver anxiety.
- After controlling for other factors, caregivers were 4 times more likely to report anxiety if they were dually affected by HIV illness and caring for a child orphaned by AIDS.

Finding 3: Stigma is an important factor in increased risk for anxiety

- Externalized stigma partially explains why cumulative exposure to HIV drastically elevates caregiver risk for anxiety.

Conclusions:

- Simultaneously living with HIV while caring for a child orphaned by AIDS cumulatively increases caregiver risk for anxiety.
- This cumulative impact of HIV exposure on risk for anxiety is partially mediated by the experience of externalized stigma.
- We need programs to prevent and reduce anxiety among caregivers, especially those living with HIV and caring for a child orphaned by AIDS. These programs need to address the effects of stigma associated with living with HIV and caring for a child orphaned by AIDS.

This research was generously funded by:

Policy Brief: TB in children with AIDS-affected caregivers

Citation: Cluver, L, Orkin, M, Kuo, C, Moshabela, M, Boyes, M. (2013). The hidden harm of home-based care: Pulmonary tuberculosis symptoms among children providing home medical care to HIV/AIDS-affected adults in South Africa. AIDS Care, 25, 748-755.

Millions of children undertake personal and medical care for family members who are unwell with HIV/AIDS. No research has examined whether such care provision places children at elevated risk for infectious diseases. This study aimed to identify risk factors for paediatric pulmonary TB symptoms in South African children. This research is a collaboration between South African government, the National Action Committee for Children Affected by AIDS (NACCA), Oxford University, and the University of KwaZulu-Natal.

The Questions:

- What are the risk factors for pulmonary TB symptoms in South African children?
- Is there a cumulative effect of identified risk factors on contracting pulmonary TB?
- What proportion of TB symptomatic children had been tested and received treatment?

The Research:

- Cross-sectional survey of 6002 children aged 10-17 years in rural and urban sites in the Western Cape, Mpumalanga, and KwaZulu-Natal, South Africa.
- Validated scales and symptom checklists were used.

Finding 1: Risk factors for pulmonary TB symptoms in South African children

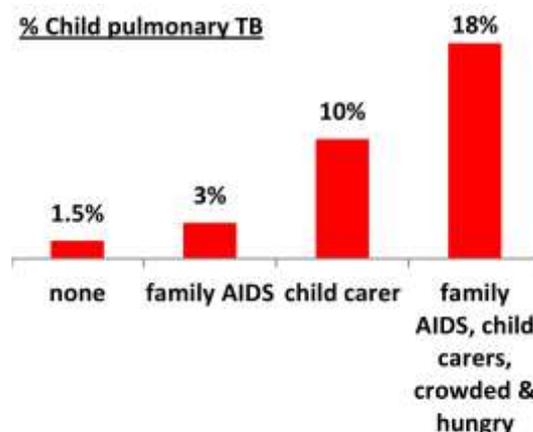
- Children who were *exposed to bodily fluids* whilst providing medical care were over **3 times** more likely to be TB symptomatic than children not exposed to bodily fluids.
- Children with an *AIDS-ill caregiver* were **1.6 times** more likely to be TB symptomatic than children whose caregiver was not AIDS-ill.
- Children who were *food insecure* were **1.5 times** more likely to be TB symptomatic than children who have enough to eat
- *AIDS-orphaned* children were **1.4 times** more likely to be TB symptomatic than children not orphaned by AIDS.
- Children living *in overcrowded conditions* were **1.4 times** more likely to be TB symptomatic than children in homes that were not overcrowded.

Finding 2: Cumulative effect of exposure to risk factors

- There was a clear cumulative effect of exposure to identified risk factors
- The proportion of TB symptomatic children rose from only **1.5%** among children exposed to none of the identified risk factors to **18%** amongst those exposed to all the risk factors

Finding 3: Proportion of symptomatic children who had been tested for TB and received treatment

- Only **25%** of TB symptomatic children had been tested for TB (sputum test)
- Of those who reported being tested or receiving a diagnosis only **11%** reported ever receiving treatment



Conclusions:

- Exposure to bodily fluids while providing care, having an AIDS-sick caregiver, food insecurity, being AIDS-orphaned, and household overcrowding are all risk factors for TB in South African children
- There is a cumulative impact of risk factors and children exposed to all these multiple risks are 12 times more likely to be TB symptomatic than children exposed to none.
- TB testing rates in symptomatic children are low, and improved health and community services are required.

This research was generously funded by: