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The hidden harm of Home-Based Care: Pulmonary tuberculosis symptoms among children
providing home medical care to HIV/AIDS-affected adults in South Africa

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Abstract

Millions of children in sub-Saharan Africa undertake personal and medical care for family members who are unwell with AIDS. To date, no research has investigated whether such care provision places children at heightened risk for pulmonary tuberculosis. This study aimed to address this gap by identifying risk factors for pediatric pulmonary tuberculosis symptomatology. In 2009-2011, 6002 children aged 10-17 were surveyed using door-to-door household sampling of census enumeration areas. These were randomly sampled from six urban and rural sites with over 30% HIV prevalence, within South Africa's three highest tuberculosis burden provinces. Validated scales and clinical tuberculosis symptom checklists were modeled in multivariate logistic regressions, controlling for sociodemographic co-factors. Findings showed that, among children, severe pulmonary tuberculosis symptomatology was predicted by primary caregiver HIV/AIDS-illness (OR1.63 CI1.23-2.15 $p<.001$), and AIDS-orphanhood (OR1.44 CI1.04-2.00, $p<.029$). Threefold increases in severe tuberculosis symptoms were predicted by the child's exposure to body fluids through providing personal or medical care to an ill adult (OR3.12 CI1.96-4.95, $p<.001$). Symptoms were also predicted by socioeconomic factors of food insecurity (OR 1.52 CI1.15-2.02, $p<.003$) and household overcrowding (OR1.35 CI1.06-1.72, $p<.017$). Percentage probability of severe tuberculosis symptoms rose from 1.4% amongst least-exposed children, to 18.1% amongst those exposed to all above-stated risk factors, independent of biological relationship of primary caregiver-child and other sociodemographics. Amongst symptomatic children, 75% had never been tested for tuberculosis. These findings identify the risk of tuberculosis among children providing home medical care to their unwell caregivers, and suggest that there are gaps in the health system to screen and detect these cases of pediatric tuberculosis. There is a need for effective interventions to reduce childhood risk, as well as further support for community-based contact-tracing, tuberculosis screening and anti-tuberculosis treatment for children caring for ill adults in contexts with a high burden of HIV and tuberculosis.

Introduction

In 2006, Richter, Foster and Sherr highlighted that ‘the impact of chronic parental illness on children is one of the most poorly understood and neglected difficulties faced by AIDS-affected children’ (2006). Since then, emerging evidence from sub-Saharan Africa has demonstrated that children whose primary caregivers are unwell with AIDS experience heightened health and developmental risks such as elevated rates of psychological distress (Bauman et al., 2006; Cluver, Orkin, Boyes, Gardner, & Nikelo, 2012) and reduced access to education (Evans & Becker, 2010; Guo, Li, & [Sherr, 2012](#); Robson, 2000).

In addition, this group of ‘Young Carers’ often undertake a high burden of personal and medical care for the AIDS-unwell person, including washing, feeding and administering medication ([Bauman, et al., 2006](#); [Skovdal & Ogutu, 2009](#)). Qualitative findings suggest that this may have positive impacts on children’s sense of responsibility and identity as an important contributor to the family (Skovdal, Ogutu, Aoro, & Campbell, 2010). However, no known studies to date have examined whether children’s provision of care is also linked to increased risk of illness themselves, including transmission of highly-communicable HIV-associated infections such as tuberculosis (World Health Organisation, 2011b).

Symptomatic pulmonary tuberculosis in childhood – when untreated – brings high risks of mortality and long-term disability. In South Africa, 50,474 case notifications for tuberculosis were made for children under the age 15 in 2011 (World Health Organisation, 2011b), with pulmonary tuberculosis the most common manifestation. However, it is likely that there are many more cases of tuberculosis among children because the majority of pediatric tuberculosis cases remain untested and are not reported (Marais, Hesselning, Gie, Schaaf, & Beyers, 2006), partly due to difficulties in diagnosis and low frequency of childhood screening (Dye et al., 2006; Marais, Obihara, et al., 2005).

Pediatric tuberculosis is acquired predominantly through contact with adults ([Loeffler, 2003](#))

including living with a tuberculosis-infected adult (Sinfield, Nyirenda, Haves, Molyneux, & Graham, 2006) or presence of an infectious adult with tuberculosis in nearby households (Middelkoop, Bekker, Morrow, Zwane, & Wood, 2009). Studies in Southern Africa have identified additional risk factors for acquisition of pediatric tuberculosis including household overcrowding, under-nutrition ([Beisel, 1996](#)), being orphaned (amongst HIV-positive children) ([Braitstein et al., 2009](#)) and exposure time, ventilation and period of adult infectivity ([Wood et al., 2010](#)). Research in the developing world has demonstrated that adult providers of care, such as medical personnel and lay health providers, are at increased risk of contracting tuberculosis from patients (Joshi, Reingold, Menzies, & Pai, 2006). However, little is known about the prevalence and risks for pediatric tuberculosis within the context of familial AIDS-illness and childhood provision of care (Middelkoop, et al., 2009; UNAIDS, 2010).

This study aimed to identify: i) whether orphanhood status (by AIDS or other causes) and caregiver illness (by AIDS or other chronic illness) are associated with increased risk of pediatric pulmonary tuberculosis symptomatology; ii) whether there are associations of tuberculosis symptoms with other hypothesised risk factors including care provision; and iii) whether there are cumulative effects of risk factors on pediatric pulmonary tuberculosis symptoms.

Methods

Globally, South Africa is the only 'highest tuberculosis burden country' that has a rising tuberculosis rate (World Health Organisation, 2011a). This is closely linked to the HIV epidemic, with an estimated 60% of adult tuberculosis patients co-infected with HIV (World Health Organisation, 2011b). This cross-sectional community-based survey¹ was conducted in

¹ This was part of a wider study on health and educational outcomes for children in HIV/AIDS-affected families, and was planned in collaboration with the South African government departments of Social Development, Health and Education, and with NGOs

South Africa's three highest tuberculosis-burden provinces: Western Cape, KwaZulu-Natal, and Mpumalanga (Abdool Karim, Churchyard, Abdool Karim, & Lawn, 2009), in six health districts with over 30% antenatal HIV-prevalence. Sites comprised deep rural, dense rural, farming rural, peri-urban, urban and urban-homeland areas. Within these sites, stratified random sampling of census enumeration areas (or designated tribal areas in rural areas) and door-to-door consecutive household sampling was used. A community-based sample, rather than hospital or clinic contact-sampling, was chosen due to low levels of testing and notification for both HIV and tuberculosis ([Marais, Hesselning, et al., 2006](#)). Participants included one randomly-selected child from all those aged 10-17 years per household (n=6002), with data collection between November 2009 and June 2011. Children were interviewed at home, in community centres or in a private room in their school, thus ensuring inclusion of both school-attending and non-attending children.

Procedures: Ethical approval was given by University of Oxford, University of Cape Town, University of KwaZulu-Natal, and Provincial Health Departments of Western Cape, Mpumalanga and KwaZulu-Natal. Both children and primary caregivers gave written voluntary informed consent, with 97.2% response rate. Confidentiality was maintained, except where children were at risk of significant harm, in which case referrals to health and social services were made. All children (and where possible, their families) reporting severe tuberculosis symptomatology were directly supported by the research team to access health services. With the assistance of experienced interviewers, children completed 40-60 minute questionnaires in the language of their choice, including a symptom-based tuberculosis checklist and hypothesized risk and protective factors. Symptom checklists have been used extensively in South Africa to identify current pulmonary tuberculosis in clinical and research practice (Kruk, Gie, Schaaf, & Marais, 2008; Marais et al., 2006; Marais, Gie, et al., 2005), partly due to limitations in the use of biomarkers: low reliability of sputum tests amongst

including UNICEF and Save the Children.

children in South Africa (Feja & Saiman, 2005; World Health Organisation, 2011b), high levels of false-negative and false-positive tuberculin skin tests – which indicate infection rather than disease (Marais, Obihara, et al., 2005) – and challenges in assessing child chest radiographs (Gie, 2003). All survey items were pre-piloted with a child advisory group of 14 youth, independently piloted in child focus groups prior to use, and were translated and back-translated into isiXhosa, isiZulu, siSwati, Sesotho, and Xitsonga. Copies of all scales and items used in the study are available on www.youngcarers.org.za.

Measures: Outcome: *Pulmonary tuberculosis symptoms:* An 8-item symptom checklist was derived from the World Health Organisation's Practical Approach to Lung Health (Ottmani, 2005) and the South African National Department of Health (2007). Symptoms were: past-month serious cough >3 weeks, discoloured sputum, chest pains, fatigue/weakness, weight loss, night sweats, fever and coughing blood. To distinguish children with severe pulmonary tuberculosis symptomatology, a conservative threshold was set of four or more symptoms of fever, discoloured sputum, fatigue, weight loss and night sweats *in addition to* two or more symptoms of coughing blood, chest pains and cough >3 weeks (Demissie, 2007).

Potential risk factors: *Potential sociodemographic risk factors* of urban/rural location, child gender, age and household overcrowding were measured using census items (Statistics South Africa, 2001). Household poverty was measured by household availability of the South African Social Attitudes Survey's top eight perceived necessities for children, such as three meals a day, enough money to pay for necessary medicine and for school fees (Barnes, Noble, Wright, & Dawes, 2009), and was dichotomised as lacking one or more basic necessities. Food insecurity was measured as insufficient food for more than 2 days in the past week, using a scale from the National Food Consumption Survey (Labadarios et al., 2003). Due to low levels of HIV testing in South Africa (Peltzer, Matseke, Mzolo, & Majaja, 2009) and unreliability of death certificates (World Health Organisation, 2011b), *cause of parental death and primary caregiver HIV/AIDS-illness* was determined using the symptom-based

Verbal Autopsy method ([Lopman et al., 2006](#)), validated in previous studies of adult mortality in South Africa, with sensitivity of 89% and specificity of 93% (Kahn, Tollman, Garenne, & Gear, 2000). A South African study of verbal autopsy reporting by 2,477 10-17 year-olds and their primary caregivers found 69%-99% child-caregiver agreement on HIV symptoms (E. Becker, Kuo, Operario, Cluver, & Moshabela, in submission). Determination of AIDS-related parental death or morbidity required a conservative threshold of three or more opportunistic infections; e.g. Kaposi's sarcoma, shingles and chronic diarrhea, as well as HIV-status where known and disclosed, and use of anti-retroviral medication. Orphanhood used the UN definition of loss of one or both parents before age 18 (UNAIDS, 2004). *Children's provision of personal and medical care and exposure to body fluids* was measured using a checklist based on the 'Young Carers Tasks and Outcomes Questionnaire' (S. Becker, 2009), adapted to the South African context after qualitative research and extensive pre-piloting (Cluver, Operario, Lane, & Kganakga, 2012). Personal or medical care included: administering medication, dressing, toileting or bathing, helping with mobility and massaging the chest to relieve respiratory symptoms. Exposure to body fluids included sputum and phlegm. Finally, in order to provide a tentative indication of access to tuberculosis-related health services amongst children, *rates of sputum testing and diagnosis (whether positive or negative)* were assessed with items developed in collaboration with the South African National Department of Health.

Analyses were conducted using multivariate logistic regression, controlling for sociodemographic co-factors of urban/rural location, child gender, age and whether children's primary caregivers were their biological parents. The model included the following hypothesized risk factors: household poverty, food insecurity and household overcrowding, adult illness status (HIV/AIDS-unwell, other chronic illness, healthy) and child orphan status (AIDS-orphaned, orphaned by other causes, non-orphaned), child provision of personal or medical care within their household, and whether care provision involved exposure to body fluids. In order to examine cumulative risks of significant factors whilst controlling for socio-

demographics, regression coefficients were substituted into the logistic regression equation to yield fitted probabilities (Bartholemew, Steele, Moustaki, & Galbraith, 2008). 95% confidence intervals (CI) are reported.

Results:

Sample characteristics

The mean age of children was 13.5 years (SD 2.8), with 55.6% (3337) female, 50% (3001) living in rural areas and 30% (1801) living with a primary caregiver who was not their biological parent. 13.5% (810) children were orphaned by AIDS, while 15.9% (95) were orphaned by other causes; 25.5% (153) lived with an AIDS-ill primary caregiver and 14% (840) with a primary caregiver with another chronic illness. On average children had moved homes 1.29 times (range: 0 – 11) and 32% of children had moved homes at least twice. 19.5% (117) of children experienced past-week food insecurity, 41.8% (251) lived in overcrowded conditions, 12.7% (762) undertook personal or medical care for an unwell person, with a fifth (149) of these children exposed to body fluids whilst undertaking home-based care. Overall, 285 children (4.7%) had severe pulmonary tuberculosis symptoms.

Predictors of severe child pulmonary tuberculosis symptomatology (Table 1)

Severe child tuberculosis symptoms were independently predicted by primary caregiver HIV/AIDS-illness (OR1.63 CI1.23-2.15 $p<.001$), but not by other primary caregiver chronic illnesses (such as cancer, diabetes), or by having a healthy primary caregiver. In addition, child tuberculosis symptoms were independently predicted by AIDS-orphanhood (OR1.44 CI1.04-2.00, $p<.029$), but not by other-orphanhood and non-orphanhood.

Child tuberculosis symptoms were also predicted by household crowding (OR1.35 CI1.06-1.72, $p<.017$) and child food insecurity (OR1.52 CI1.15-2.02, $p<.003$). Children's provision

of home personal or medical care per se did not predict severe tuberculosis symptoms, but when this home care involved exposure to body fluids such as sputum and phlegm it was strongly predictive, with a more than threefold increase in children's likelihood of severe pulmonary tuberculosis symptoms (OR3.12 CI1.96-4.95, $p<.001$).

Cumulative effects of risk factors on child tuberculosis symptoms

Independent of child age, gender, urban/rural location, household poverty, non-AIDS orphanhood, caregiver other chronic illnesses, and relationship of child to the primary caregiver, there was a clear cumulative effect of identified risk factors on child pulmonary tuberculosis symptoms. The percentage probability of severe symptomatology in child pulmonary tuberculosis rose from 1.4% amongst children with none of the identified risk factors, to 18.1% amongst those with all risk factors concurrently, i.e. children who are AIDS-orphaned and living with an HIV/AIDS-unwell primary caregiver, are exposed to body fluids through care provision, lack sufficient food and live in crowded homes (Figure 1).

Access to tuberculosis testing or diagnosis

Access to testing and diagnosis amongst both high-risk and severely symptomatic children was low. Amongst children who were at high risk of tuberculosis – i.e. providing personal or medical care for an HIV/AIDS-unwell primary caregiver that included exposure to body fluids – only 7% reported ever having been asked to take a sputum test or any tuberculosis test. Amongst children with severe tuberculosis symptomatology, 25% reported ever having been asked to take a sputum test or receiving a diagnosis and 11% reported ever receiving treatment.

Discussion

With 22.5 million people in sub-Saharan Africa living with symptomatic AIDS (UNAIDS, 2010), and 14.8 million children orphaned by AIDS by 2012 (UNICEF & UNAIDS, 2011),

there is a clear need to better understand the health-related consequences of living in an AIDS-affected family. This is the first known study to examine associations between children's provision of home-based medical care, and symptoms of tuberculosis. It demonstrates increased risk for severe pulmonary tuberculosis symptoms amongst children affected by familial AIDS, heightened by exposure to body fluids during care provision to AIDS-unwell family members, and exacerbated by socio-economic factors of living in high-density households and food insecurity – factors also associated with living in an AIDS-affected household (Richter, 2010).

Strengths of this study include a large sample of 6000 children, in multiple provinces including both urban and rural sites, and the use of community-based sampling, which allowed the study to include families not accessing health services. However, this study has limitations that indicate valuable areas for future research. In this sample, children's HIV status or CD4 count was not known, and future studies could examine whether tuberculosis risks associated with provision of care are heightened for HIV-infected children. Only a tiny proportion of this sample would have been perinatally HIV-infected, due to birth dates 4-14 years before the beginning of the antiretroviral rollout in South Africa and low rates of survival in the pre-antiretroviral period ([Newell et al., 2004](#)), but others could have been infected during childhood. Children who were infected with HIV may also have had higher rates of non-pulmonary manifestations of tuberculosis, and future research could valuably include these as outcomes. However, regardless of whether the HIV-infected primary caregiver was a biological parent, risks of child pulmonary tuberculosis symptoms rose with overcrowding, food insecurity and exposure to body fluids through the provision of care to an AIDS-unwell family member. This clearly identifies important groups of children to target for tuberculosis testing and treatment.

There are also limitations associated with all methods of testing pediatric tuberculosis (World Health Organisation, 2011b). Although tuberculosis symptom checklists are increasingly used

in clinical practice in Southern Africa, and may be an important addition to community-based research on child wellbeing in the region, future research could valuably include biomarkers and tuberculosis notification records alongside symptom-based screening. In addition, further research is needed to understand pathways by which children are exposed to body fluids in the provision of care, for example whether this indicates a greater child role in caregiving, or extreme illness experienced by the adult, or both (Skovdal, 2011).

With these limitations in consideration, these findings have implications for policy and programming. Health systems responses to HIV/AIDS and tuberculosis in high-burden, low-resource settings have increasingly focused on home provision of care, supported by visits from lay health workers (Schneider & Lehmann, 2010). There is a clear need to recognise the important role of children as active members of these families, including their participation in providing care and support for unwell adults ([Skovdal et al., 2010](#)). But children also require supportive and safe environments in order to promote their own development, and families have been identified as the best source of care for vulnerable children (Betancourt et al., 2011; Richter et al., 2009). In short, we do not want to remove children from their families, nor do we want to prevent families from providing care. But if we are to reduce child tuberculosis infection in family contexts, it is essential that effective measures to reduce exposure are implemented. These findings suggest the value of targeting food insecurity and household overcrowding, usually in contexts of poor ventilation. In particular, findings show that children's provision of care to unwell family members *per se* does not increase their risk of tuberculosis infection, but that risk is related to their exposure to body fluids (particularly phlegm and sputum) in the process of providing care. By providing families with information, protective equipment and additional home-based support, it may be possible to reduce child health risks.

In light of low reported access to tuberculosis testing and treatment, interventions to improve tuberculosis referral systems and increase uptake of tuberculosis testing and treatment may

also be of great value in reducing child morbidity and mortality. These findings support increasing calls for community-based case-finding, contact-tracing (Bekker & [Wood, 2010](#)), symptom-based screening (World Health Organisation, 2006) and preventative chemotherapy (Marais, Obihara, et al., 2005) for children in high tuberculosis-burden countries (World Health Organisation, 2006).

Future research is needed to test whether children in other HIV-endemic countries face similar risks. However, findings from this large multi-community sample demonstrate a thirteen-fold increase in severe tuberculosis symptomology associated with family AIDS and children's provision of medical care, and exacerbated by socio-economic vulnerability. It is clear that, without adequate prevention and treatment for pulmonary tuberculosis in high HIV and tuberculosis contexts, children are paying an unacceptably high price for home and community-based care.

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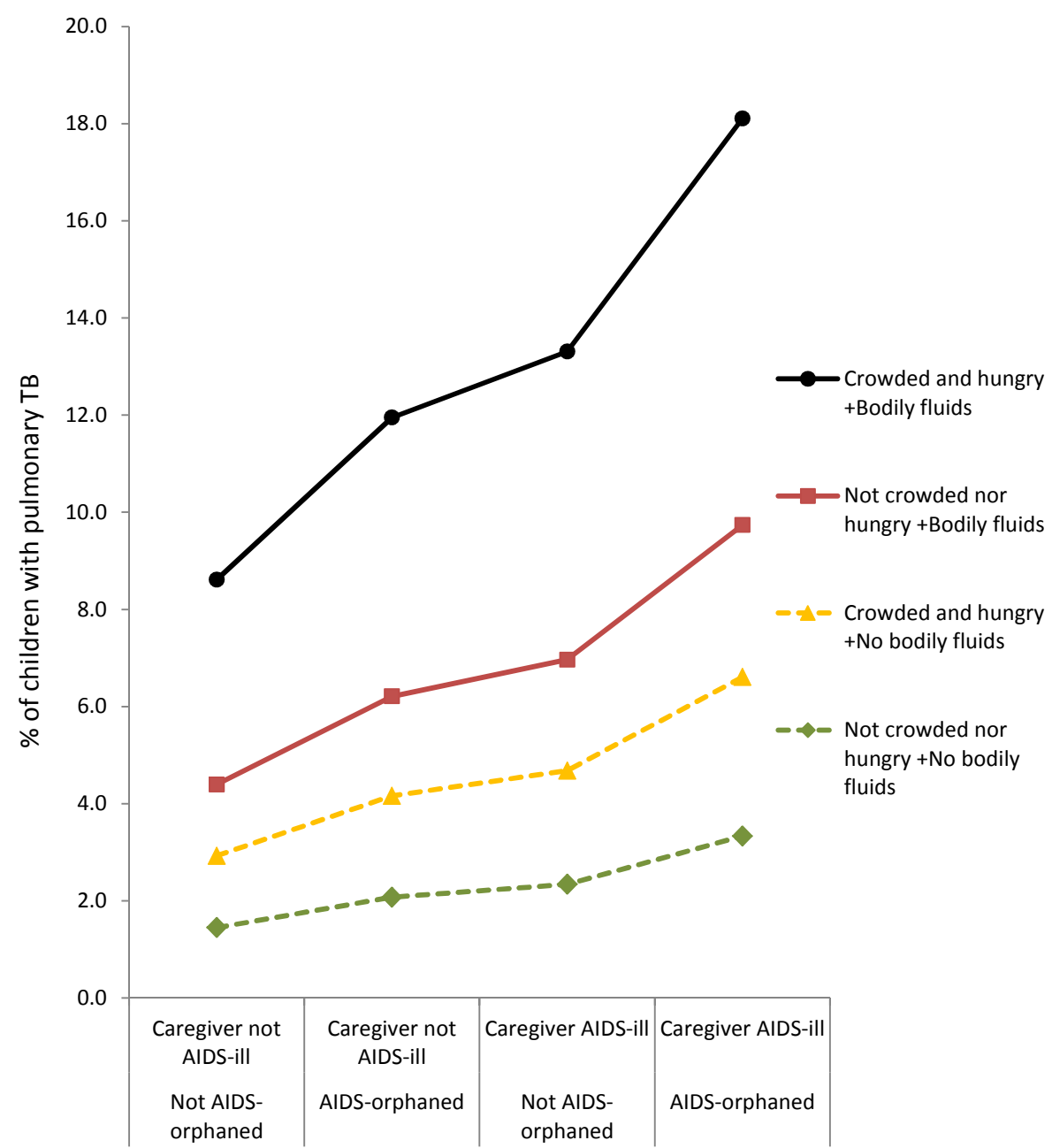
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Table 1. Predictors of child pulmonary tuberculosis

	<i>B</i>	Standard Error	<i>p</i> Value	Odds Ratio (95% CI)
Rural location	.16	.13	.229	1.17 (.90 - 1.52)
Child gender	.17	.13	.181	1.18 (.93 - 1.52)
Age of Child	.01	.03	.731	1.01 (.95 - 1.07)
Household poverty	.11	.16	.472	1.12 (.82 - 1.53)
Household overcrowding	.30	.14	.017	1.35 (1.06 - 1.72)
Food insecurity	.42	.14	.003	1.52 (1.15 - 2.02)
AIDS-ill primary caregiver	.49	.14	< .001	1.63 (1.23 - 2.15)
Other-ill caregiver	-.05	.21	.829	.96 (.64 - 1.44)
AIDS-orphanhood	.37	.17	.029	1.44 (1.04 - 2.00)
Orphanhood by other causes	-.18	.19	.911	.84 (.58 - 1.22)
Child provides personal or medical care	.02	.18	.911	.98 (.69 - 1.40)
Exposure to body fluids whilst providing care	1.14	.24	< .001	3.12 (1.96 - 4.95)
Non-biological caregiver	.068	.14	.626	1.07 (.81-1.41)

Note: Outcome variable is child pulmonary tuberculosis; significant *p* values are bolded

Figure 1: Percentage probability of tuberculosis amongst children, by exposure



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