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Modelling the impact of maternal HIV on uninfected children: correcting current estimates

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ABSTRACT

A mathematical model, populated primarily with data from South Africa, was developed to model the numbers of children affected by maternal HIV, and the number who will experience long-term negative developmental consequences. A micro-simulation model generated two scenarios. The first simulated a cohort of women whose HIV status mimicked that of a target population, and mother–child dyads by way of age- and disease-specific fertility rates. Factors defining risk were used to characterize the simulated environment. The second scenario simulated mother-child dyads without maternal HIV. In the first scenario an estimated 26% of children are orphaned, compared to 10% in the absence of HIV. And a further 19% of children whose mother is alive when they turn 18 are affected by maternal HIV. School drop-out among all children increased by 4 percentage points because of maternal HIV, similarly population level estimates of abuse and negative mental health outcomes are elevated. Relative to HIV unaffected children, HIV affected have elevated risk of poor outcomes, however not all will suffer long-term negative consequences. Interventions to protect children should target the proportion of children at risk, while interventions to mitigate harm should target the smaller proportion of children who experience long-term negative outcomes..

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Introduction

The medium and long-term consequences for the millions of children affected by HIV and AIDS across 3–4 generations in high HIV-prevalence contexts have received little attention. Research on children affected (but not necessarily infected) by HIV has focused on the distressing immediate and short-term health, development, educational, and social outcomes associated with orphaning as a result of maternal or paternal death (Sherr et al., 2014).

A focus on the consequences of parental death leads naturally to a focus on the numbers of children orphaned as a summary measure of the "secondary" impact of adult HIV. On the one hand, orphan numbers are a significant underestimate of the number of affected children because children can be adversely affected while HIV positive adults on whom they rely are still alive. On the other hand, these figures are possibly an overestimate of those in need of intensive external intervention, because with strong support of their families, they may well avoid major long-term negative consequences (Stein et al., 2014).

Despite its limitations, orphan numbers have remained a convenient summary measure. In part because an appropriate alternative has not been provided. As an alternative, we report on the results of a micro-simulation modelling exercise to estimate the number of children affected by (maternal) HIV in a high-prevalence context, and the proportion of these children at elevated risk of significant long-term harm. The model draws on what we have learned about the consequences of adult HIV on children [1], and what we know, from other fields of child development research, about the long-term implications of such consequences (Stein et al., 2014).

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The model is the result of a USAID/PEPFAR funded process designed to identify the likely long-term impacts of adult HIV for affected children (von Zinkernagel, 2014). The process consisted of three phases. Phase 1 comprised a review of the evidence of negative consequences for children affected by HIV and AIDS (Sherr et al., 2014). In the absence of available data of long-term impacts of HIV in the family on children, Phase 2 considered the likely long-term implications of the evidence reviewed in phase one, examining the broader child development literature from related fields (such as parental death, separation, abuse etc) (Stein et al., 2014). In phase 3, findings from the two prior phases were used to inform the development of a model to estimate long-term impacts which stem from being affected by parental or caregiver HIV and AIDS. A number of different modelling approaches were considered (Desmond et al., 2014). In this paper we discuss the details of the approach taken in phase 3 and key findings.

Model development

The model aims to estimate the number of children, in a given context and time period, who are affected by adult HIV, and what proportion of them are likely to experience long-term negative consequences as a result, based on existing literature. We also draw on studies of children affected by HIV which identifies a range on negative consequences and, critically for modelling, the pathways that lead to them (Sherr et al., 2014). As this literature is focused on immediate and short-term impacts, it does not tell us if children are likely to recover from these consequences or if the consequences are likely to endure. We, therefore, draw on insights from the broader child development literature which suggest that certain consequences, such as school drop-out, are likely to have long-term implications.

Widening the focus out from orphaning highlights a range of challenges to child development of exposure to adult HIV (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013; Murphy, Marelich, Graham, & Payne, 2015; Sherr et al., 2014). Negative consequences observed include a range of health impacts, constrained cognitive development, diminished school performance and increased drop out, negative mental health, increased risk of abuse and higher rates of adolescent risk behaviour, including sexual risk behaviour (Goldberg & Short, 2016; Guo, Li, & Sherr, 2012; McNally, Hadingham, Archary, Moodley, & Coovadia, 2006; Sherr et al., 2014; Ssewanyana et al., 2018). There are several different pathways through which children are affected by adult HIV, mainly through challenges that HIV poses to the care environment for children (Goldberg & Short, 2016; Sherr et al., 2014). If children are HIV infected, they face lifelong risk of comorbidities, and are more likely to experience cognitive and motor development delays, HIV-related stigma, and poor mental health s (Abubakar, Van Baar, Van de Vijver, Holding, & Newton, 2008; Chi et al., 2015; Fair & Brackett, 2008; Goldberg & Short, 2016; Sherr, Mueller, & Varrall, 2009; Thomas, 2006; Vreeman, Scanlon, McHenry, & Nyandiko, 2015). For children living with a caregiver with HIV, adult illness can exert financial pressure on the household through out-of-pocket expenditure and inability to work, reduced child care and supervision, an increased burden of child work and responsibility, child anxiety and fear and increased rates of violence in the home and stigma towards the family. All may have negative impacts on children (Meinck, Cluver, & Boyes, 2015; Sherr et al., 2014), including on child psychosocial wellbeing (Meinck et al., 2015), educational outcomes, social relationships (Orkin, Boyes, Cluver, & Zhang, 2014) and healthy growth (Jumare et al., 2019). The child may also experience increased risk to their health and wellbeing at family (Richter et al., 2009) and community levels (Casale, 2015). HIV may diminish the physical and psychological resources of caregivers, placing them at high risk for developing mental health disorders, limiting their capacity to provide quality care, and placing their children at risk for poor behavioural and developmental outcomes (Bass et al., 2016; Goldberg & Short, 2016; Sherry et al., 2000). Maternal and/or paternal HIV associated mental health disorders can impact child outcomes (Lachman, Cluver, Boyes, Kuo, & Casale, 2014). Depression and anxiety, particularly, are common amongst mothers living with HIV (Malee et al., 2014; Myer et al., 2008; Peltzer, Rodriguez, & Jones, 2016).

The literature on the immediate and short-term impacts of HIV on affected children point to pathways and consequences. The evidence on the longer-term consequences is still emerging, although there is increasing evidence from longitudinal and modelling studies that some of these negative consequences may persist (Desmond et al., 2014; Robbins et al., 2019; Sherr, Skeen, Hensels, Tomlinson, & Macedo, 2016; Stein et al., 2014; von Zinkernagel, 2014).

The limited availability of empirical studies on the long-term consequences does not imply that these cannot be informatively modelled (Desmond et al., 2014). Stein et al drew on the broader child development literature to inform predictions of the, as yet, unobserved medium- and longer-term consequences for children affected by HIV and AIDS (Stein et al., 2014). From data investigating child development in contexts of significant adversity analogous to that experienced by children affected by HIV, they conclude that most children

affected by HIV are likely to be resilient. This is not to suggest that they do not suffer, only that most are likely to escape long-term negative developmental consequences of being affected. However, even among resilient children, when adversities accumulate, the proportion likely to experience long-term harm increases (Hunt & Tomlinson, 2018; Sameroff, 2010). It is likely, therefore, that the proportion of children suffering long-term negative consequences is much higher among those children who are affected by HIV, who are also living in poverty, in contexts with high levels of stigma, and who experience abuse or maltreatment, particularly when at the hands of more than one perpetrator (Hunt & Tomlinson, 2018).

The literature on children affected by HIV and the reflections reported in Stein et al suggest that to estimate the number of children affected and the number of children likely to experience long-term negative consequences, we need to consider parental wellbeing prior to death and the interaction of adult HIV with other contextual factors, such as household poverty (Stein et al., 2014). The impacts on children clearly start before caregiver death. Families with resources and appropriate supports can protect their children from harm to a large extent.

The model structure, outline below, is based on these insights. We model consequences of maternal HIV which have been consistently reported in the literature and which may well to lead to long-term negative outcomes: mortality; school enrolment; mental health and sexual risk behaviours. In each case, we know when affected children are risk of these (during adult illness or after death etc.), what may aggravate these risks (poverty, child's age etc.) and that the risks have been linked to long-term negative outcomes. What we do not know is how common the risks are at the population level, i.e., how many children face risk environments (for example poverty and maternal illness during the teenage years) and therefore how common, at the population level, these outcomes are likely to be. The model seeks to begin to address these gaps.

Two important limitations are noted. Firstly, this model estimates only the effects of maternal HIV status on children. It focuses on the indirect implications stemming from compromised maternal care, or a mother's death. Due to data limitations, it does not include the impact of paternal HIV or the HIV infection of other adults in the household, although both have been shown to influence child outcomes (Case & Ardington, 2005; Cluver, Gardner, & Operario, 2007). Second, the model does not consider the impact of paediatric HIV infection or exposure of the child to HIV and/or ART during pregnancy, whether the child is infected. Children infected with HIV face severe challenges and require specialized responses. Demographic models have been used to estimate mortality rates associated with infection in the population, but they have not examined the impact of being HIV+ on schooling and similar outcomes. Thus, further research and modelling exercises are required to estimate the full impacts of the epidemic on children.

Model structure

The model simulates outcomes for a cohort of *women* (who may become mothers) and their *children*. The model only considers the potential relationships between mother and child. The women are completely independent of one another. Similarly, children are completely independent of one another except in the case of siblings, and siblings are correlated only in that they are exposed to the same context and risk factors generated by a shared mother. They do not influence one another directly.

The model is implemented in three sections (Figure 1): one section deals with the women (panel a), another with the children's mortality and schooling (panel b), and the last with children's risk behaviour (panel c). Each section can be further divided into sub-models (supplementary annex A).

The child outcome models (Figure 1(b & c)) are calibrated according to the risk environment. This environment is defined by the HIV health state of the mother during a given period, the child's gender and age, and the socio-economic context. Once a child has suffered abuse, abuse becomes part of the environment, leading to an increased risk of depression and/or

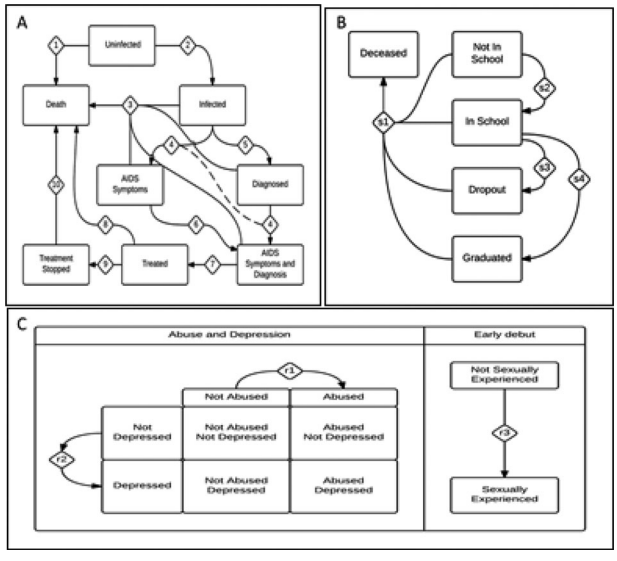

Figure 1. Structure of model components.

anxiety (clinical), early sexual debut, and inconsistent condom use in every subsequent period. To link the mother's state to the child's gender and age requires estimates of the age- and health-state-specific fertility rate.

The model generates a scenario by simulating the cohort of women so that their HIV status mimics that of a target population and context. The women give birth to children according to the given fertility rates, thus associating each child with a mother. The incidence of HIV, the progression rates of the mothers through the stages of HIV, and the fertility rates of mothers are based on source data to construct a heuristically useful population.

Over time, the outcomes for women and children are simulated by scheduling competing events for them. For example, among women, in the first year of the model, a time of infection and a time of death (based on the healthy state) are provisionally scheduled from a survival function implied by the given data. These two dates are compared; if the scheduled date of the women's infection comes first, then the mother transitions into being infected e. Since death from the infected state is governed by different equations and rates than death from the healthy state, the death of the mother is then rescheduled together with competing events, namely becoming diagnosed or symptomatic. Time of death is similarly rescheduled when the mother transitions into treatment, or thereafter if she stops treatment. In effect, the model numerically generates an ensemble of mother–child dyads, which facilitates the calculation of a wide range of expectation values and correlators that are too complex to be calculated analytically or (conveniently and flexibly) by exhaustive multidimensional numerical integration. The model was built with the modelling platform modgen (www.statcan.gc.ca/microsimulation/modgen/modgeneng.htm).

Model scenarios and data sources

To simplify interpretation, the model was run for a single age cohort of women and their children. An entire population would require explicit, independent, influence of both age and time on maternal risk. A population picture could in theory be developed by running a series of cohorts and overlapping the results, but for heuristic investigations aimed at generating insights, this would introduce a great many degrees of freedom and emergent complexities.

The results of two scenarios are compared here. Both scenarios are based on a cohort of 100,000 women born in 1985. The cohorts are identical, except that one excludes, and one includes HIV. Both scenarios assume half the cohort of women live in poverty and that half do not.

The data used in the model are from South Africa. A full list of the data sources and assumptions is provided in Annex B. The background demographic and epidemiological information are taken primarily from the ASSA model (Actuarial society of South Africa, 2011). The use of South African data to provide the epidemiological backdrop implies high HIV prevalence and high levels of (largely successful) antiretroviral treatment. The following selected values provide an indication of the characteristics of the population modelled: HIV incidence in the model peaks at 6% per annum at 19 years of age. Fertility, in the absence of HIV, peaks at 17% per annum when women in the model are 25 years of age. It is assumed that 20% of HIV positive women will be diagnosed while still asymptomatic, rising to 80% once symptomatic. In the model, antiretroviral treatment becomes available in year 16 (corresponding to 2001). Treatment coverage increases each year until it reaches 90% of women in 2012 who are eligible and diagnosed. It is assumed that 3% of those on treatment are lost to follow up each year.

The estimates of risks of negative outcomes for children are primarily derived from the Young Carers dataset (www.youngcarers.org.za). The model requires estimates of risk for boys and girls, by age, by health status of the mother and by socio-economic status. These were generated using regression analysis. Data on the impact of HIV on school enrolment was available for all school-aged children. In the model, the risk of these outcomes is included only from 12 years of age onward. As children younger than 12 are not exempt from experiencing these outcomes, the model underestimates the occurrence of these events among younger children.

Results

Mortality patterns for the cohort of 100,000 women in the absence of HIV are depicted in Figure 2(a); the implications of these patterns for children (given age-specific fertility rates) are presented in Figure 2(b). The results suggest that 90% of children in an HIV-free context will reach the age of 18 with their mothers still alive.

In a context with HIV, the situation is markedly different. Figure 2(c) shows the distribution of women across eight mutually exclusive states: HIV− or HIV+ (asymptomatic and undiagnosed; asymptomatic and diagnosed; symptomatic and undiagnosed; symptomatic and diagnosed; on treatment; or stopped treatment) or deceased. Despite high levels of treatment availability assumed in this scenario, mortality rates remain far higher than those in the no-HIV scenario.

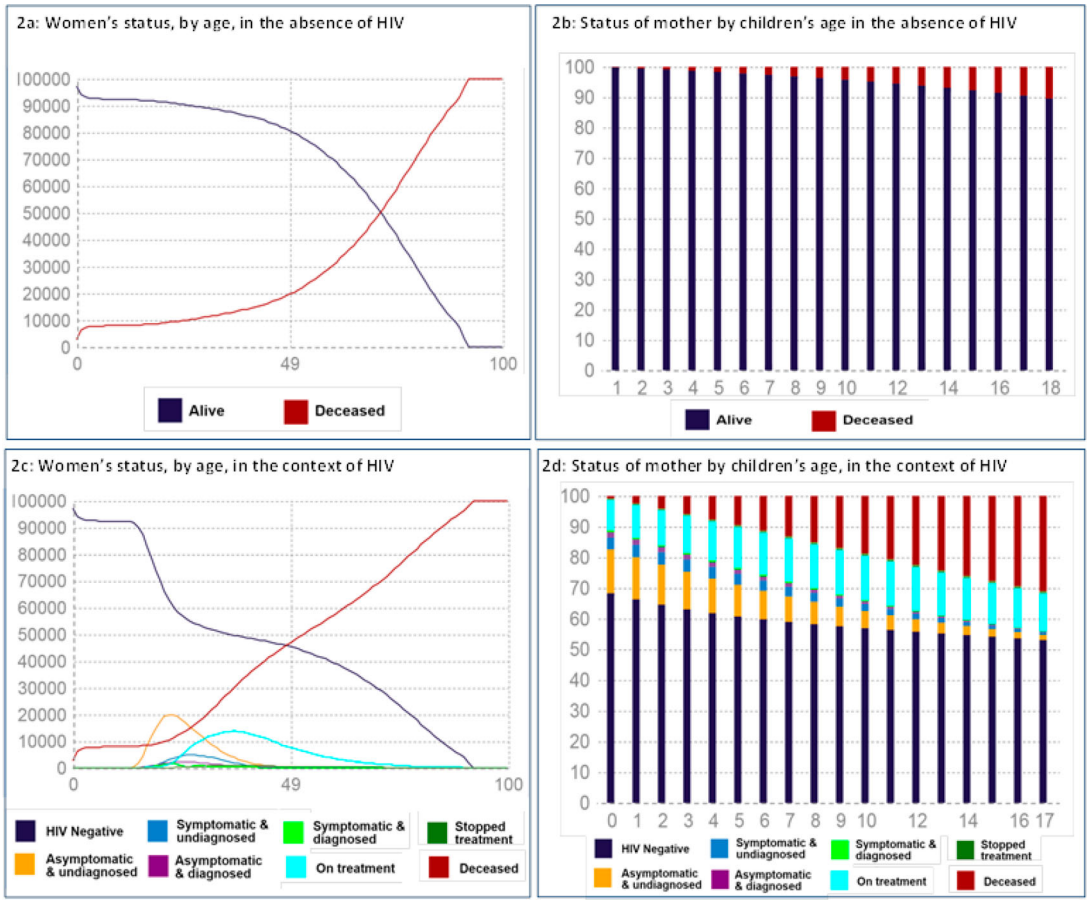

Figure 2. Maternal status.

The status of mothers, by children's age, is shown in Figure 2(d). In total 35% of all children will be affected by maternal HIV in some way before they reach 18 years of age. An estimated 16% of all children (nearly half of HIV-affected children) will be orphaned by age 18 because of HIV and AIDS. This is in addition to the 10% of all children orphaned for other reasons. Although their mother is still alive when they reach 18, 19% will be affected by maternal HIV during their childhood.

Figure 3(a) depicts the estimates of the impact of maternal HIV on school completion. In the scenario with no HIV, 61% of children graduate from secondary school. In the scenario which includes the possibility of maternal infection, the completion rate across all children falls by 4 percentage points to 57%. The modelled decrease is because only 50% of the 35% of children affected by maternal HIV graduate. Sub-groups of children affected by maternal HIV, such as those whose mother's die earlier in life, have even lower graduation rates. Changes at the population level are significant. If South Africa had a 4-percentage point drop, about 40,000 fewer schoolchildren would graduate from secondary school per annum.

Figure 3(b) shows the percentages of children who experience at least one episode of clinically- diagnosable depression and/or anxiety symptoms before they reach 18 years of age. HIV leads to a noticeable difference in depression and anxiety at the population level. Compared to the no-HIV scenario, children affected by maternal HIV have a 10-percentage point higher incidence of ever having an episode of a common mental disorder.

Figure 3(c) shows the percentage of children who suffered one or more incident of emotional or physical abuse by age 18. The population estimate for the HIV scenario is higher than the no HIV scenario, but not substantially. The small increases are because the risk is concentrated among children who have AIDS-symptomatic mothers during their teenage years, and these children do not constitute a large proportion of the population.

The risk of a negative outcome for a child in the model is greatly increased when risk factors cluster. Figure 3(d) provides an example, showing the cumulative risk of suffering at least one episode of depression or anxiety among a sub-population of girls living in a low-income family, who have previously suffered abuse and whose mother has died, in comparison to girls without these two adversities and all children in the HIV

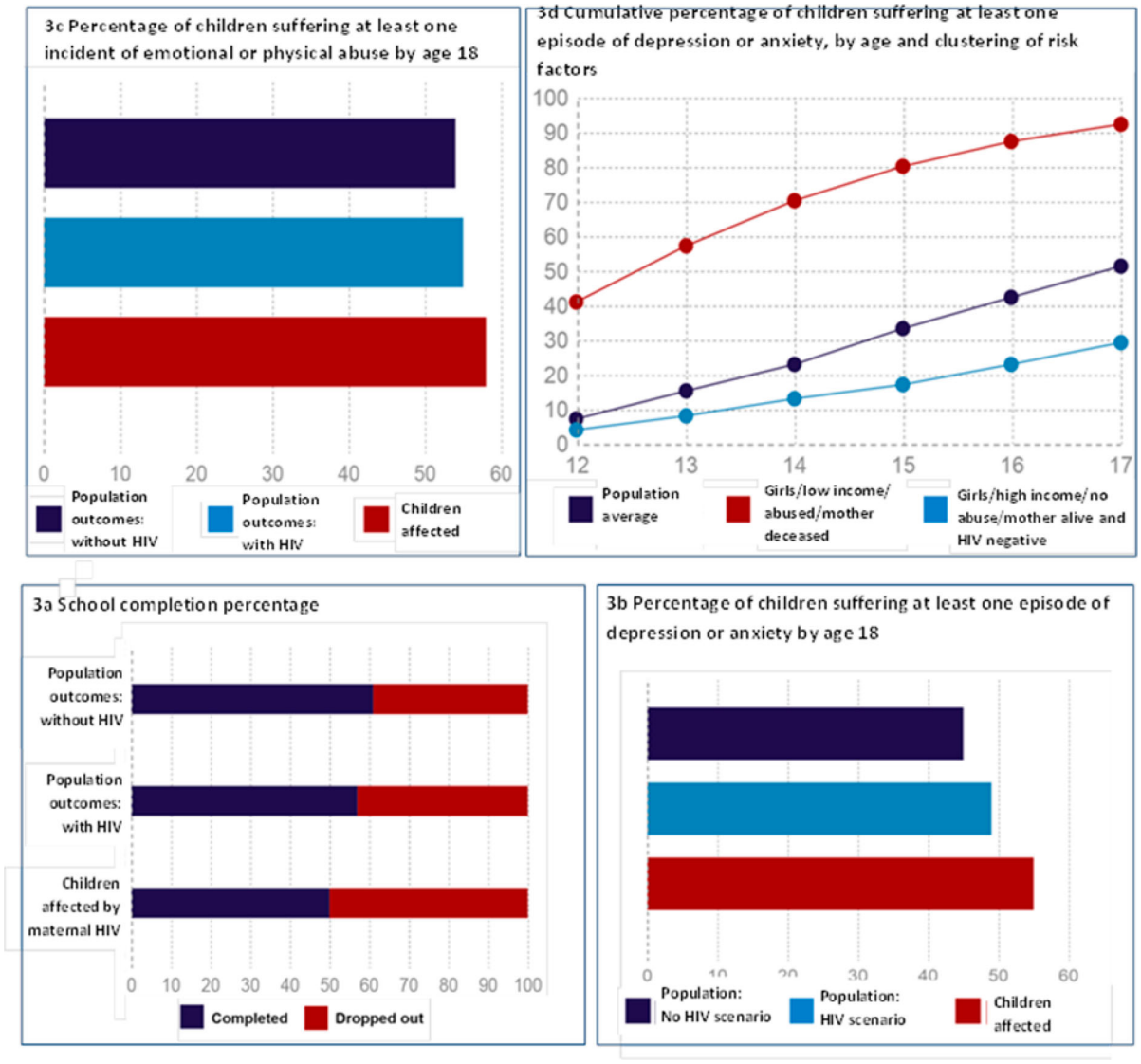

Figure 3. Child outcomes.

scenario. The figure indicates that for the high-risk group, at least one episode of clinical-level depression or anxiety is a near certainty, with over 90% of in the group estimated to be affected by 18 years of age.

We do not report the results for condom use or early sexual debut, as the differences between HIV affected children and unaffected children were minimal at the population level. The causes of this are examined in the discussion section.

Discussion

The results highlight the extent to which using estimates of the number of orphans to gauge the number of children affected by HIV can be misleading. In the context of high levels of treatment, more than twice the number of orphaned children will have a mother who is living with HIV. Not all these women will die before their children turn 18 years of age, but most of them will either become ill in this period or go on to long-term chronic treatment. Relative to unaffected children, this large proportion of children will be at elevated risk of school drop-out, poor mental health outcomes and abuse, but not all affected children will suffer such outcomes. This suggests that there is a large group of children, larger than the number of orphans, who need to be reached by efforts to prevent harm, but a much smaller group that requires intensive mitigation interventions.

We do not report the estimates of early sexual debut or consistent condom use because the two scenarios produced almost identical estimates. The modelled pathway to impact for these outcomes was primarily through increased rates of abuse during adolescence leading to increased sexual risk behaviour. The small difference in

abuse estimates between the "with" and "without HIV" scenarios led to only minimal differences in sexual risk behaviours estimates. Unpacking why the model predicts only a small increase in abuse reveals a significant gap in our understanding of the risks faced by HIV affected children. Data on adolescents suggest that the greatest risk of abuse occurs when their caregiver is seriously ill (Meinck et al., 2015). But as shown above, relatively few children are likely to be living with a symptomatic mother during adolescence. This is an interesting finding, given that current research on HIV-affected but seronegative children focuses on adolescents (Alipui & Gerke, 2018; LeCroix et al., 2019). Younger children spend much more time with symptomatic mothers. If there is an increase in abuse for children at these earlier ages, there will be a larger population level impact. Given the established link between early-life abuse and later risk behaviours, this increase could have significant implications for HIV incidence. Currently we do not have the necessary data on the risks of abuse for young children with symptomatic caregivers and cannot model the long-term impacts.

In the HIV scenario, a large proportion of children spend a significant number of their childhood years with their mothers on antiretroviral treatment. This highlights the importance of understanding risks for children associated with having a mother on treatment. There are data on how adult treatment reduces risks of school dropout and other economically driven outcomes, such as child labour (Sherr et al., 2014). We assume that when mothers are on treatment, child mental health outcomes improve, and abuse rates decrease in a similar fashion. This assumption needs to be verified; if it is incorrect and significant strains remain for children whose mothers are on treatment, and/or the improvement is less marked, we are underestimating the impact on children of having a mother on treatment.

The lack of data from high-prevalence contexts on child outcomes when parents are on treatment, on child mental health and abuse outcomes among affected children in their first decade of life, and links between these and later outcomes, highlight the need for more longitudinal studies to fill these gaps.

In addition to reflecting on the model results, we were able to learn a great deal from the process of modelling itself. There are two major motivations for building models. Models can be developed to better understand the present situation and models can be developed to predict the future. Both motivations played a role in this effort. As a first step, though, the priority is to better understand the present situation. Building this model forced us to re-examine the available data, particularly what they reveal about distribution of impacts. Consider the example of depression and anxiety. When building a model, it is not enough to know that adult HIV is linked to child depression and anxiety. We need to examine the distribution of impact, asking if many children experienced low levels of depression or if there is a sub-group of children who are severely depressed, and if the children who are depressed are the same children who suffer from anxiety. Similarly, we need to know more about the distribution of risks for the outcomes of interest. It is not enough to know that living with an AIDS-symptomatic caregiver during adolescence increases risk, we also need to estimate how common it is for adolescent children to have a symptomatic caregiver.

Conclusions and recommendations

The results of these efforts to better understand the present situation of HIV affected children, and the resultant model, point to several important policy implications:

- In high-prevalence settings a large proportion of children are at increased risk of adverse outcomes because of adult HIV (35% in our scenario). This suggests that large-scale social and health policy interventions are needed to reduce risk at the population level, to prevent children experiencing harm
- A much smaller proportion of children will suffer serve long-term adverse developmental outcomes. This implies the need for intensive targeted individual interventions to mitigate harm.
- Risks associated with maternal HIV-related ill health are likely to concentrate in the first decade of life. This is the period of life in which the experience of adverse events is most likely to have long-term implications. Given this distribution of risk, interventions which seek to reduce adolescent risk would do well to complement efforts to directly target adolescents with supportive interventions for affected families with younger children.
- Longitudinal data is needed on both HIV+ and HIV− children, beginning with children exposed to HIV during pregnancy and/or born into affected families, and children of all ages living with adults on treatment.

Early childhood lays the foundation, while mid- and late- childhood determine the opportunities and barriers to the attainment of the potential embodied in early foundations. The costs and rewards of these formative periods are realized in adulthood and during subsequent parenthood. When an adult on whom a child relies is HIV positive, the child's risk of enduring adverse experiences is increased. In high-prevalence contexts, large numbers of children experience repeated distress or compounded impacts, placing them at risk of enduring

harm with the potential for life-long negative consequences and effects into the next generation of children (Hunt & Tomlinson, 2018). Understanding how risk environments in these contexts are shaped and where the potential to intervene lies is essential to protecting children, across their life course, and their future children. This modelling exercise aimed to contribute to this understanding, and further work is required to address gaps in our current knowledge.

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CD contributed to the design and analysis of the model and drafted the paper. PL programmed the model and commented on drafts, LC analysed data for the model calibration and reviewed and contributed to drafts, MT assisted with model designed and reviewed and contributed to drafts, LR assisted with the analysis of results and reviewed and contributed to drafts XH and MM contributed to literature reviews and contributed to drafting and AW oversaw the model design and programming, and reviewed and commented on drafts. The contents in this article are the sole responsibility of the authors, and do not necessarily reflect the views of USAID, PEPFAR or the United States Government. The contents in this article are those of the authors and do not necessarily reflect the view of the U.S. President's Emergency Plan for AIDS Relief, the U.S. Agency for International Development or the U.S. Government. We thank our fieldwork teams and all participants and their families. USAID/PEPFAR through the Leadership, Management and Governance Project managed by Management Sciences for Health.

Disclosure statement

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