Consequences of adult HIV for affected children: Modelling the impact

BACKGROUND

The long-term consequences for the millions of children affected by HIV and AIDS across three generations have received little attention. Research and programs have focused on the distressing immediate and short-term health, development, educational, and social outcomes associated with parental death. A careful consideration of the child development research on long-term implications of other causes of childhood adversity, however, provides an indication of what long-term consequences to expect for HIV affected children. Identifying the long-term consequences of the HIV epidemic for children in this and subsequent generations highlights the long-term benefits of interventions that prevent or mitigate harm. Taking a long-term view may alter the priority accorded to different types of intervention. With this in mind the PEPFAR Orphans and Vulnerable Children Technical Working group, in partnership with Management Sciences for Health and the Human Sciences Research Council, undertook a three-phase project.

- **Phase 1: Review evidence linking children affected by HIV and AIDS (i.e. living with one or more infected primary caregiver or parent, or having lost one or more primary caregiver or parent) to consequences for their physical health, and psychological and social outcomes.**

- **Phase 2: Link evidence of short-term consequences for physical health, and psychological and social consequences identified in Phase 1, to long-term outcomes addressed in the broader child development literature.**

- **Phase 3: Build a model to estimate the number of children at risk and population-level short and long-term consequences stemming from adult HIV.**

Phase 1 showed that over the last 10 years we have learned a great deal about how adult HIV infection can lead to negative outcomes for children. We understand better in what areas children are affected, and the mechanisms through which they are affected.

- HIV affected children have been observed to be at greater risk of school dropout, poor mental health outcomes, abuse, poor nutrition, child labour and limited access to healthcare.

- HIV taxes the standard of care adults are able to provide, particularly when coupled with poverty. Adults may be preoccupied with their own condition, financially burdened by the cost of accessing medical treatment, suffering from poor mental health, or physically weak. Extended hospitalization or death may eliminate a source of children's care entirely.
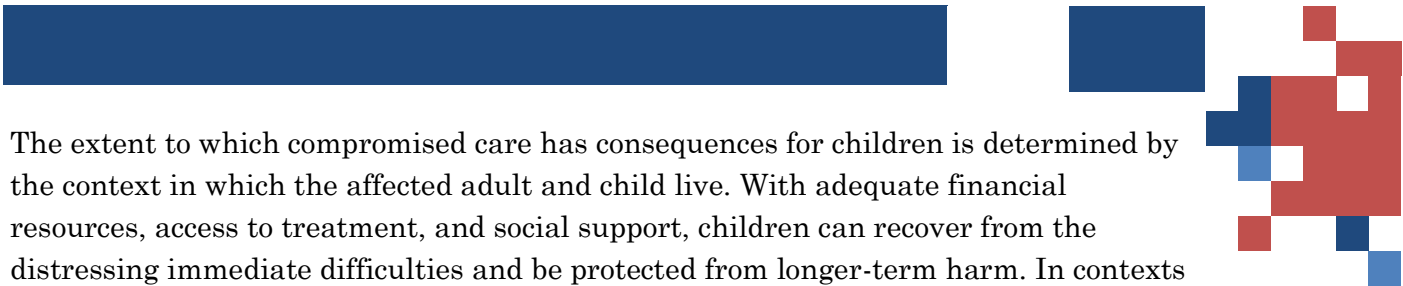
The extent to which compromised care has consequences for children is determined by the context in which the affected adult and child live. With adequate financial resources, access to treatment, and social support, children can recover from the distressing immediate difficulties and be protected from longer-term harm. In contexts characterized by poverty, stigma and social exclusion, children are likely to receive less help and protection, and negative consequences are more likely to occur and to be serious and long lasting.

Children affected by HIV and AIDS have experiences in common with children who face other adversities, including: parental death from other causes, divorce, poor parental mental health, inadequate nutrition, exposure to violence, stigmatization, poverty and institutional care. These areas of child development research have benefitted from long-term follow-up studies. Phase 2 identified the following insights from these areas of research which are likely be applicable to HIV-affected children:

■ All children experience distress at the time of an adverse event, but only some will suffer longer-term harm.

■ The consequences of childhood adversity depend on the context in which the adversity occurs, and the characteristics of the affected child.

■ Parental or caregiver love and attention, and a supportive family are critical to the coping ability of children regardless of the age at which the adversity occurs.

■ Multiple or prolonged adversities, without opportunities to recover, greatly increases the chances of long-term negative consequences.

■ Long-term consequences can be serious. Early adversity has been linked to a range of negative behavioural, economic and adult health outcomes, including social and psychological problems, decreased income and shortened life expectancy.

Despite our increasingly nuanced micro-level understanding of the consequences for children in HIV-affected families, highlighted in Phase 1, the discussion at the macro-level remains focused on orphan numbers. This orphan framing can mislead policy and program efforts. We know from the HIV-specific evidence and the broader child development literature that the numbers of single and double orphans presented in isolation misrepresents the nature of the problem, its duration and magnitude:
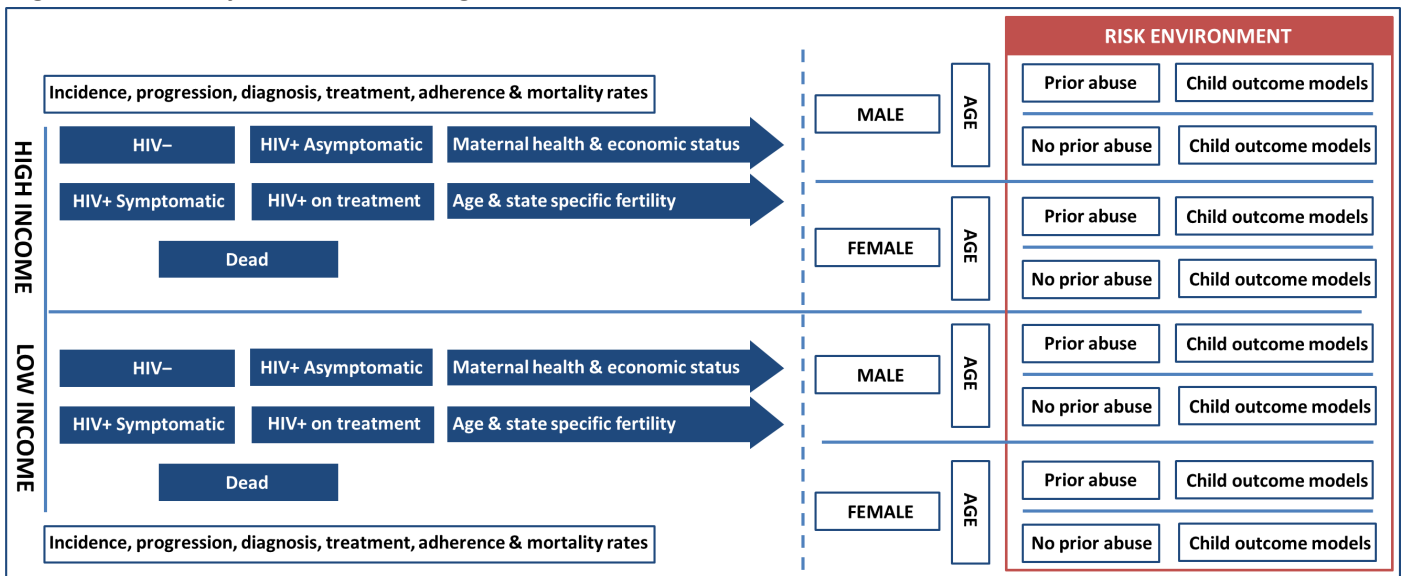
■ Many children suffer negative consequences prior to their parent's death;

■ Negative consequences can be long-term and do not stop when a child turns 18 (the age at which they no longer meet the definition of an orphan);

■ Not all orphans or affected children will suffer debilitating negative consequences.

One reason for the continued use of orphan numbers is the availability of estimates. In Phase 3 of this project we have designed a model to provide alternative metrics. The model is a first step towards providing a different macro picture of the consequences of adult HIV for affected children. The model provides estimates of risk, and poor outcomes, at a **population level.** It allows us to examine how estimates vary if contextual factors such as poverty and adult adherence to treatment are altered, or if programmes which reduce risk for affected groups are implemented. This summary provides details of the model, preliminary results and discusses emerging issues and policy implications.

THE MODEL

The model explores the effects of maternal HIV status on children, focusing on the indirect implications stemming from compromised maternal care or a mother's death. The model does not consider the impact of paediatric infection. Due to data limitations it does not include the impact of paternal HIV or the HIV infection of adults in the extended family, although both are likely to influence child outcomes. The model was built with modgen (www.statcan.gc.ca/microsimulation/modgen/modgeneng.htm). The model design is summarized in figure 1.

Figure 1: Summary of the model design

There are two agents in the model, Women (Mothers) and Children. At a given point in time the women can be uninfected, HIV+ but asymptomatic, symptomatic, on treatment or deceased. The distribution of women across states is determined by the context: HIV incidence, disease progression, diagnosis rates, treatment availability and effectiveness, treatment adherence and mortality. The risk for a child of a negative outcome in each time period is determined by their risk environment. This environment is characterized by the mother's health, the child's sex and age and the socio-economic context. The following negative outcomes were modelled:

- School dropout;

- Physical and/or emotional abuse;

- Depression and/or anxiety;

- Early sexual debut and inconsistent condom use.

Once a child has suffered abuse, that abuse becomes part of the environment and the risk of depression and/or anxiety, early sexual debut, and inconsistent condom use in every subsequent time period, is increased. As new data become available, prior school dropout and poor mental health outcomes can be similarly included as environmental factors.

Limitations: Adult caregivers other than the mother are not included. There was not sufficient data to include outcomes associated with HIV exposure during pregnancy, poor nutrition, child labour and reduced access to health care. Outcomes were only included for the ages for which we have data. As a result, risks of abuse, depression and anxiety, prior to 12 years of age, are not included. Due to a lack of data the impact of PMTCT interventions on diagnoses and timely uptake of treatment were not modelled.

RESULTS SUMMARY

To simplify interpretation, the results presented are for **a single age cohort of women and their children.** Two scenarios are outlined, both are based on results for a cohort of 100,000 women born in 1985. The cohorts are identical, except that one includes no HIV, and the other high levels of HIV and high rates of access to treatment. Both scenarios assume half of the cohort of women live in poverty. The estimates of the risk of negative outcomes is primarily derived from the Young Carers dataset (www.youngcarers.org.za).

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

Figure 2a: Women's mortality rates, by age, in the absence of HIV
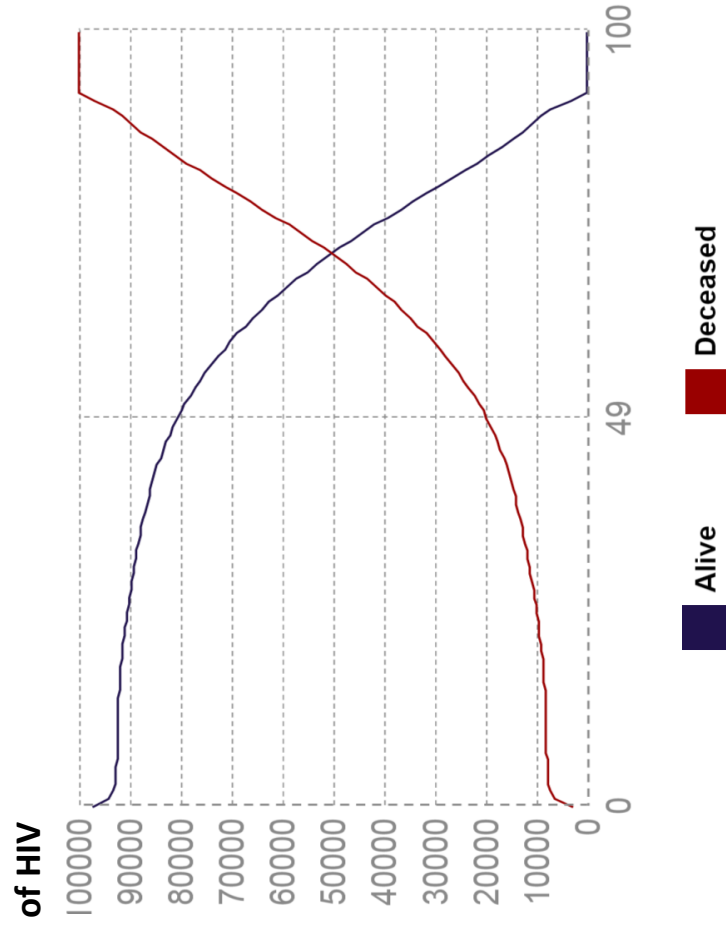

Figure 2b: Status of mother by children's age – no HIV scenario
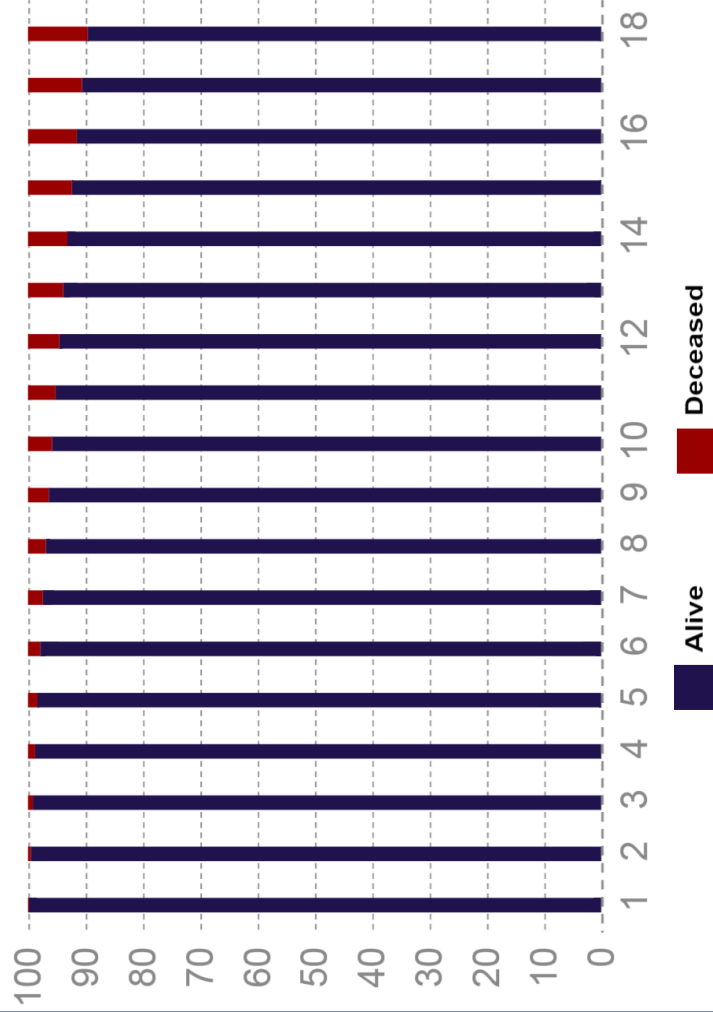
Figure 3a shows the distribution of women across eight mutually exclusive states associated with living in a context with HIV. Despite high levels of treatment availability assumed in this scenario, mortality rates remain far higher than those in the no-HIV scenario. This is because of the assumptions made about diagnosis rates, treatment effectiveness and adherence levels.

The majority of HIV-state changes for women – infection, diagnosis, occurrence of symptoms, uptake of treatment and AIDS-associated death – occur when women are between the ages of 15 and 45. This is also the peak period for reproduction and child rearing.

The status of children's mothers, by children's age, is shown in Figure 3b. In the HIV scenario, 16% of children will, by age 18, be orphaned as a result of HIV and AIDS. Although their mother is still alive when they reach 18, a further 19% will be affected by maternal HIV during their childhood. **In total 35% of all children will be affected by maternal HIV in some way.**

Figure 3a: Women's status in the context of HIV
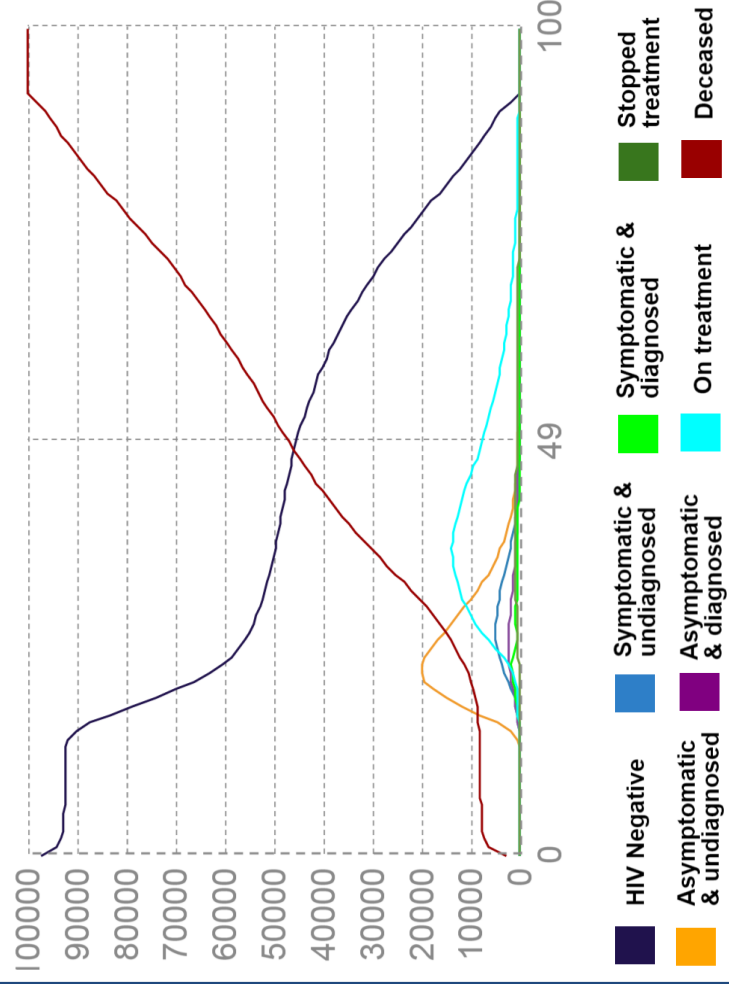

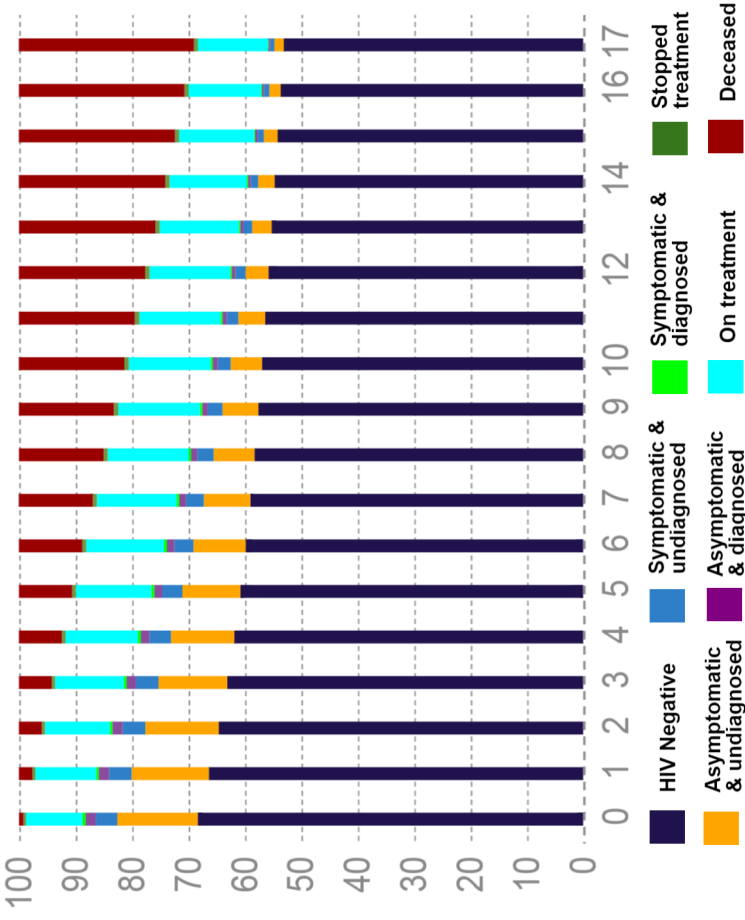## Figure 3b: Status of mother by children's age, in the context of HIV

Figure 4 depicts the estimates of the impact of maternal HIV on school completion. In the scenario with no HIV, 61% of children graduate from high school. When HIV is present the population level completion rate falls by 4 percentage points to 57%. Population changes are significant, if South Africa had a 4 percentage point change it would imply 40,000 fewer graduates. The modelled fall in graduation is because only 50% 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 yet lower graduation rates.

Figure 5 shows the percentages of children who experience at least one episode of 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.
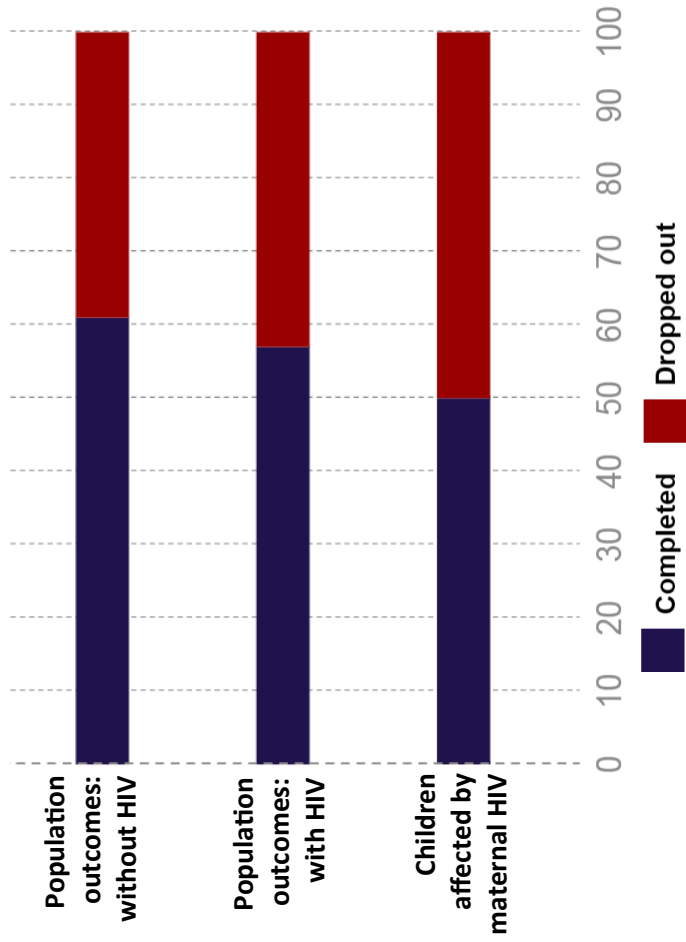
Figure 5: Percentage of children suffering at least one episode of depression or anxiety by age 18

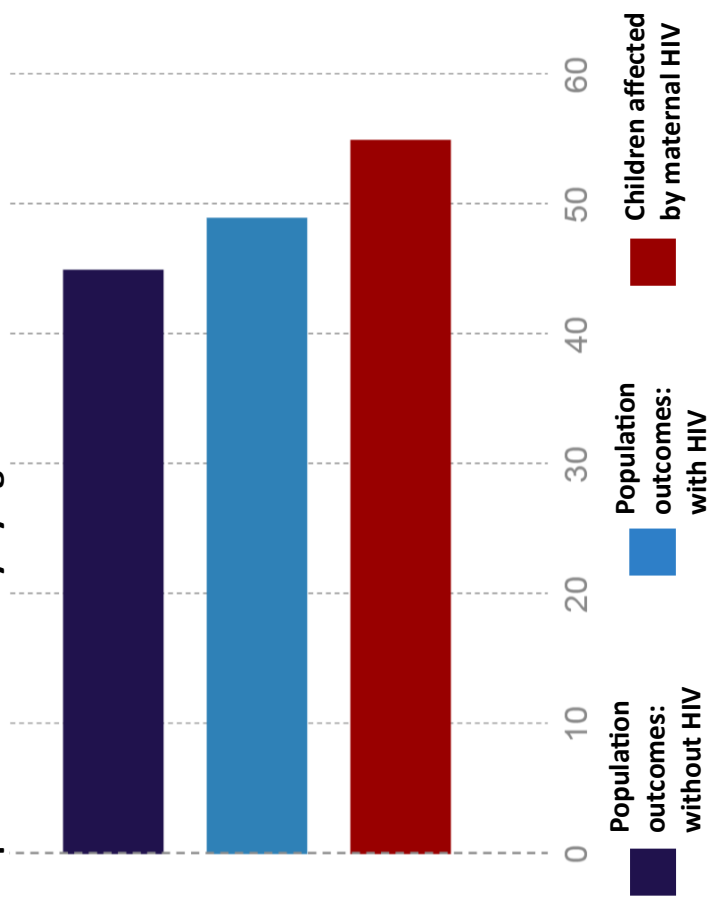## Figure 4: School completion percentage

Figure 6 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 slightness of the increases is because the risk is concentrated among children with symptomatic mothers, and they do not constitute a large proportion of the population.

Risks are not evenly spread. Figure 7 provides an example, 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 have lost their mother, in comparison to girls without these adversities and all children in the HIV scenario.

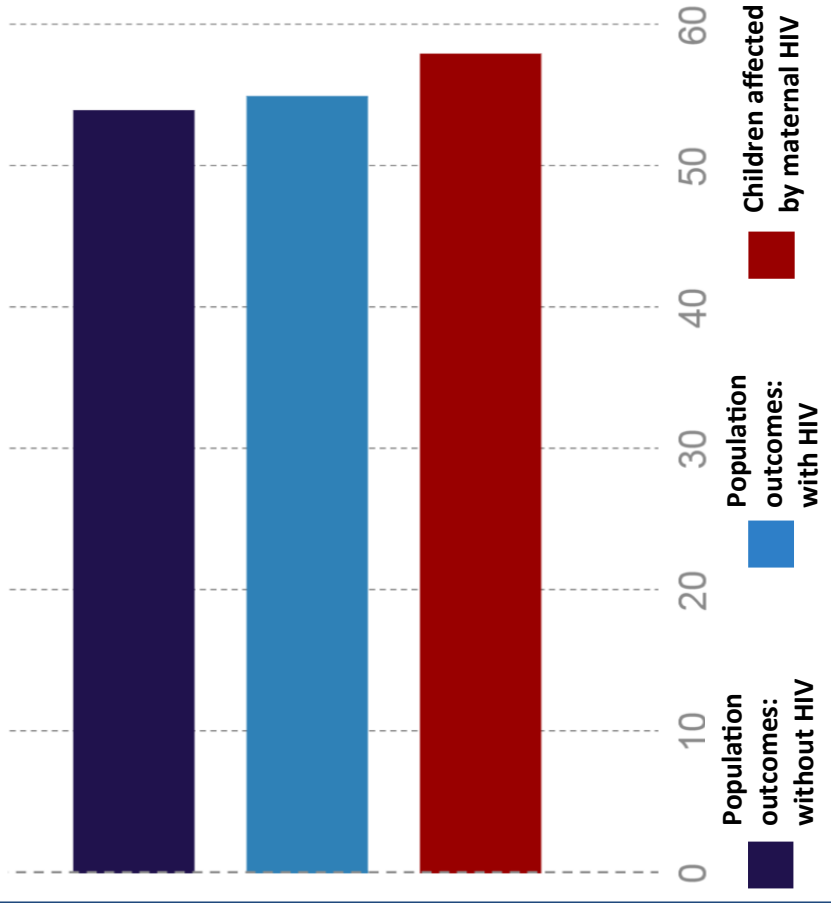## Figure 6: Percentage of children suffering at least one incident of emotional or physical abuse by age 18

- Population outcomes: without HIV
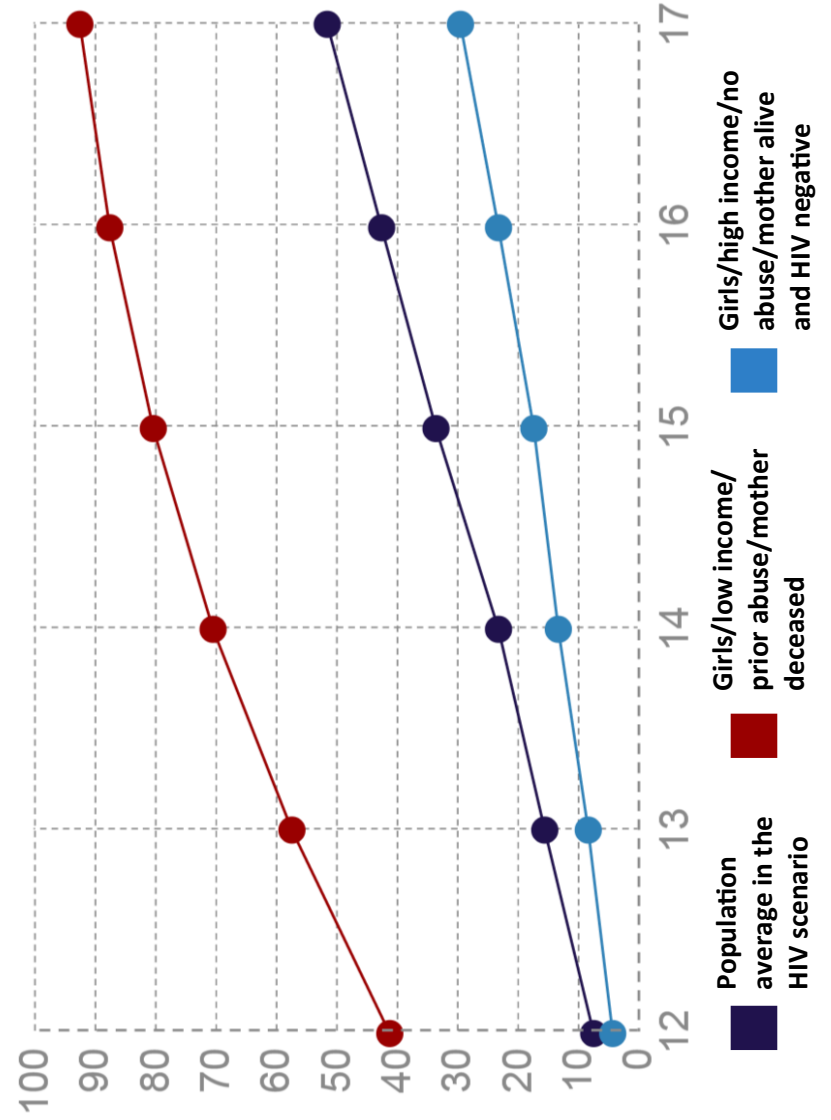- Population outcomes: with HIV
- Children affected by maternal HIV

Figure 7: Cumulative percentage of children suffering at least one episode of depression or anxiety, by age and clustering of risk factors

- Population average in the HIV scenario
- Girls/low income/ prior abuse/mother deceased
- Girls/high income/no abuse/mother alive and HIV negative

EMERGING ISSUES

Orphan estimates undercount the number of children at risk of long-term adverse effects, and overestimate the number who will suffer long-term negative consequences.

- In the context of high levels of treatment, **more than twice the number of children than are orphaned will have a mother who is infected with HIV**. Not all these women will die before their children turn 18 years of age, but most of them will become ill in this period or go on to long-term chronic treatment.

- School dropout, poor mental health outcomes and abuse all increase in HIV contexts, but **not all affected children will suffer such outcomes**.

The two scenarios did not differ greatly in their estimates of early sexual debut or consistent condom use. 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 scenarios led to only minimal differences in sexual risk behaviours estimates.
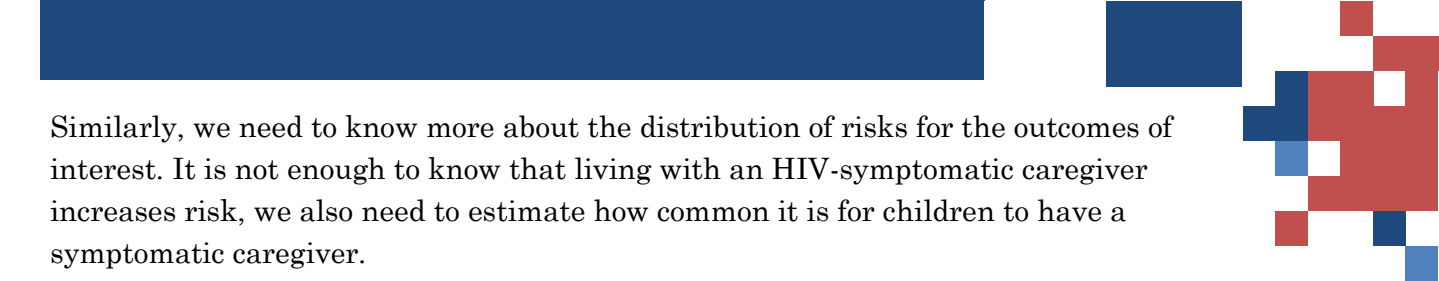
Unpacking why the model predicts only a small increase in abuse reveals a serious gap in our understanding of the risks faced by HIV affected children. Data on adolescents suggest that the greatest risk of abuse occurs when the caregiver is seriously ill. But as shown in Figure 3b, relatively few children are likely to be living with a symptomatic caregiver during adolescence. Younger children spend much more time with symptomatic mothers. If there is an increase in abuse for children at these ages, there will be a larger population level impact. Given the established linked between early-life abuse and later risk behaviours, this increase could have significant implications for HIV incidence. Currently we do not have the data to confirm this and to use the information to model long-term impacts.

The large amount of time mothers spend in the treatment state highlights the importance of understanding risks for children associated with having a mother in this state. There is data on how adult treatment reduces risks of school dropout and other economically driven outcomes, such as child labour. We assume that when mothers are on treatment, child mental health outcomes and abuse rates improve in a similarly marked 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 of this maternal HIV stage.

The lack of data on child outcomes when parents are on treatment, on child mental health and abuse outcomes among affected children in the first decade of life, and links between these and later outcomes highlights the need for more data. Longitudinal data designed to fill these gaps should be a priority.

IMPLICATIONS

There are two major motivations for building models. Models can be developed to better understand the present and models can be developed to predict the future. Both motivations played a role in this effort, but as a first step the priority is to better understand the present. Building this model has forced us to re-examine the available data, particularly what it tells us about distribution of impacts. For a model, it is not enough to know that adult HIV is linked to child depression and anxiety. We need to examine the distribution, 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 HIV-symptomatic caregiver increases risk, we also need to estimate how common it is for children to have a symptomatic caregiver.

The results of these efforts to better understand the present and the resultant model, point to a number of important policy implications:

- In high-prevalence settings a large proportion of children are at increased risk of adverse outcomes as a result of adult HIV (35% in our scenario). Moreover, this is a moving target because the entry and progression of adults through the HIV states described is ongoing. This suggests that **interventions are needed to reduce risk at the population level** requiring extensive coverage.

- A much smaller proportion of children will suffer long-term adverse outcomes. This implies the need for **targeted interventions to mitigate harm.**

- Given the high level of contextual adversity, the seriousness of the outcomes for altering life trajectories, and the consequent potential for long-term suffering, including in the subsequent generation of children, **intensive interventions for mitigation** will likely be needed.

- Risks associated with maternal HIV related ill health are likely to concentrate in the first decade of life. This is also the period of life in which the experience of adverse events is most likely to have long-term implications. Given this distribution of risk, **supportive interventions should be targeted to affected families with young children**.

- **Longitudinal data is needed**, beginning with children born into affected families, and children of all ages living with adults on treatment.

The adults of the future are shaped by the childhoods of today. Early childhood lays the foundation, mid and late childhood determine the opportunities and barriers to the attainment of the potential embodied in that foundation. In adulthood the costs and rewards of these formative periods are realized. 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, placing them at risk of enduring harm with the potential for life-long negative consequences and effects into the next generation of children. Understanding how risk environments in these contexts are shaped and where the potential to intervene lies is essential to protecting children, their futures, and their future children. This modelling exercise aimed to contribute to this understanding, further work is of course required.

FURTHER READING

For further information on Phase 1: Sherr L, Cluver LD, Betancourt TS, Kellerman SE, Richter LM. & Desmond C. 2014. Evidence of impact: health, psychological and social effects of adult HIV on children. AIDS. 28 (suppl 3):S251-S259. http://journals.lww.com/aidsonline/toc/2014/07001

For further information on Phase 2: Stein A, Desmond C, Garbarino J, Van Ijzendoorn MH, Barbarin O, Black MM, Stein AD, Hillis SD, Kalichman SC, Mercy JA, Bakermans-Kranenburg MJ, Rapa E, Saul JR, Dobrova-Krol NA & L Richter. 2014. Predicting long-term outcomes for children affected by HIV and AIDS: perspectives from the scientific study of children's development. AIDS. 28 (suppl 3):S261-S268. http://journals.lww.com/aidsonline/toc/2014/07001

For further information on the model design, Phase 3: Desmond C, Bruce F, Tomlinson M, Marlow MB, Aber, JL, Ouifki R. & A Welte. 2014. Modelling the long-term impacts on affected children of adult HIV: benefits, challenges and a possible approach. AIDS. 28 (suppl 3):S269-S275. http://journals.lww.com/aidsonline/