Children in the Era of HIV Treatment Scale-up

By Chris Desmond

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## About the LMG Project

Funded by the USAID, the Leadership, Management and Governance (LMG) Project (2011-2016) is collaborating with health leaders, managers and policy-makers at all levels to show that investments in leadership, management and governance lead to stronger health systems and improved health. The LMG Project embraces the principles of country ownership, gender equity, and evidence-driven approaches. Emphasis is also placed on good governance in the health sector – the ultimate commitment to improving service delivery, and fostering sustainability through accountability, engagement, transparency, and stewardship. Led by Management Sciences for Health, the LMG consortium includes the Amref Health Africa; International Planned Parenthood Federation; Johns Hopkins University Bloomberg School of Public Health; Medic Mobile; and Yale University Global Health Leadership Institute.
I. Introduction

Interventions to meet the needs of children affected by HIV have evolved. Experience, research, and changing epidemiological environments have prompted adaptations and improvements in both policy and practice. A focus on mitigating the impact of orphaining has shifted to protecting HIV-affected children by strengthening families. Increasingly, links have been drawn between protecting affected children and the contribution these efforts can make to improving other aspects of the response, including: reducing the risk of infection of the next generation, because these are often the same children; and improving adult adherence as a spin-off of household level interventions originally designed to support children.

In this policy note, we examine how treatment (prevention of mother-to-child transmission [PMTCT] and antiretroviral therapy [ART]) uptake and adherence has altered the nature and scale of the impact on children, as follows:

- There are fewer HIV+ children.
- Orphan numbers are decreasing.
- There are greater numbers of children exposed to HIV during pregnancy, delivery, and breastfeeding who are uninfected.
- More children are affected by adult HIV within the family as a result of increased adult longevity and increased fertility.
- The population of adolescents is larger than ever, and HIV incidence rates remain high, although they are past their peak.

A careful consideration of the changing nature and scale of the impact of HIV on children is needed to inform the continued evolution of the response to children in the era of treatment. The numbers, however, should not be considered in isolation. We must recall how the response has evolved to date and to reflect on the current and growing evidence of the range of challenges faced by children in the context of HIV. This reduces the chance of repeating past mistakes and ensures that forewarnings in recent research findings are given due consideration.

It is becoming clear that as the HIV response works its way towards the 90-90-90 targets and eliminating AIDS, the programs developed to support children have a critical part to play in knitting together prevention, treatment, and care interventions to improve the effectiveness and efficiency of each. HIV clusters in families, as do the factors that complicate all aspects of the response. Therefore, addressing these factors at the household level has the potential to render benefits not only for children affected by HIV, but also in terms of improved prevention for adolescents and young women, treatment access for children and men, and improved adherence and retention in care among both adults and children [1].
2. An Evolving Response

Children have been and continue to be on the margins of the HIV and AIDS response. Recognition that HIV or AIDS could infect or affect children lagged substantially behind recognition of the virus’ impact on adults. When AIDS was first recognized, there was a general reluctance to acknowledge the possibility that children might be infected [2]. In part, this was due to the conviction that the disease was restricted to the gay community. It was only in 1986 that the Centers for Disease Control (CDC) recognized perinatal transmission as the source of most pediatric HIV infections [3]. Transmission through breastfeeding was not widely accepted until 1990 [4]. Similarly, attempts to directly prevent pediatric infections were delayed by the presumption that HIV prevention among women would be a sufficient response to protect children [5]. The lag in testing and treatment of children is now widely acknowledged [6].

A similar lag occurred with respect to care and mitigation for children affected by AIDS. In 1990, Susan Hunter and Elizabeth Preble drew attention to orphaning in central and eastern Africa and called for policies and programs to address children’s HIV-related needs [7, 8]. AIDS orphaning became the index of the third wave of the epidemic: infections, illness, and death [9]. Children losing parents was just the tip of the iceberg, only the most visible sign of the social upheaval the epidemic was causing.

In 2000, supported by USAID, Susan Hunter and John Williamson provided regional information on orphaning, which was calculated from data maintained by the US Census Bureau [10]. In the same year, Geoff Foster and John Williamson published a paper outlining the multiple risks children faced when their parents became HIV-infected and ill, and eventually died [11]. Both publications helped to mobilize a massive international response, partly out of deep empathy for the plight of children and partly out of a fear that regional violence and instability would be caused by a generation of homeless children [12]. The President’s Emergency Plan for AIDS Relief (PEPFAR) was launched in 2003 in response to the growing HIV and AIDS epidemic, with a 10% reserve set aside for orphans and vulnerable children.

Many of the early interventions for children tended to focus on those who had lost one or both parents to AIDS, often operationalized as orphans from all causes due to the difficulty of specifically identifying AIDS orphans. Targeting AIDS orphans soon prompted reactions pointing out that: (1.) children suffered adverse effects of HIV and AIDS long before their parents died and they became orphans; (2.) orphans were seldom worse off than other poor children in the same community; (3.) the perceived inequity of targeting orphans often prompted a backlash; and (4.) the majority of children lived with a remaining vulnerable parent, often their mother [13].

In 2004, UNICEF and partners, including the United States government, released the Framework for the Protection, Care and Support for Orphans and Vulnerable Children Living in a World with HIV and AIDS. The Framework proposed strategies focused on strengthening families, community-based responses, essential services, government-led social protection, and public awareness, but it maintained orphaned children as the main target population [14]. Where the Heart Is, which was launched in Toronto in 2006, argued that the response to children had to be broadened from orphans to all vulnerable children. Further, it argued that the critical psychosocial needs of affected children must be addressed through support to parents, and that government and civil society action must work together to improve population wellbeing through improved access to health, education, and social services for all children in high HIV prevalence communities [15].
The PEPFAR 2006 OVC Guidance promoted a quality initiative to try to ensure effective services beyond the distribution of commodities to children (school satchels, shoes, blankets), defining “reach” as three or more of six essential services (education, health, shelter, food and nutrition, psychosocial support, protection from abuse and neglect, and economic strengthening) [16]. While intended to promote quality, the “3+” message at times had the opposite effect. Quality was hampered when partners extended beyond their technical capacity and provided lower-cost commodities in an effort to meet both high targets and 3+ services for every child. To help remedy the situation, in 2008, PEPFAR launched a quality assurance and improvement initiative aimed at developing local standards for direct service delivery [17]. The standards supported a better understanding of quality over quantity, but many partners continued to struggle to achieve both quality and high targets — particularly in areas with pervasive poverty [18].

The Joint Learning Initiative for Children Affected by HIV and AIDS (JLICA), which was launched in 2008, emphasized the vulnerability of all very poor children in HIV-affected communities, as well as the joint deprivations experienced by children as a result of poverty and HIV [19]. JLICA recommended family strengthening, both through supportive services and economic assistance [20].

The 2011 PEPFAR OVC portfolio review specifically recommended changing the terminology from “orphans and vulnerable children” to “children in the HIV epidemic,” to avoid overlooking infected children, children living in HIV-affected households, and children living in households in HIV-affected communities, some of whom could become HIV-affected at any time. This would also help to promote integrated services for children that would encompass prevention, treatment, care, and support [21] and respond to the wider ambit of PEPFAR’s 2008 re-authorization [22], which broadened the definition to “other children affected by, or vulnerable to, AIDS.”

In 2012, PEPFAR announced its new Orphans and Vulnerable Children (OVC) Programming Guidance at the XIX International AIDS Conference. Among other things, the guidance promoted a broader approach to children affected by HIV and AIDS, including: strengthening parents and caregivers as the primary strategy for improving child outcomes; strengthening programming and interventions for children differentiated by “ages and stages” of childhood, with a specific focus on early childhood and adolescence; and stipulating that 10% of program budgets must be devoted to monitoring and evaluation (M&E) to support evidence-based, cost-effective programming.

The continual evolution of the response has been backed by research. The now substantial body of work on children affected by HIV has identified a number of pathways through which adult HIV affects a range of development outcomes [23]. This work has supported the shift away from a narrow focus on orphaning by demonstrating how many of the impacts precede the loss of a parent. Research continues and new pathways are being identified — most notably, emerging evidence that children who are HIV-exposed but uninfected may be at increased risk of a range of negative outcomes.

3. Established and Emerging Risks

Prior to expanded access to ART, the greatest concerns for children were that those vertically infected and left untreated would endure suffering due to ill-health, repeated separations from caregivers, distressing hospital procedures, and be at increased risk of premature death during infancy and early childhood. The second group of concerns were that children would: be psychologically and socially
disturbed by parental illness; suffer isolation and discrimination as a result of transferred stigma associated with their parent’s condition; shoulder huge burdens of care and work in the household to compensate for adult incapacity; be orphaned and bereaved when their infected parent/s died; and suffer displacement, neglect, and abuse at the hands of exploitative families and communities.

The situation has changed dramatically with the expansion of treatment, although treatment has not expanded nearly enough to eliminate any of these concerns. By 2015, almost half of adults living with HIV worldwide received life-saving ART, thereby decreasing the risk of vertical transmission to their children and reducing the rates of orphanhood. Roughly half of children infected are on treatment. Without treatment, 50% of vertically infected children are likely to die before their 2nd birthday and 75% by their 5th birthday.

**Health and developmental risks of being infected with HIV**
Known risks of perinatal HIV infection to infant’s health and development include severe illness associated with secondary infections, progressive neurological disease, anemia, hepatitis, and cardiopathy [24] — all of which are often aggravated by non-disclosure. If children survive, progressive stunting is one the most common abnormalities seen [25]. Psychosocial development is also affected, including mental health outcomes such as depression, cognitive delay, and impaired language development[26].

The overwhelming majority of children and adolescents living with HIV were infected vertically [27] and are more likely to face psychosocial stresses associated with one or both of their parent’s HIV infection, in addition to their own illness.

**Known developmental risks of being affected by parental HIV**
Children living with HIV-positive parents and other caregivers, or who have to deal with parental death, face a range of stressors associated with distress, anxiety, and depression [28]. Associations between orphanhood due to AIDS and vulnerability to HIV infection in adolescence have been fairly consistently reported [29], as have indications that link parental HIV status, perinatal infection, and adolescent sexual risk behavior [30].

**Developmental risks of being exposed to but not infected by HIV**
In 2013, 1.3 million women living with HIV gave birth (unchanged since 2009). This means that 1.3 million children in that year were exposed to HIV in utero during birth or through breastfeeding [6]. With no change, 1.3 million HIV exposed but uninfected (HEU) children will be born each subsequent year, a growing population of concern. It is estimated that HEU children now comprise a third of all children born in southern Africa [31]. We know relatively little about long-term consequences of fetal and breastfeeding exposure to HIV [32], or about fetal exposure to antiretroviral drugs. Preliminary work in the area suggests that both may cause a number of adverse physiological changes [33].

HEU children are reported to have higher mortality and morbidity than do infants born to HIV-uninfected mothers. A recent systematic review found increased mortality is associated with shorter breastfeeding, low maternal cluster of differentiation 4 (CD4) levels, poor maternal health, and death of the mother [34]. The reported higher rates of morbidity are thought to be the result of impaired immune function [35] and higher risk of exposure to infections in households associated with living with HIV-infected adults.
A 2015 systematic review found that uninfected but HIV-exposed children are more likely to be stillborn, premature, of lower birth weight, and smaller-for-gestational age than unexposed children — especially in Sub-Saharan Africa [36]. It has long been known that these birth outcomes disrupt early developmental processes, particularly in adverse socioeconomic conditions. Without proper compensatory environmental experiences, this can lead to poorer child development outcomes [37]. Growth failure has also been reported among HEU infants [38] resulting from compromised parental care, mixed breastfeeding, and infections [39]. Regardless of cause, stunted children are at risk of having, on average, poorer short- and long-term developmental outcomes, including fewer years of schooling and lower adult wages [40].

4. Treatment and the Changing Scale and Composition of OVC Populations

The widespread availability of PMTCT interventions and the provision of ART for adults and children have changed the nature and scale of impact on children. On one hand, they have reduced the size of certain at-risk populations (HIV+ children and orphans). On the other hand, they have increased the size of others (HEU and children affected by parental HIV). Pediatric treatment, when available and accessed, has led to dramatic increases in the life expectancy of HIV+ children. PMTCT has dramatically reduced the number of pediatric infections. However, HEU children remain at increased risk of negative development outcomes and PMTCT has led to increases in the number of these children. Parents with good adherence are living longer, thus delaying and possibly avoiding orphaning. However, increased adult life expectancy increases the number of children affected, as keeping HIV+ adults alive and well increases fertility. The population of adolescents continues to grow – although HIV incidence rates have fallen from their peak, they remain high for this population, particularly for girls.

We provide an outline of these different impacts in three countries: South Africa, Uganda, and Nigeria. The three were selected to provide examples from different regions. We use Spectrum modeling to estimate all of the impacts, except for the number of children affected by parental HIV. For this latter impact, we use a model previously developed for USAID/PEPFAR, which examines the impact of maternal HIV on affected children. The baseline data for the models are drawn from the UNAIDS country projections. For the treatment scenarios using Spectrum, we use the treatment coverage and adherence assumptions provided by UNAIDS, which are optimistic.
Panel A: In each of the three countries, the number of children age 0-14 years who are living with HIV declined substantially since the early 2000s. This was a result of a combination of rapid expansion in access to PMTCT and low rates of access to pediatric treatment. Far fewer children were infected each year, thanks to PMTCT, while those who were infected and not on treatment died quickly, leading to a rapid decline in numbers. The gradual separation of the lines indicates the current (and hoped for) expansion in access to pediatric ART. The steepness of the decline in South Africa reflects the rapid pace at which PMTCT was rolled out. The rapidly widening gap between the lines reflects the relatively rapid pace of roll-out of pediatric treatment. The more gradual decline in Nigeria reflects the slow pace of expansion in access to pediatric ART. The situation in Uganda reflects increased access to PMTCT, but also a decline in prevalence among mothers. When this prevalence increased again, the number of HIV+ children again started to rise. Although the population of HIV+ children is declining in all countries, there remains a significant number of children whose average age is increasing and who are in need of additional support to maintain adherence to treatment and manage the transition to adulthood, including to sexual activity.
Panel B: Impact of Treatment on Orphaning

Panel B: Reductions in adult mortality associated with increased access to ART have reduced the rate at which parents are dying, and as a result, the rate at which children are orphaned. Some of these children will avoid being orphaned before 18 years of age; for others, orphaning will be delayed, but it will still occur before they reach 18. This is examined in panel C. Children stop being classified as orphans once they reach 18 years of age. Therefore, high treatment rates must be maintained for a number of years for the impact to be seen. In South Africa, even if high treatment rates are further increased, by 2020, there will still be 1 million children who could be classified as orphaned by AIDS. In Nigeria, the impact of treatment is only seen late, as treatment roll out has been slow. The gap only becomes large if it is assumed that Nigeria will achieve target treatment levels. The graphs of the total (all cause) number of orphans provide an indication of the impact of treatment relative to the entire orphan population. In South Africa and Uganda, this is large; in Nigeria, where HIV prevalence is low, it is small. Orphan numbers are declining. The decline is, however, gradual and requires treatment levels to reach and maintain high target levels if the decline is to continue.
Panel C: The figures track the children of a cohort of mothers born in 1985 (and turned 18 in 2003). Three scenarios are presented: one with no HIV (to provide a baseline); one with HIV but no treatment; and one with HIV and the high levels of treatment assumed in the UNAIDS projections. In all countries, HIV affects a significant proportion of children. In the absence of treatment, this would have led to dramatic increases in orphaning, particularly in the high-prevalence South African context. In the treatment scenario, there is less orphaning, with parents spending a significant proportion of children’s lives on treatment. The impact on orphaning is not as dramatic in this cohort model as in the population.
models in panel B. This is because population models measure the prevalence of orphaning, which is heavily influenced by delayed orphaning. The cohort model highlights the importance of adherence in avoiding orphaning. For adults — who are often infected before their children are born — to live to see their child reach 18 years of age, requires highly effective treatment. If adult populations do not have high levels of adherence and retention, orphaning will be delayed but not avoided. Keeping adults alive gives them the opportunity to have more children. As a result, while fewer children will be orphaned, more children will be affected.

**Panel D: Adolescents’ Risk and Population Size**

**SOUTH AFRICA**

**UGANDA**

**NIGERIA**

Panel D: All three countries are well past the peak in HIV incidence. The peak in South Africa and Nigeria was more recent than Uganda. In Uganda, however, there was recently a marked increase. Although the peak in incidence is past, there remains a significant risk of being infected by 19 years of age, particularly for girls. The risk for both males and females then continues to rise after 19 years of age. The size of the adolescent population continues to grow in all three settings.
The figure above depicts the relative size of risk groups (in 2017). The first group of columns shows the proportion of the child population that is affected by maternal HIV and AIDS (data on paternal HIV is not of sufficient quality to estimate the same). The next three groups of columns depict sub-populations of the affected group: those who have been orphaned by HIV; those who are HIV+ and on treatment; and those who are HIV+ but not on treatment. The HIV+ populations are mutually exclusive to one another, but they include some orphans. The HIV+ population figures include only those who are under 15 years of age. The final group of columns depicts the proportion of children who will be infected via sexual transmission before they reach 19 years of age. There is a growing body of evidence that those children who will be infected during childhood will be disproportionately from households affected by HIV. This will occur for two reasons: (1) HIV-affected households are, by definition, more likely to be in high prevalence areas; (2) there is evidence that the impacts of adult HIV can increase the risk that affected children will become infected [41].

5. **Summary of the Population Changes**

In the above panels, we have examined the impact of treatment and the maturing epidemic on four groups of children affected by HIV and AIDS. The central observations for each can be summarized as follows:

1. **HIV+ children (Panel A):**
   - The size of this population is decreasing as a result of successful PMTCT interventions.
   - Access to ART for this population has increased, but it remains an issue.
   - HIV+ children need continued support to deal with the burden of long-term HIV infection, long-term treatment, and the transition to adulthood. This will require more than drugs.
2. Orphans (Panel B):
   - Adult ART has reduced the prevalence of orphaning. This is a combination of averted and delayed orphaning.
   - Orphan populations will, for some time, remain well above those that would have been expected had the HIV epidemic not occurred.

3. Children affected by parental HIV (Panel C):
   - High rates of adult ART will increase the number of children affected by HIV, as adults live longer and have more children.
   - The sub-population of affected children that is exposed but not infected will grow, both because of PMTCT and because of increased fertility.

4. Adolescents at risk of HIV infection (Panel D):
   - Incidence rates are long past their peak, but adolescents continued to face high risks of HIV infection.
   - As a result of normal population growth, the size of the adolescent population continues to grow in all affected countries. This population continues to face high risks of infection, particularly among girls.

6. Recommendations

We aim here to provide thoughts on the direction in which the response to children should be heading, given the trajectory it has been on, new evidence on previously missed or underestimated risks, and the changing structure of the child population with the scale-up of treatment.

We argue for the importance of continuing with the shift towards a family-centered approach. This approach has the potential to benefit all children affected by HIV, including those infected and those at risk of infection during adolescence. Moreover, it has the potential to improve adult treatment outcomes via improved uptake, adherence, and reduced loss to follow-up.

HIV clusters at the household/family level. Household/family-level factors (socio-economic status, mental health of members, domestic violence, social isolation, etc.) influence outcomes for children affected by HIV, adult treatment uptake and adherence, and adolescent risk of HIV infection [13]. Addressing and mitigating household-level stresses can improve outcomes across the board. If household-level interventions are expanded to include efforts to test and link all household members to treatment and explicitly address household-level barriers to ART adherence, they could improve outcomes for several household members, which, in turn, would help to improve outcomes for children [1]. By improving adult health outcomes and reducing financial and other stresses, such programs could improve parenting capacity. Positive parenting has a strong relationship with adolescent risk behavior and its associated risk of HIV infection [42].

PMTCT programs provide an obvious entry point for such broadened family-strengthening interventions. The households of girls and young women identified through PMTCT interventions could easily be recruited into family-based strategies. Caregivers could be encouraged and supported to have all children in the household tested. Adult household members could be offered testing and linked to treatment if necessary. The situation of the family could be assessed and a package of services designed according to their strengths and needs, including differentiation based on HIV status.

components include economic strengthening, social support, health care access, infant and young child development, and adolescent transitions. Households with HIV-positive members would benefit additionally from adherence and disclosure support.

It will be essential to assess the situation of the household, as it will not be necessary or cost effective to provide all services to all HIV-affected households. All households should be visited to encourage testing, connections to treatment, and information on early child development (ECD). However, not all households will require ongoing home visits or inclusion in economic strengthening and other such interventions. Prioritization of households based on risk criteria will be necessary to ensure those who need and would benefit most from added intervention, receive it. While situational, risk criteria would look at underlying factors such as poverty status and presence of gender-based violence, which may indicate higher risk of defaulting on treatment or higher risk of HIV transmission.

PMTCT programs are an obvious entry point, particularly when the importance of ECD interventions for HIV+ or exposed children is considered. However, there are numerous other points of entry, including adult testing and treatment interventions. A simple question as to whether the client has children could trigger an initial home visit and assessment.

The recognition of the household clustering of HIV and of factors that continue to challenge prevention, treatment, and care highlight the importance of household-level intervention. Organizations implementing programs for OVC have a wealth of experience in family-based care and support. With some minor adjustments, they could compound their contribution to children and family well-being while simultaneously strengthening all other aspects of the HIV and AIDS response.

References


