Evidence of impact: health, psychological and social effects of adult HIV on children

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There is a growing evidence base on the immediate and short-term effects of adult HIV on children. We provide an overview of this literature, highlighting the multiple risks and resultant negative consequences stemming from adult HIV infection on the children they care for on an individual and family basis. We trace these consequences from their origin in the health and wellbeing of adults on whom children depend, through multiple pathways to negative impacts for children. As effective treatment reduces vertical transmission, the needs of affected children will predominate. Pathways include exposure to HIV in utero, poor caregiver mental or physical health, the impact of illness, stigma and increased poverty. We summarize the evidence of negative consequences, including those affecting health, cognitive development, education, child mental health, exposure to abuse and adolescent risk behaviour, including sexual risk behaviour, which has obvious implications for HIV-prevention efforts. We also highlight the evidence of positive outcomes, despite adversity, considering the importance of recognizing and supporting the development of resilience. This study is the first in a series of three commissioned by President's Emergency Plan for AIDS Relief (PEPFAR)/United States Agency for International Development (USAID), the summary provided here was used to inform a second study which seeks to identify insights from the broader child development field which will help us predict what long-term negative consequences children affected by HIV and AIDS are likely to experience. The third study discusses the design of a model to estimate these consequences. Although comprehensive, the review is often hampered by poor-quality research, inadequate design, small sample sizes and single studies in some areas. © 2014 Wolters Kluwer Health | Lippincott Williams & Wilkins

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Introduction

HIV and AIDS are most prevalent amongst adults in their reproductive years, resulting in far-reaching implications for children. Infected adults are often parents or are responsible for or involved in the care of children. Over the past decade, a great deal has been learnt about the implications of adult HIV for children to try and understand which children are more vulnerable and why. There is a substantial body of literature providing an increasingly clear picture of the immediate and shortterm effects of adult HIV on children. In this study, we provide an overview of this literature, highlighting the multiple risks for children which stem from adult HIV infection. We discuss how these risks change as the health

of the adult changes, and how such changes can lead to children enduring potentially harmful experiences that could compromise their lifelong wellbeing and, indeed, increase their own vulnerability to HIV infection. Achieving an AIDS-free generation depends on reducing this vulnerability.

One of the best known/studied risks for children of adult HIV infection is vertical transmission. Advances have been made in understanding and preventing vertical infection. Although effective prophylaxis is available, the vast majority of HIV-exposed children reside in low and middle-income countries (LMICs), where, in some, prevention of mother-to-child transmission (PMTCT) interventions remain limited and require considerable

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expansion. Increased access to antenatal care, additional funding and improved programme design will further reduce the number of infections among children. Whereas this is a cause for celebration, it is not the end of the story. Many children will be exposed to HIV even if not infected. Recent evidence suggests biological exposure alone can have negative implications, and these children will be born into households affected by HIV, resulting in further health, psychological and social risks. Whilst there is established evidence of the enormous challenges faced by HIV-positive children [1], this study focuses on the risks and outcomes of exposed children, and other children living in affected households. As the successes of PMTCT grow, so will the number of exposed and affected children, a problem in urgent need of solution.

We discuss how adult HIV affects children during four phases of adult HIV progression – before HIV infection, at diagnosis, in the period following adult infection and illness and, lastly, adult death. This study draws on available evidence, prioritizing meta-analyses and systematic reviews when available.

Although we organized this review by stages of adult infection, it is important not to view infected adults and affected children in isolation. Most children reside in households together with families [2], however broadly defined [3], and their early life experiences are shaped and refined by this contextual environment. All children, especially very young children, rely on adults for protection, care, developmental stimulation, nutrition and healthcare access [4]. HIV infection in a family can disrupt or strain the supportive capacity of an affected adult and the family, and potentially lead to a range of hardships for children as they grow and develop [5]. The risk is amplified because HIV, being primarily sexually transmitted, is a disease which clusters in families [6]. Family resources play an important role in protecting children against the extent and severity of exposure and vulnerability to adverse consequences. For most parents, part of their HIV management involves shielding children from and attempting to ameliorate negative consequences of the disease. Access to treatment, mental health coping, financial resources, employment, social support and community protection have been shown to buttress adult adaptation and may minimize effects on children [6]. The resources available to the family therefore play a major role in determining the extent to which children can be protected. Appreciating the family context is, therefore, essential when considering the type and severity of risks for the child.

The study is the first in a series of three, the first two of which are based on three and nine, respectively, President's Emergency Plan for AIDS Relief (PEP-FAR)/United States Agency for International Development (USAID)-commissioned background studies. The three background studies on the evidence of the

consequences of HIV and AIDS on affected children are the basis of this summary and informed the development of the second set of nine studies which drew from the broader child development literature to shed light on the likely long-term outcomes; these are summarized in the study by Stein *et al.* in this issue. Finally, the third study by Desmond *et al.* (also in this issue) builds on these to suggest how we might model the consequences of adult HIV on children.

Before HIV infection: who is at risk and what does it mean for children?

Social experiences and behaviours can predispose adults to HIV infection, including migrancy and minority status, sexual behaviour and drug use, and are also independently associated with developmental challenges for children who are dependent on these adults [7-9]. This immediately raises the possibility that HIV-affected children are more likely than other children to be living in environments which are challenging even in the absence of HIV and AIDS. These dynamics are important to consider when reviewing studies purporting to measure the impact of HIV, as negative child outcomes may be attributed to HIV, which are not only the result of adult infection, but partly or wholly due to the social environment and factors which predisposed the adult to infection in the first place. Given that the accumulation of adverse experiences is particularly problematic for children [10], it is important to consider that the challenges associated with HIV often occur alongside existing challenges. The accumulation of these risks can exacerbate negative outcomes.

An HIV diagnosis: potential for compromised care-giving

Many women, and sometimes their male partners, are first tested for HIV during pregnancy, locating the diagnosis within their pregnancy experience. Adjustment to being infected and preparation for treatment in non-pregnant adults can often be paced over time [11]. Such readiness is predictive of coping as well as adherence [12]. In prenatal care, waiting is not possible as preventing vertical transmission must begin as early as possible. Thus, events are accelerated, emotions conflicted and perhaps not unexpectedly, ante-natal and postnatal depression in HIV infection is high [13].

At any time, HIV diagnosis heralds profound mental health and adjustment challenges [14], often compounded by stigma [15]. Numerous studies indicate that compromised parental mental health, as a result of learning HIV status, has immediate effects on the quality and quantity of attention a parent is able to devote to their young child [16–18].

Newly diagnosed parents need to adjust to their HIV status, consider disclosure, and accommodate relationship changes and treatment management frequently whilst experiencing clinical levels of stress, depression [19], anxiety [20] and even suicidality [21]. Moreover, it is well established that mood affects parenting [22], with consequences on child development [23]. These difficulties may continue for some time, as unlike other conditions such as heart disease, HIV diagnoses are often not shared and may remain a burdensome secret.

HIV infection and illness: direct and indirect risks for children

The most direct risk of adult infection for a child is that HIV can be passed to the infant vertically. When PMTCT implementation challenges are fully addressed, vertical transmission becomes a rare occurrence [24]. Even with decreasing rates of vertical transmission, children born to HIV-positive mothers will be exposed to HIV and antiretroviral therapy (ART). So as PMTCT coverage expands, risks associated with HIV exposure will become more prominent. Exposed but uninfected children show increased mortality and diminished cognitive capacity [25], although less severe than infected children [26] and often reversible

Adult infection and illness introduce a range of indirect risks. Parenting is a demanding job. Caregiver absence, physical and emotional, may be only the first stage of declines in child care. Ill or hospitalized parents can be physically absent, bed-ridden or exhausted from incapacitating illness. Infected and uninfected partners are faced with challenges as they come to terms with spousal infection and care [27]. Children may be called upon to take on adult roles and provide care directly to ill adults, to perform adult household chores, care for younger children [28] or supplement adult livelihood activities. These demands can foster cycles of risk for children leading to poor health, school drop-out and engagement in transactional sex as a means of income generation [29].

HIV illness can bring severe and lasting economic deprivation. Healthcare access comes at a cost, including transport and opportunity costs of clinic visits and sometimes substantial treatment costs. Studies show co-occurring economic stressors of adult HIV infection, such as loss of earnings, diversion of income to healthcare expenditure, disruption of savings and premature sale of irreplaceable assets to meet healthcare costs [30,31]. All of these create a challenging environment for children to thrive.

The trajectory of adult illness is highly contingent on access to healthcare, ART, adherence and treatment efficacy over time. The advent of ART has revolutionized

prognosis and life expectancy with clear survival advantages. Remaining asymptomatic is a protective factor for child development in that parents can continue to support and care for children, children can return to school and the need for child labour is decreased [32].

Adult death: compounding risk

A number of risks are associated with caregiver death. These include risks associated with bereavement and those associated with changes in the living arrangement of affected children.

Bereavement associated with caregiver death can have negative, although not typically long-lasting, mental health effects on children [33]. However, given that HIV infections cluster in households, multiple adult deaths as well as sibling deaths magnify the risks associated with bereavement. Moreover, the absence of palliative care and a supportive environment further magnifies risks [34].

The loss of a caregiver as a result of death, or debilitating illness, can lead to significant changes in children's living arrangements. The caregiver may have been an important advocate and intimate comforter for the child. In such cases, even if the child is not moved to a new household. the standard of care they receive may fall or the child may feel themselves poorly treated. When children are moved, typically they remain within the extended family network. Population-based surveys in highly affected countries suggest that the vast majority (90%) of orphans live within extended families, whereas 10% live with unrelated caregivers. The closeness of the relationship appears to matter; the evidence suggests that the less direct the relationship between an orphan and the head of the household, the greater the chance that the child will be discriminated against [35,36].

Population-based household surveys typically do not cover children in institutions. As a result, it is unclear how many HIV-affected children live in institutional care or on the street. There is, however, evidence to suggest that in highly affected countries, the number of children's homes is increasing [37]. It is not clear if this is linked to HIV or to the perverse incentive of additional funding for children's homes in the context of HIV [38,39]. If children do find themselves in institutions following a death (or because of poverty or a severely ill caregiver), they face a number of developmental [40], emotional and abuse risks [41].

Risks do not inevitably lead to harm

The extent to which risks are translated into harmful experiences is shaped by the context in which the risks

occur, and the characteristics of the infected caregiver and affected child. The level of social support affected families receive, the economic status of the family, the availability of relevant services and the level of stigma all determine the degree to which the child can be shielded. Child characteristics which shape the extent to which a child faces risks and may be harmed by them include age, sex and personal adaptability [42].

Low social support has been associated with children's depression and anxiety symptoms [43], and negative adjustment amongst adults living with HIV and AIDS [44]. Along with these findings, strong positive associations between peer support [45], social support and improved psychological well being have been reported specifically among HIV and AIDS-affected children [46,47]. By contrast, negative peer interactions such as bullying and gossip are identified as risks.

A number of services can reduce risks for children. Prophylactic cotrimoxazole, for HIV-exposed but uninfected children, is associated with reduced rates of morbidity and mortality [48]. Cash transfers or other means of family economic support can mitigate risks associated with financial pressure [49]. Quality health and education services provide protection. Children from marginalized populations, who are not able to access services, even if they are available, are at perhaps the greater risk.

Caregiver and child characteristics shape the level of risk for children. A distinction is drawn in the literature between maternal, paternal and double orphans. The loss of both parents is regarded as the most serious loss, whereas the majority of studies find that maternal orphans with surviving fathers are at greater risk than paternal orphans with surviving mothers. This is because children are more likely to remain living with a surviving mother than with a surviving father. In some contexts, however, the reverse is observed, with paternal orphans being at a greater risk, likely because of the social access fathers facilitate in these contexts [50].

The age and sex of affected children shape their level of risk. Stressful environments and exposure to pathogens are likely to be more serious for younger children. Younger children are also more dependent on caregivers, so influences on caregiving quality due to death or illness have intense impact. Households may delay the enrolment of younger children in school if the family is already finding it difficult to meet the costs associated with keeping older children enrolled. The harmful effects of institutional care are also worse for younger children. Older children, however, may be at a greater risk of being withdrawn from school to help with productive activities in the home, earn additional income or to provide care to ill family members.

Stigma is a key determinant of negative outcomes for HIV-infected adults, children and families [15]. A study in South Africa found that stigma was one of the main mediators of the link between family AIDS and child psychological distress [51]. Studies also show that poor child mental health in the presence of family HIV may be mediated by stigma directly [52] or indirectly by some of the negative correlates of stigma such as bullying [53].

Adverse consequences for children of adult HIV infection

Although risks do not inevitably lead to harm [54,55], numerous studies of children affected by HIV have observed that often risks do lead to harm, at least in the short term with potentially long-term implications.

Psychological adjustment

Conclusive evidence, now synthesized in several systematic reviews, demonstrates that parental HIV is associated with child psychological distress, such as depression, anxiety and post-traumatic stress [56-58]. Most of this research has focused on children orphaned by AIDS, finding heightened rates of depression and posttraumatic stress reactions compared to children who are not orphaned, and also compared to children whose parents died of causes other than AIDS illnesses or violent deaths [59]. More recently, studies have found heightened rates of depression, post-traumatic stress and, in particular, anxiety amongst children whose parents or primary caregivers were alive but unwell with symptomatic AIDS [60,61]. Qualitative data suggest that this anxiety is linked to fears for the health and survival of their parents [62]. Two studies in LMICs have identified clear pathways between familial AIDS, poverty and child psychological distress [63], as well as pathways from poverty to child educational and sexual risks. Negative psychological impacts are enduring, with worsening mental health status for AIDS-orphaned children over a 4-year period [64]. These findings are similar to those reported from a broad range of settings [65] in sub-Saharan Africa, the United States [66,67] and China [68-72]. Indeed some studies specifically draw attention to the elevated risks for HIV-affected youth [73,74], as well as describing the complexity of attributing discrete causal pathways with both adult and child HIV potentially contributing to outcomes.

Cognitive impacts

Two recent systematic reviews [75] identified 54 and 21 [76] studies, respectively, with the majority showing some form of cognitive delay in children both infected and affected by HIV [74]. All domains of development are implicated, including expressive and receptive language [77], memory, information processing, visual-spatial tasks, executive functioning [78] and decision-making

[79]. However, caution is needed in balancing the established effects and causal pathways, with some studies highlighting the importance of family background factors, and others finding no specific effects of antiretroviral exposure for all compounds. Given the neurotropic nature of HIV, interventions and special need provision should be anticipated. A recent review [80] identified four well established interventions to improve child neurocognitive functioning in low and high-income settings [81–84].

Nutrition

Exposure to HIV has been linked both with low birth weight and slower early growth [85]. However, this is often recovered within the first year. Although the risk associated with HIV exposure may be temporary, risks associated with economic strain may persist. In South Africa, for example, both maternal and paternal orphans were more likely to report not eating dinner the previous night and to have gone to bed hungry the previous night compared to non-orphans [86]. It may, however, also be a result of discrimination when food is available, but HIV-affected children receive differential amounts of food or experience meal with-holding [87].

Schooling

Adult illness, mental health challenges or economic constraints can affect families' abilities to meet children's basic needs including education. A systematic review found specific educational effects of family HIV, including disadvantage in school enrollment and attendance, school behaviour, performance, completion and educational attainment. Children who lost their mothers, double orphans, higher poverty and girls may be more vulnerable [88]. Pathways from parental AIDS to school disruption and problems include child psychological distress, parental illness keeping the child at home to help and children dropping out of school in order to earn money for the household [54,89,90]. Severe AIDSinduced household poverty is a major pathway, particularly when there are costs (fees, transport, uniforms, etc.) associated with education [91].

Exposure to violence

HIV-infected women are disproportionately subjected to various forms of verbal, physical and sexual abuse. Children in AIDS-affected families have been shown to endure a threefold higher level of abuse [92]. Two studies in sub-Saharan Africa clearly identify child abuse as a link to future HIV infection [93,94].

Sexual health

Research from sub-Saharan Africa has consistently linked orphanhood and parental AIDS illness with HIV seroprevalence and HIV risk behaviours among youth. A recent systematic review and meta-analysis found significantly greater HIV seroprevalence among orphaned (10.8%) compared with non-orphaned youth (5.9%) [95].

Whereas a portion of this association might be explained through vertical transmission, a positive relationship between orphanhood and risk behaviours also appears likely. Five of the included studies found significantly greater risk for pregnancy among orphans compared with non-orphans. Trends across 17 of the included studies showed elevated reports of sexual risk behaviours among orphans compared to non-orphans, including higher likelihood of girls' unprotected sexual intercourse, multiple lifetime partners, forced or unwilling sex, transactional sex and earlier sexual debut. Adult and perinatal infection [96] has also been shown to be related to sexual risk behaviours [97], as has parental AIDS illness [51,90].

Resilience and coping, and post-traumatic growth

Psychological resilience is defined as good mental health, despite serious threats to adaptation or development [98,99]. An HIV diagnosis brings with it many challenges, but the majority of children do not succumb, and some do well. There is solid evidence of post-traumatic growth when adults with HIV infection experience life changes which are positive and enriching [100]. Treatment has enabled many people with HIV to resume employment and lead a full and productive life. Fear of rejection is common, but many couples do not experience rejection, and social support has strong benefits. For some, parenting gives meaning to their life. Some children show resilience regardless of high levels of HIV and AIDS-related distress [101,102].

There are good arguments against pathologizing children and point to the importance of encouraging coping and resilience [54,55]. In every study, some children cope (and cope well). These two systematic reviews on resilience amongst HIV-affected children highlight a variety of factors and interventions to mitigate risk and promote protective factors including social support, adaptability, positive activities cash transfers and parenting skills. Research on interventions that directly target promotion of resilience in children affected by HIV has been limited. However, there are promising findings from a handful of studies on interventions to promote resilience which underscore the importance of both family-based and peer support interventions. [103–105]

In conclusion, there is compelling, multi-country evidence that HIV infection and AIDS illness and death in adult caregivers raise risks of parental economic health and mental health problems. Increasing evidence shows that this HIV-related distress can lead to changes in the family environment, challenges in parenting, and potentially to negative impacts on parent–infant interaction [106,107]. In addition, research shows that children in AIDS-affected families experience increased risks of physical and

emotional abuse and exposure to domestic violence in the home as well as increased levels of exposure to sexual abuse. The presence of adult HIV infection severely challenges the family system and child care through pathways linked to poverty, stigma, ill health and adjustment. These assaults are not isolated or single, but weave a complex web with cumulative effects on both the adults with HIV and the children for whom they care.

To date, studies of the effects of adult HIV on children in LMICs are restricted to immediate and short-term impacts. Longer-term follow-up studies are needed, including cohort studies with reliable and repeated measures. The identified negative outcomes in the immediate and short term may well have longterm implications for affected children. The nature of these impacts will be determined not only by context and individual particularities but also by the extent to which impacts are concentrated and clustered in a subpopulation of highly affected children. The impacts will be shaped further by the type of care affected children receive and the extent that it mitigates or compounds negative effects over time. Research on children affected by HIV has not adequately addressed such questions of concentrating and clustering, and has yet to consider compounding.

What we now know is that adult HIV presents severe challenges for children. The already deprived circumstances of families in the most heavily affected countries make it difficult for them to protect children from these challenges. The potential for mitigation and resilience is also affected by the low level of available supportive services beyond the already strained resources of extended family and community. This means that the hardships faced by children affected by adult HIV are likely to both persist and accumulate.

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Conflicts of interest

There are no conflicts of interest.

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