

Parenting and HIV
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Highlights:

- 1/3 of children in sub-Saharan Africa are cared for by an HIV-positive caregiver.
- Parental HIV is associated with an elevated risk of developmental problems.
- HIV affects parental responsiveness and may lead to avoidant coping
- Low-cost parenting interventions have been tested in LMIC for HIV endemic settings.

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Abstract

With the widespread use of antiretroviral therapy and successful prevention of mother-to-child transmission the development of HIV-negative children with HIV-positive parents has become an important focus. There is considerable evidence that children's developmental risk is heightened because a parental HIV-diagnosis is associated with a range of potential problems such as depression, stigma and financial difficulties.

Up to a third of children in sub-Saharan Africa (SSA) are cared for by an HIV-positive parent or caregiver. We review the mechanisms by which HIV affects parenting including its negative effects on parental responsiveness in the early years of parenting and parental avoidant coping styles and parenting deficits in the later years. We describe low-cost parenting interventions suited for low resourced HIV endemic settings.

Introduction

The shifting epidemiology of HIV and its impact on parenting

The HIV pandemic has had enormous consequences for families [1], particularly in countries with high HIV prevalence and especially in sub-Saharan Africa (SSA) where the majority of affected families live. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates the number of children orphaned by AIDS globally to be 13 million [2]. There is now substantial literature on the absence of parental figures in the HIV context on children's development and adjustment [3-5]. However the introduction and wide-scale uptake of antiretroviral therapy (ART) over the last decade has changed the landscape dramatically [6]. Prevention of Mother to Child Transmission (PMTCT) programmes ensure that the vast majority of children are now born HIV-negative. While this has changed the life chances of many children, there are increasing numbers of HIV-negative children growing up in households with a parent who has a chronic condition requiring lifelong treatment. The developmental literature in recent years has shifted to focus on the development of HIV-negative children who have an HIV-positive parent. A series of recent systematic reviews report associations between parental HIV, illness or death, and children's physical, educational, social and emotional outcomes [7-12]. These include children who are exposed in-utero but who remain HIV-negative themselves, and *HIV-affected* children who may not have been directly exposed to the virus but whose parents may have become HIV-positive during the course of their childhood. This group may also include children who have an HIV-positive father or caregiver who is not their biological parent. Recent estimates suggest a third of all children in SSA are cared for by an HIV-positive parent, most commonly their biological mother [6].

This review will concentrate on exposed HIV-negative children in epidemic areas and consider key mechanisms by which HIV may affect parenting. We focus specifically on mothers as primary caregivers, given this is most common in SSA epidemic regions, however evidence on fatherhood [13] and non-traditional families [14] are equally important, and are addressed elsewhere in this special issue. Secondly, interventions that have been developed for families in low resourced HIV endemic areas will be described.

While this review focuses on HIV-negative children it should be remembered that parents living with HIV and caring for children who are themselves HIV-positive have been declining in numbers (70% decline in new infections 2000-2015 due to ART)[2]. However, they still reflect a substantial group with approximately 2.6 million children living with HIV in 2015 [15], the vast majority of whom are in Africa. This is generally considered a group in need of specialist care and support [16,17] particularly around disclosure of their diagnosis [18,19] and adherence to medication support [8, 16, 18].

The impact of parental HIV on children

A number of reviews summarise the evidence on the effects of parental HIV on child development [9-12, 21-23]. The studies cover a wide range of child ages and sometimes include unvalidated measures to assess child development, thus limiting our understanding of the development of HIV-exposed uninfected children.

Moreover, the results are not entirely consistent. There is evidence however that HIV-exposed uninfected children may be at increased risk of internalising and externalising symptoms, have lower cognitive scores including reading ability, delayed motor development, lower secondary school attendance and difficulties concentrating at school, as well as increased sexual risk behaviour and abuse victimisation [10] compared to HIV-unexposed children. Some studies have also reported increased mortality, hospitalisation and under-nutrition [24,25].

Improvement in maternal health as a result of access to ART and increased duration of breastfeeding are particularly beneficial for these children, improving their growth and nutritional status and reducing morbidity and mortality [25, 26]. Most studies conclude that the contribution of parenting to supporting the physical health, nutrition or stimulation, nurturing and emotional development of children is substantial and that negative effects on children are *not* inevitable. In one large cross-sectional study of 10-17 year olds, children of HIV-positive parents reported experiencing less positive parenting than children whose parents were HIV-negative [27].

Mechanisms by which HIV may impact on parenting

A diagnosis of parental HIV-infection is associated with decreased social support, high levels of stigma, poorer nutrition as well as economic and employment

consequences and negative effects on parental mental health [7]. These place enormous stressors on family life [28]. Parental depression has been shown to adversely impact children's development and is very common amongst parents with HIV. In the perinatal period for example, at least 23% of women meet criteria for depression and 40% experience significant depressive symptoms [29]. Parental depression is associated with poorer adherence to ART, low clinic attendance, and lower levels of exclusive breastfeeding. Moreover, disturbances in parental attention and responsivity may compromise children's development. These negative effects of depression on parenting are most marked in circumstances of socio-economic disadvantage and poor support [30], which commonly pertain in the context of HIV [31].

Parents recently diagnosed with HIV experience preoccupations around stigma, life expectancy, the fidelity of their relationships and possible lack of social support. These cognitive processes mediate the effect of HIV diagnosis, parental stress and depression on parenting. Thus, rumination and preoccupation about negative thoughts affect both attention capacity and responsiveness, which are critical to sensitive parenting [23, 30, 32]. Important components of sensitive parenting include attention to child cues and associated contingent responsiveness which is key to children's cognitive development: emotional scaffolding especially in stressful situations is important for child emotional regulation and behavioural development, and sensitivity to children's cues is key for the development of attachment [23, 30].

In Figure 1 we illustrate two (not mutually exclusive) pathways by which HIV may impact on parenting. The first concerns the way in which increased anxiety and depression affect parenting (as above) and the second is the use of avoidant coping style to manage stressors related to the diagnosis [33, 34]. Both active and avoidant coping are commonly reported among HIV infected mothers in the first two years post-partum [35, 36]. Avoidant coping includes distraction, escape, denial, emotional venting, self-blame, lack of control and substance use. Active coping remains stable while longitudinal evidence shows that avoidant coping tends to increase over time in the later postpartum period [35, 36]. Mothers often use these coping strategies to deal with the stress of living with HIV in highly stigmatised contexts where they have little access to support. While substance use is considered an avoidant coping strategy, there is very little research to demonstrate how commonly this occurs in

SSA populations. Where both substance use and HIV are present, risk of reduced parenting capacity is likely to escalate, although the specific relative influence of either one on parenting capacity may be difficult to disentangle [37]. Avoidant coping has been shown to increase significantly between 6-21 months post-partum, and in some research [35] is associated with parenting stress and lowered parenting attention and responsivity which can affect parent-child communication and ultimately the mental health of both parent and child [34, 38]. In middle childhood avoidant coping strategies are common among women living with HIV, and are particularly associated with parenting deficits (i.e., poor parenting practices, lack of parental involvement, and poor parenting style) [39] and parenting stress [34, 38].

Figure 1 Mechanisms underlying the effects of HIV on parenting and child emotional and behavioural development

Interventions to mitigate the impact of HIV on parenting in Africa

There are upwards of 36 million adults living with HIV across the globe; 25 million of them live in Africa [2] and many are parents [6]. Thus, increased efforts have been made to draw attention to the parental needs (including parental health and mental health), and parenting capacity [7, 9, 10, 23, 40, 41] of HIV-positive parents, and in designing and testing interventions to support families.

Important considerations here are the child's age, developmental stage as well as parental HIV disease progression [31, 33]. Disease progression is an important defining feature in interventions, as different stages of disease management (diagnosis, treatment initiation, illnesses) place different demands on parents. During the perinatal period, the time when most women receive their diagnosis, the focus is primarily on supporting parents to adjust to both the medical and psychological demands of being HIV-positive [42, 43]. Adherence to ART, breastfeeding and providing child stimulation are all important factors in the early years of life.

Increasing years on ART treatment are accompanied by the need to prepare for periods of illness. This becomes more important as HIV disease progresses, often coinciding with middle and later childhood [27, 33, 44, 45]. Support for parent-child communication about HIV and HIV disclosure then become particularly salient [8, 33]. During adolescence the focus shifts towards a need for parent-led education about health, HIV and sexual behaviour in an effort to reduce the vulnerability to HIV

infection, given that parent-led education has been shown to reduce sexual debut and other adolescent health risks more effectively than peer or school led education [33, 46, 47].

Several parenting interventions have been developed in Africa; these include interventions with a focus on supporting parents with HIV-specific and HIV non-specific content and information, and parenting skills.

Parental adjustment to an HIV diagnosis in the perinatal period

A number of interventions focus on the perinatal period [48-51]. Most interventions are delivered through home-visiting programmes and focus on health education to enhance parental health behaviours, HIV awareness and support around maternal health (including education on the link between adherence and mental health), child health as well as information on reducing vertical transmission.

Improving parental capacity and skills amongst HIV-positive parents

There is an increasing need for locally adapted and culturally relevant interventions that specifically focus on the needs of HIV-positive parents. Table 1 summarises the content and results of three interventions in the African context that directly address parenting and HIV as a central focus while using parenting, child, or family resilience approaches. These represent examples of the application of long established parenting support principles to the specific needs of HIV infected parents in middle childhood in SSA. They are distinctive in that they are HIV specific, are designed to utilise user-friendly and simple materials and tools, which have been developed through extensive formative and pilot work and have undergone evaluation. These interventions focus directly on building parenting capacity, and on improving the parent-child relationship (Table 1).

A few other HIV-sensitive parent support interventions, summarised in recent reviews [40, 56], have been developed outside of Africa and are currently being tested in Asia and the United States. Some interventions in the United States have begun to focus specifically on parental self-care [57] as a model for intervention. The extent to which these interventions may be transferable to African contexts remains unknown.

While not directly addressing HIV, Cluver and colleagues have developed parenting support (14 sessions by lay counsellors) specifically addressing harsh parenting amongst parents with adolescents in communities with high HIV-prevalence [60]. Although this intervention is tested in HIV-endemic communities, its content does not directly address parental HIV. Harsh parenting can include lack of affection, inconsistent supervision, verbal and emotional abuse and corporal punishment in these contexts [61].

Conclusion

Experience, research and changing epidemiological environments have all led to adaptations and improvements in policy, and a shift in practice in the field of HIV to recognise the parenting needs of HIV affected families. It is critical that research focuses on developing sustainable, evidence-based interventions to ensure these children's development and in building human capital. To be implemented at a wide scale in low resource settings, it is critical that these interventions remain low intensity and are designed to be delivered through task shifting, allowing the use of lay professionals. There is increasing evidence that local health care workers and lay counsellors can deliver evidence-based interventions to enhance early child development. It is important that this work be expanded as it is likely to be the most sustainable way in which policy can improve child development in the long term. Support and collaboration with local institutions in epidemic regions is necessary to ensure that local researchers are encouraged to adapt and augment existing evidence-based parenting interventions that have been widely tested outside of the context of HIV, and that could be applied to the HIV context. This is particularly relevant since significant prior investments have been made in ensuring these interventions are theoretically sound, well developed and informed by the broader parenting literature. This would likely accelerate the timeline by which parenting support may become entrenched in local practice.

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This review examines the global empirical literature regarding disclosure of parental HIV infection to children. Thirty-eight articles published in English-language journals prior to 2011 were retrieved and reviewed regarding disclosure process, reasons for disclosure/non-disclosure and impacts of disclosure/non-disclosure. Disclosure rate was relatively low worldwide. This review offers a comprehensive review of HIV sensitive parent support interventions worldwide.

9. * Chi, P. and X. Li, **Impact of Parental HIV/AIDS on Children's Psychological Well-Being: A Systematic Review of Global Literature**. AIDS and Behavior, 2013. **17**(7): p. 2554-2574.

This review examines the global literature on the impact of parental HIV/AIDS on children's psychological well-being. Fifty one articles reporting quantitative data from a total of 30 studies were reviewed. Findings were mixed but tended to show that AIDS orphans and vulnerable children had poorer psychological well-being in comparison with children from HIV-free families or children orphaned by other causes, but that the period prior to parental stress was more strongly associated with poor outcome rather than parental death per se.

10. ** Goldberg, R.E. and S.E. Short, **What do we know about children living with HIV-infected or AIDS-ill adults in Sub-Saharan Africa? A systematic review of the literature**. AIDS Care, 2016. **28**(sup2): p. 130-141. **

This is the most recently published review on the effects of parental HIV on child outcomes. It identified 47 empirical research articles examining the population prevalence of children living with HIV-infected or AIDS-sick adults, or the consequences of adult HIV infection or AIDS illness for child well-being. This review confirms that this population of children is substantial in size, and that the

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