COMMENTARY

# 5.3 Following the Special Populations Home: Children and Families

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## INTRODUCTION

This excellent review has highlighted the multiple linkages between HIV and psychiatric risks for 'special populations'. By summarizing a range of worldwide data, this chapter provides a compelling and evidence-based argument for strong associations between mental health problems and heightened risks of HIV infection, adherence and disease progression. In addition, HIV infection also leads to increased psychological distress in a range of populations in high- and low-income countries. The chapter also outlines the central importance of political buy-in for the development and implementation of effective interventions, particularly for groups facing stigmatization. In many ways, it is this exposure to stigma – concerning HIV status, sexual orientation, sex work, drug use or combinations of these – that links such diverse groups. Whilst the chapter rightly outlines the differences between the generalized epidemic of Sub-Saharan Africa and the concentrated epidemics of high-income countries, it also underlines the common

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aspects of the experience – that people living with HIV and AIDS worldwide share vulnerabilities related to the social and economic sequelae of infection.

This commentary follows on to explore what happens when we follow our special populations home to their children and their families. What do we know about the impacts of HIV/AIDS on those who provide emotional care (and in lower income countries, much of the medical and social care) for HIV-infected people? And what are the long-term psychological implications for children of living with family illness, orphanhood or within a family affected by AIDS? Recent debate has highlighted the importance of considering the mental health impacts of family AIDS through the lens of resilience as well as that of risk [1, 2] and of recognizing children as social actors in their own rights, influencing their families as well as being influenced by them [3]. In order to understand the full extent of HIV mental health burden on children, it is crucial to navigate the pathway between detailed understanding on the one hand and avoidance of pathologizing children on the other.

Of course, these groups of children – AIDS-orphaned, living with AIDS-unwell caregivers, HIV-positive children and HIV-exposed children, are far from being mutually exclusive, and many children experience two or more of these simultaneously and in succession. It is also notable that – particularly in Sub-Saharan Africa – 'parents' frequently refers to 'primary caregivers' who may or may not be biological parents [4]. When we consider the impacts of HIV/AIDS on children and families, we need to understand this in the context of various – and changing – family structures. Recent research suggests cumulative effects of HIV/AIDS-orphanhood and caregiver HIV/AIDS sickness on child outcomes [5] and further research examining these overlaps is clearly required. It is also important to note that mental health outcomes for AIDS-affected children in Sub-Saharan Africa are generally measured using self-report rating scales. Whilst the basic reliability and validity of many of these scales has been assessed [6–8], to date the diagnostic performance of these scales has not been evaluated. Symptom thresholds may vary across populations [9] and research identifying appropriate clinical cut-offs for children and adolescents in Sub-Saharan Africa is clearly needed.

## IMPACTS OF HIV/AIDS: AIDS-ORPHANHOOD:

In the past decade increasing numbers of controlled studies and systematic reviews have identified negative psychological impacts on children of parental HIV/AIDS [10, 11]. Most of this research has focused on children orphaned by parental HIV, finding heightened rates of depression and post-traumatic stress compared to children who are not orphaned, and also compared to children whose parents had died of other causes such as non-AIDS illnesses or violent deaths [12]. These findings seem similar across broad settings – Sub-Saharan Africa, the United States and

China [13–16]. Perhaps, most worryingly, new findings show that the negative psychological impacts are long-lasting, with worsening mental health status for AIDS-orphaned children over a 4-year period [17]. Not surprisingly the broader early childhood developmental literature would point to the fact that chronic stress, toxic trauma and scant ameliorating input may contribute to a continuum of burden, which may manifest itself in later life with reduced chances of children meeting their potential [18].

## IMPACTS OF HIV/AIDS: PARENTAL ILLNESS

More recently, studies have found heightened rates of depression, post-traumatic stress disorder (PTSD) and in particular anxiety amongst children whose parents or primary caregivers were alive but unwell with symptomatic AIDS [19, 5]. Qualitative data suggests that this anxiety is linked to fears for the health and survival of their parents [20]. Therefore, the impacts of parental AIDS illness seem to be at least as severe, if not more so, than those of AIDS-orphanhood. However, very little is known about the impacts of parental asymptomatic HIV-positive status on children, and this requires further investigation.

## IMPACTS OF HIV/AIDS: HIV-POSITIVE CHILD STATUS

Studies of HIV-positive children and adolescents have found increased depression and internalizing mental health problems in multiple countries [21, 22], as well as neurocognitive impacts for HIV-positive children that may have implications for emotional and behavioural difficulties [23]. It is unclear whether the cognitive and developmental challenges are caused by exposure to the virus, exposure to treatment, exposure to HIV-positive parents or a complex combination of all [24]. For perinatally infected children, parental HIV and often orphanhood are integral to their experiences of growing up with the virus [25]. Those infected sexually, in later childhood or adolescence, are likely to share many of the difficulties described in Cournos' and colleagues' chapter above, as well as those particular to children. Little is known about the psychological impacts of HIV acquired through sexual abuse on children, although it is likely that these are particularly severe [26].

## MECHANISMS OF DISTRESS IN CHILDREN

Understanding *how* parental HIV/AIDS leads to negative child outcomes or to resilient outcomes is essential for informing effective interventions for AIDS-affected children. It is also important to identify modifiable factors in pathways of risk and resilience [27]. Whilst AIDS-orphanhood and parental and child HIV-positive status are currently irreversible, the linkages between these and child

psychological distress are not direct, but rather indirect pathways via social and economic sequelae of HIV/AIDS. Elements that are reversible may need to be high intervention priorities. The biggest predictor of double orphanhood (death of both parents) is the HIV rate in a country 9 years previously. A policy that would ensure combination antiretroviral treatment for parents could mitigate parental illness and death, which in turn could enhance parenting environment through increased employment and healthy functioning. Similarly, early identification and treatment of child HIV may mitigate negative outcomes.

## STIGMA AND POVERTY IN CHILDREN LIVING WITH FAMILY HIV

Perhaps the strongest pathway from family AIDS to psychological distress is stigma. Quantitative and qualitative evidence demonstrates the severe effects of both internalized and enacted stigma [28] on people living with HIV/AIDS, their families and their children [29–35]. For both HIV-positive and AIDS-affected children, stigma can take forms such as peer exclusion, bullying and discrimination related to misunderstandings regarding routes of infection, for example, people being afraid to touch them, to share eating utensils or toilet seats. Given that childhood and adolescence are essential developmental stages in establishing social identity, the impacts of stigma may be especially harmful. Stigma may also cause chain effects such as lowered social support [36, 37], loss of income, family conflict, intimate partner violence and – in extreme cases – community violence, which themselves lead to psychological distress.

In addition, the household-level economic shock of HIV/AIDS is an important mediator between parental AIDS illness and death, and child mental health [38]. Medical and funeral expenses, combined with the loss of income-earning adults, have particularly severe impacts on AIDS-affected families in contexts where social security provision is limited or lacking [39, 40].

The combined impacts of stigma and poverty seem to have an especially serious link to increased levels of child abuse – possibly related to the challenges of parenting and supervision in highly stressful contexts (Cluver *et al*., 2012). Studies in South Africa of children who are orphaned by AIDS or have AIDS-ill parents are more likely (by a factor of two to three) to experience physical, emotional and sexual abuse [41]. The extreme negative psychological impacts of child abuse have been extensively demonstrated – with long-term implications for suicidality, depression and risk of HIV infection [42–45].

## PARENT–CHILD RELATIONSHIPS AND DISTRESS

Psychological distress amongst children and adolescents is also directly related to the mental and physical health of their parents or caregivers [46–49]. The extensive psychological impacts of adult HIV infection that are described in Cournos *et al*.'s

[50, 51] chapter are linked to the psychological impacts of HIV on the parent-child relationship. Children report psychological distress that fluctuates with the extent of illness and disability that their parents are experiencing – understandably, the more unwell their parents, the more worried the children [52]. These linkages demonstrate that antiretroviral medication and effective psychological support for adults is likely to have positive effects on their children's mental health. Interventions for post-natal depression in HIV-positive women, for example, have shown specific child development gains [53]. For HIV-positive children and adolescents, their own poor physical health (as well as those of their parents) is linked to depression and anxiety [54, 55]. Studies suggest that disclosure to perinatally infected children of their own HIV status, and to all children of their parents' HIV status, has long-term positive impacts, but must be done with care and sensitivity to minimize potentially negative effects in the short term [56].

## PSYCHOLOGICAL DISTRESS IN CHILDREN AND HEALTH OUTCOMES

In their chapter, Francine Cournos *et al*. [57, 58] highlight the impacts of psychological distress on numerous outcomes in the lives of HIV-positive people. For children, this is equally true. New research shows associations between psychological distress in HIV-positive adolescents and their adherence to antiretroviral medication. A recent systematic review found that psychological distress related to parental HIV/AIDS has direct impacts on children's educational achievement and ability to concentrate [59, 60]. Moreover, the psychological impacts of parental HIV and orphanhood seem also to raise sexual vulnerability [61, 62], particularly girls' exposure to transactional sex and older sexual partners – both risks for HIV infection. Systematic reviews and studies have demonstrated increased HIV-infection risks amongst children orphaned and in AIDS-affected families [63], and studies in the United States [64], and Sub-Saharan Africa [65] suggest that poor mental health is associated with sexual risk. Further research is needed to understand the role of psychological factors in this pathway of risk. Child mental health needs to be addressed, not only as an important aspect of public health but also in the context of evidence of its role in HIV prevention and educational outcomes.

## REDUCING PSYCHOLOGICAL DISTRESS IN CHILDREN

Reducing the psychological impacts of family AIDS and HIV-positive status on children has been increasingly prioritized by international agencies such as United Nations International Children's Emergency Fund (UNICEF) and Save the Children, by donors such as United States Agency for International Development (USAID)-President's Emergency Plan For AIDS Relief (PEPFAR)

and by governments in high-prevalence countries, such as in the National Plans of Action for Children Affected by AIDS that are written on a 5-yearly basis by sub-Saharan African states.

Evidence of effective interventions to improve the psychological health of AIDS-affected children remains limited, and a 2009 systematic review found no included studies [66]; however, in the past 4 years the move to evaluate interventions has shown promising direction. The identification of modifiable pathways of risk from family AIDS to psychological distress also suggest where interventions might be able to buffer or break such pathways [67]. Some risk factors such as stigma require further intervention development and research [68], but others have good evidence for successful interventions. For example, there is strong evidence for effectiveness of income transfers to reduce poverty in families affected by illness and death [69, 70], and there is now scientific consensus that antiretroviral medication reduces HIV/AIDS-related disability and death amongst children and their parents [71]. Access to clinical and home-based palliative care for people living with chronic HIV/AIDS illness may be particularly important in mitigating the high levels of anxiety experienced by children of AIDS-ill parents. In addition, systematic reviews in the developed world, and a very small body of evidence in the developing world, have shown effectiveness of home visiting and parenting programmes in reducing and preventing child abuse [72, 73].

## CONCLUSIONS

Chapters and commentaries within this book have highlighted the interlinked and causal relationships between HIV and psychiatry, from neurocognitive disorders to depression, and the implications of psychological factors in adherence and prevention. However, these linkages do not stop at the clinic door, nor do they only impact on the person living with HIV. The evidence reviewed in this chapter demonstrate the major implications of HIV for the children and families of those infected, and the consequential effects of such psychological distress on children's developmental and sexual risks. However, the story is not all negative. Many governments, funders and non-governmental organizations are recognising the importance of improving mental health for AIDS-affected children and families, and the evidence base is growing rapidly. It is essential for practitioners, programmers, policymakers and researchers to consider children and families as a special population in the public health response to HIV.

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