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A Family Disease: Mental Health of Children Orphaned by AIDS

and Living with HIV+ Caregivers

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HIV/AIDS is a family disease. It impacts *all* members of the nuclear and extended family emotionally, financially, and through the pervasive stigma which accompanies HIV infection. Much of the care and responsibility for AIDS-affected people, and for their children, rests within the wider family. Families are also the focus of efforts to find solutions for the care of children who are infected or affected by HIV/AIDS. This chapter examines the mental health of parents and children living in HIV-infected families. We will focus on two main regions: sub-Saharan Africa and the United States (US). This is because 1) the great majority of available evidence comes from these two regions, and 2) these two regions are affected by the same disease, but represent very different epidemics in very different social contexts. However, it is to be noted that the number of studies in the US remain very small, and so comparisons between regions should be treated with caution.

In sub-Saharan Africa, HIV is largely transmitted through heterosexual contact, often within marriage (Hudson, 1996). Theories which aim to explain the massive spread of the epidemic in sub-Saharan Africa emphasize the effects of societal factors including labour migration, poverty and gender inequality (Dunkle et al., 2004), which exacerbate behavioural and biomedical factors associated with HIV transmission. HIV-prevalence rates for women in Sub-Saharan ante-natal clinics range from 12% in Zimbabwe to nearly 40% in Swaziland, and overall prevalence rates in adult populations (15 to 49 year olds) are as high as 26% (see Table 1) (UNAIDS, 2008). In South Africa, as in many other countries, Black African and other impoverished groups are most severely affected by HIV.

In the United States, the heterosexual epidemic again disproportionately affects specific ethnic groups, in particular African-Americans and Latinos (Centers for Disease Control and Prevention, 2007). For example, in 2005 approximately 64 percent of all females living with HIV/AIDS in the US were African American (Centers for Disease Control and Prevention, 2007). However, whilst heterosexual transmission remains a source of infection,

other major sources of infection include transmission between men who have sex with men (MSM) (Centers for Disease Control and Prevention, 2007, 2009), intravenous drug use (Des Jarlais et al., 2005), and forced sex in prison (Springer & Altice, 2005). This means that many families in the US are coping not only with HIV-infection, but also with a range of other associated social problems.

[Table 1 about here]

As of 2008, an estimated 20 million children worldwide had lost a parent to HIV/AIDS, and even with the expansion of antiretroviral treatment access by 2015 the number of orphaned children will still be overwhelmingly high. The vast majority of these children (approximately 12 million) live in sub-Saharan Africa (UNAIDS, 2008). In South Africa alone, 3.4 million children are parentally bereaved, with around 65% of deaths attributable to HIV/AIDS (Anderson & Phillips, 2006). In areas where anti-retroviral treatment (ART, or Highly Active Anti-Retroviral Treatment, HAART) is available and accessible, parents are surviving longer and many are able to survive until their children reach adulthood. Far less is known about numbers of children who are living with an HIV+ parent or caregiver. To the best of our knowledge there are no available data revealing proportions of HIV-infected people who care for children, or the number of children living in HIV-affected families. We can estimate that these numbers are in the millions in countries with generalized epidemics, but further research is essential in order to identify this potentially vulnerable group. We also know very little about the proportion of children living with caregivers who are on ART medication, or the benefits for the health and well-being of these children, compared with those living with caregivers who are not.

Most children living with an HIV+ parent or caregiver are not themselves HIV+; however, a significant proportion of these children are. About 17 percent of new HIV infections annually are in children of up to 14 years of age (UNAIDS, 2008). Pooled analyses of data in sub-Saharan Africa studies indicate most of these infections occur through vertical transmission (Newell et al., 2004), although findings from South Africa highlight other routes of transmission including sexual abuse and infection in health facilities (Brookes, Shishana, & Richter, 2004). Importantly, research suggests that children who are HIV-infected may experience distinct cognitive difficulties and mental health issues (C. Mellins, Brackis-Cott, Abrams, & Dolezal, 2006; C. A. Mellins et al., 2009), in addition to the effects of having an HIV+ or deceased parent. Additionally, the demographics of this group differ between countries in which anti-retroviral treatment has been available at different times. For example, the US has provided ART to perinatally-infected infants since the mid 1990s (Havens, Mellins, & Hunter, 2002) and now has a cohort of HIV+ adolescents who are approaching adulthood (Bush-Parker, 2000). In contrast, Botswana began providing paediatric ART in January 2002, whilst South Africa only published a plan to provide paediatric ART in the public healthcare system in late 2003.

This chapter explores the evidence suggesting that familial HIV-sickness and death impacts negatively on the mental health and wellbeing of both parents and children. Additionally, we briefly discuss the implications of this research for intervention strategies targeting children's needs. A broad framework that informs much of this chapter is Bronfenbrenner's ecological model (Bronfenbrenner, 1979). This model puts children at the centre of multiple, interacting layers of influence (see Figure 1). Proximal to the child are relationships with caregivers and the everyday care-giving environment. More distal are school and community influences, followed by wider political, policy, and cultural factors, which determine the context of child development. Key to this theoretical framework, and

supported by research on risk and resilience (Luthar, Cicchetti, & Becker, 2000; Rutter, 2006), is the cumulative and counter-balancing effects of these risk and protective factors acting on each other, and on the child, as well as the effects of the child's initiatives acting on his or her external environment. From this perspective, the impacts of adversity in particular spheres of a child's life can be mitigated by positive factors in another sphere (Bronfenbrenner, 1979). Thus, whilst HIV is a family disease, it also necessitates a family response. Not only does the infection of one family member have multiple and long-term effects on all other family members, but it is also clear that the family are the primary source of care and support for AIDS-affected children. For children where family are unavailable, unwilling, or unable to provide care, support groups within the wider communities may need strengthening and support in sustaining care for HIV/AIDS-affected children.

[Figure 1 about here]

1. Mental health impacts

Any sickness or death within a family can have an impact on children's mental health and wellbeing. Studies of children whose mothers have cancer reveal that these children often experience emotional and behavioural difficulties, as well as fears of parental death (Forrest, Plumb, Ziebland, & Stein, 2006). In 2000, a review of the impact of parental death on mental health (although this review did not include HIV-related death) reported that emotional problems may manifest differently according to developmental age (Dowdney, 2000); for example bedwetting amongst younger children and depression and guilt amongst adolescents (Dowdney et al., 1999). This review also reported more internalising problems (such as depression) amongst bereaved girls, whilst more externalising (behavior) problems were

reported amongst bereaved boys. Children's mental health is especially at risk in the context of traumatic parental death, such as suicide (Dowdney, 2000) or homicide (Black & Harris-Hendricks, 1992). Importantly, until the late 1990s, the vast majority of literature on child mental health in the context of parental illness or death was Western-focused and did not yet address AIDS-related death. However, the rapid spread of HIV and the subsequent rise in numbers of AIDS-orphans has led to a new body of evidence, clustered in sub-Saharan Africa and the US. In order to understand how familial HIV can affect childhood mental health, it is important to look at impacts on both the infected person in their care-giving role, and on children themselves.

HIV/AIDS, Parents, and Parenting

There is strong evidence suggesting that children's emotional well-being is closely connected to that of their parent or caregiver (Cluver, Gardner, & Operario, 2009; Stein, Ramchandani, & Murray, 2008). In Africa most HIV-positive women are diagnosed during pregnancy. In rural South Africa women coming to terms with a serious illness report experiencing emotions of shock, grief, and fear, as well as motivational dilemmas regarding the unborn child (whom the parent is at risk of infecting) (Rochat et al., 2006). Enduring emotional problems have also been reported in HIV-infected mothers of young children in urban South Africa (Brandt, 2009). Similarly, high levels of depression and anxiety amongst HIV+ parents of adolescents have also been reported in the US (M.-J. Rotheram-Borus, Lightfoot, & Shen, 1999).

HIV-infection can cause cognitive problems, even at early stages. At later stages of AIDS-illness, people can experience severe mental illnesses such as AIDS-related dementia or psychotic symptoms (Antinori et al., 2007). These AIDS-related cognitive impairments or feelings of depression and anxiety may for some people impact on parenting. Additionally,

for parents who have become infected through injection drug use or in prison (more likely to occur in the United States than in sub-Saharan Africa), there are likely to be other emotional and behavioural problems which can also affect children in their care. Parenting may also be made more difficult due to the stigma associated with HIV. The ongoing stigma of infection can reduce support systems, and HIV-infected parents also report ostracism and stigma when trying to access healthcare for themselves and their children (Green & Smith, 2004).

Moreover, as parents experience increasing numbers of opportunistic infections, their own physical health problems can impact on parenting capacity. In addition, many HIV-infected caregivers are also caring for other infected family members, such as spouses, siblings or children. Studies have revealed that parents are often preoccupied with worries about their and their children's HIV infection and health (Simoni, Davis, Drossman, & Weinberg, 2000). Finally, HIV/AIDS places incredible financial pressure on many families and poverty has been shown to impact on parenting, especially under stressful conditions (Aber, Jones, & Cybele Raver, 2007). Even where healthcare is free, AIDS-illness often results in loss of earnings, and in sub-Saharan Africa the costs of AIDS treatment and funerals frequently result in deficits in children's nutrition and education (Booyesen, 2002; Case & Ardington, 2005). Whilst parenting is often a challenging experience, parenting with HIV (and in the contexts of stigma and poverty) may be even harder.

Orphaned children

There is strong and remarkably consistent evidence (from both the US and sub-Saharan Africa) that AIDS-orphanhood impacts negatively on mental health and wellbeing. Contrary to early fears that orphans may be 'unsocialized' and 'potential rebels' (Barnett & Whiteside, 2002; Hunter, 1990), there is little empirical evidence of severe behavioral problems. However, multiple studies from sub-Saharan Africa reveal that AIDS-orphanhood

is associated with increased levels of emotional distress, particularly depression, anxiety and post-traumatic stress (see Figure 2 for an example) (Atwine, Cantor-Graae, & Bajunirwe, 2005; Bhargava, 2005; Cluver, Gardner, & Operario, 2007; Forehand et al., 1999; Makame, Ani, & McGregor, 2002; Nyamukapa et al., 2008). Recent data from China suggest similar emotional distress in Chinese AIDS orphans, but as yet these data lack comparisons with non-orphaned groups (Zhao et al., 2007). Furthermore, mental health impacts are not restricted to AIDS orphans. A recent large study and systematic review investigated caregivers of orphaned children (mainly grandparents) and found that these caregivers also reported heightened levels of depression and anxiety (Kuo & Operario, 2009, 2009 (Nov)). Similarly, qualitative studies have also reported heightened distress amongst grandmothers caring for orphaned children, whilst also grieving for the death of their adult child (Ferreira, Keikelame, & Mosaval, 2001). Studies conducted in the US report similar findings to those in Africa, although with additional evidence of behavioural problems among children with HIV+ parents (Forehand et al., 2002; M.-J. Rotheram-Borus, Lee, Lin, & Lester, 2004). However, the extent to which these behavioural problems may be connected to other social problems in HIV-infected families in the US – such as increased likelihood for poverty, parental incarceration, and parental substance use - is not known and future research should explore this issue.

[Figure 2 about here]

Although the evidence for mental health impacts associated with orphanhood in high-HIV contexts seems clear, very few studies allow comparison of AIDS-orphaned children to other-orphaned children. One of the only large studies that did, found (Cluver, Fincham, & Seedat, 2009; Cluver et al., 2007; Cluver, Gardner, & Operario, 2008) that AIDS-orphanhood

has stronger negative impacts on mental health than orphanhood by other causes (even homicide), as shown in Figure 2. However, there is very little longitudinal evidence to allow us to understand how the effects of AIDS-orphanhood change over time. In the past two years, a small number of studies have suggested that orphanhood may be associated with an increased likelihood of HIV-infection in later life. A recent review (Cluver & Operario, 2008) found 4 studies worldwide which reported higher levels of HIV-infection amongst adolescent orphans in Zimbabwe (Birdthistle et al., 2008; Gregson et al., 2005), South Africa (Operario, Pettifor, Cluver, MacPhail, & Rees, 2007) and Russia (Kissin et al., 2007). Further studies reported higher levels of sexual risk behaviour (Campbell, Handa, Moroni, Odongo, & Palermo, 2008; Juma, Askew, & Ferguson, 2007; Nyamukapa et al., 2008; Operario et al., 2007; Palermo & Peterman, 2009; Thurman, Brown, Richter, Maharaj, & Magnani, 2006). Whilst there may be varied causes of this higher risk, one study in Zimbabwe does suggest that mental health distress may be contributing to sexual risk behaviour amongst orphans (Nyamukapa et al., 2008).

Children living with AIDS-sick and HIV+ Parents or Guardians

Orphanhood by HIV is not a single acute event, rather it is a process preceded by a parent's chronic and debilitating illness (Richter, Foster, & Sherr, 2006). This illness is also often a 'family secret'; limiting children's scope to find support outside the family. Furthermore, actually informing children about a parent's HIV-status is not simple. Many children report anger, fear and shock when a parent discloses that they have a life-threatening illness. A US study found that children to whom their mothers had disclosed showed more behavioural problems after disclosure (Shaffer, Jones, Kotchick, Forehand, & The Family

Health Project Research Group, 2001). Despite this, it is generally agreed that disclosure to children is both helpful and necessary for long-term family coping.

Very little is known about the group of children living with HIV+ or AIDS-sick caregivers. In sub-Saharan Africa, studies of children in households with a sick adult do seem to show higher morbidity, malnutrition (Mishra, Arnold, Otieno, Cross, & Hong, 2005), and school absence (Gray et al., 2006), but these studies do not examine mental health. However, there is some evidence that risks to children's emotional wellbeing may be independently associated with caregiver sickness. For example, in South Africa, the extent of caregiver sickness was shown to mediate levels of mental health problems in uninfected children (Cluver, Gardner et al., 2009). Another small South African study reported higher levels of mental distress amongst children of parents with full-blown AIDS in comparison with those whose parents did not (Gwandure, 2007). Similarly, studies in the US have reported that children of HIV infected parents (particularly adolescents) also experience emotional and behavioural problems (Armistead & Forehand, 1995; Forehand, Armistead, Mose, Simon, & Clarl, 1998; Forehand et al., 2002; Hudis, 1995; M.-J. Rotheram-Borus et al., 1999). Understanding the extent to which the mental health problems experienced by AIDS-orphaned children are established during the period of parental sickness is of the utmost importance and is an avenue for future research.

Young Carers

In the West, there is increasing advocacy and evidence to suggest that children who provide care at home for sick parents or siblings are at risk of mental health problems (Becker, 2007; Dearden & Becker, 2000; Levine et al., 2005). These children are often called '*Young Carers*' and include children looking after mentally ill, disabled, or substance-using parents. The tasks which these children engage in include household tasks, medical care, and

providing emotional support. Due to general limitations in health services, it is likely that many children in sub-Saharan Africa who live with AIDS-unwell caregivers are acting as young carers (see Figure 3 for an example); however, there is very little research examining this potentially vulnerable group of children. In the context of the AIDS epidemic, there are no reliable data on the numbers or proportions of children providing such care, or of the nature and extent of the tasks which they undertake (e.g. medical, intimate or emotional care, and care of younger siblings) (Bauman, Foster, Silver et al., 2006).

[figure 3 about here]

One quantitative study (Bauman, Foster, Johnson Silver et al., 2006) compared 50 young carers of AIDS-sick parents in Zimbabwe to 50 young carers in the US. Results revealed high levels of depression in both groups. Interestingly, mental health did not seem to be related to extent of care-giving done by children, but future studies with comparison groups of children in healthy homes or homes with other sickness may help to shed further light on this issue. In sub-Saharan Africa, very few studies (all of which are qualitative in nature) have explored children's perceptions of the impact of care-giving (Evans & Becker, in press; Robson, 2000; Skovdal, Ogutu, Aoro, & Campbell, forthcoming). In these studies, children have reported both emotional distress as well as positive experiences and competencies associated with responsibility and contribution to the household. One large-scale, quantitative ongoing study is examining the impacts of being a Young Carer in the context of HIV/AIDS (Cluver, Kgankga, & Kuo, 2010)

HIV+ children

Children living in AIDS-affected families may themselves also be infected with HIV. This section will only focus on children who have been infected perinatally (i.e. by an HIV+

parent at birth) as mental health issues may be different for children infected via abuse, drugs, injection drug use, infected blood, and consensual or forced sexual contact.

Before the introduction of paediatric anti-retroviral medication, few perinatally-infected children survived infancy (Newell et al., 2004). The limited evidence available shows risks of major developmental, motor and emotional delays due to the effect of the virus on the developing brain and nervous system (Richter, Stein, & Cluver, 2009). A recent review of HIV and mental health in sub-Saharan Africa (Jaros, Myer, & Joska, 2009) found nine studies of neurocognitive impacts of parental HIV, but very few studies which look at children over two years old, or at psychological impacts beyond motor skills, cognitive and neurological abnormalities. Those which did found that HIV+ children scored lower on the personality-social domain of the Denver scale (Boivin et al., 1995) and had less secure attachment to their mothers (Peterson, Drotar, Olness, Guay, & Kiziri Mayengo, 2001).

In the US, anti-retroviral medicine has been provided to infected children since the mid-1990s (Havens et al., 2002). In Southern Africa, rollout of ART to infants and children has been far slower, and has been hampered by difficulties such as lack of paediatric dose tablets and complexities in administering suspension formulations. However, with increasing coverage and efficacy of infant and child anti-retroviral medicine, it is possible to anticipate that this will be a substantial future demographic group for anti-retroviral therapy. This pattern of ART provision in Southern Africa, a number of years behind other regions, suggests that we can valuably look to the US and Europe for indications of potential future challenges.

In the US (particularly major cities such as New York), ARV provision to infants has resulted in a cohort that has been on anti-retroviral medication since birth and are now moving into adolescence (Bush-Parker, 2000). These adolescents show high levels of mental health problems as they adjust to the reality of a chronic, highly-stigmatised, parentally-

acquired disease (C. Mellins et al., 2006). In the light of this, there are increasing concerns regarding the negotiation of sexual relationships for this group, including disclosure to sexual partners and safe sex. Clinical observation and a small number of studies have noted that the process of adolescent assertion of independence and 'acting out' may include rejection of and/or inconsistent use of medication (C. Mellins, Brackis-Cott, Dolezal, & Abrams, 2004). This may also be because of some of the side-effects of ART medicines, such as the developing of fat deposits, make teenagers feel awkward and look different. It is extremely dangerous for children or young people to stop taking ART medication, take it irregularly, or miss doses. Not only do they immediately become more likely to get ill from AIDS-related illnesses, but by missing doses they can build up 'viral resistance', and the HIV-virus becomes able to multiply despite the ARV medication.

It is unrealistic to presume that the difficulties for perinatally infected infants, children, and adolescents in Southern Africa will be identical to those experienced by perinatally infected children in the US. However, it may be useful to examine closely the experience of the developed world with this group, to attempt to learn lessons from this work, and put in place interventions based on this research. In particular, it may be important to develop early methods of communication to children regarding their HIV status and their anti-retroviral use, as a major issue for HIV+ children in both Sub-Saharan Africa and elsewhere is that of disclosure. Most children who have been infected with HIV at birth are not told of their HIV-status until they are thought to be old enough to understand (and often to keep the family secret). Disclosure to children of their own HIV-status often also means disclosure of the parent's HIV-status. Research has revealed that disclosure to children of their own HIV status often causes anger towards the parent, resentment and fear, and can disrupt family life for some time. However, children agree that disclosure is important, and

many have already guessed by the time they are told of their own HIV status (Armistead et al., 1999; Shaffer et al., 2001).

Risk and protective factors – developing interventions

It is important to develop effective interventions in order to help communities cope with the effects of familial HIV on children's mental health. In order to do this, it is essential to understand the *mechanisms* through which having a caregiver with HIV impacts on child mental health and wellbeing. What is it about HIV-infection, AIDS-sickness and death which renders children especially vulnerable? Only a few studies specifically examine potential mechanisms through which parental HIV/AIDS illness influences children's mental health. There is also a lack, as yet, of longitudinal data that would allow stronger inferences to be made about causal relationships between risk and protective factors and child outcomes; having reasonable confidence in these causal paths is vital for programme and policy design. Whilst there are many programmes and policies which aim to improve mental health for AIDS-affected children, very few of these have been empirically evaluated. In this section we will look at 1) potential mechanisms through which familial HIV may influence child wellbeing, and 2) evidence for what can be effective in improving children's mental health outcomes.

Caregiver sickness and effects of HIV: To the best of our knowledge, no known studies have examined the effects of maternal HIV on parenting and childcare; however, two separate bodies of research suggest that HIV/AIDS may compromise parenting ability. Firstly, there is evidence that HIV diagnosis and illness is associated with depression and reduced social support (Stein et al., 2005), and secondly that infants are negatively affected by parental depression and reduced social support (Stein, Ramchanani, & Murray, 2008). Interestingly, one study in South Africa reported that the extent of caregiver illness positively

predicted the level of mental health problems in children, but this group of caregivers included both AIDS-sick parents and elderly grandparents (Cluver, Gardner et al., 2009). Caregiver sickness can limit parental attention, monitoring, and bonding between child and caregiver, thus raising the likelihood of mental health problems and risk behaviours in children.

AIDS-exacerbated poverty: As discussed previously, AIDS-illness and death have direct and major implications for family poverty. In South Africa, lack of adequate nutrition, school non-attendance (due to financial reasons), and lack of access to social welfare grants were strong mediating factors of mental health problems in AIDS-orphaned children (L Cluver & M Orkin, 2009). We know far less about the effects of poverty on children living with HIV+ parents, or on children who are themselves HIV+ although current research is beginning to address these issues. Children affected by AIDS-exacerbated poverty might be more prone to assume adult responsibilities – both within and outside the home – and experience premature exposure to adult behaviours including sexual risk taking. Indeed, four studies conducted in sub-Saharan Africa have found evidence for earlier sexual debut in orphaned adolescents. (i.e. Operario et al., 2007; Thurman et al., 2006)

AIDS-related stigma: One of the strongest predictors of mental health problems amongst AIDS-orphaned children is AIDS-related stigma. A qualitative study in Scotland found that children of HIV+ parents were particularly hurt by people accusing their parents of being promiscuous or prostitutes (i.e. Strode & Barrett Grant, 2001). In South Africa, children reporting experience of AIDS-related stigma in the community show far higher levels of depression, peer problems and post-traumatic stress (Cluver et al., 2008). Stigma seems to be directed both at the HIV+ person, and at families of HIV+ people, and is often based on misguided fears of infection through socializing, sharing food or touching a person from an AIDS-affected family (Deacon, 2006; Nyblade, 2006; Strode & Barrett Grant,

2001)¹. We still know very little about how to reduce stigma and discrimination towards the families of HIV+ individuals. Reviews of strategies aiming to reduce stigma for HIV+ individuals suggest potential positive results of legal protection, availability of anti-retroviral medication, sensitization and contact with HIV+ people (Brown, Macintyre, & Trujillo, 2003; Klein, Karchner, & O'Connell, 2002); however, to the best of our knowledge no studies have examined the effects of stigma reduction strategies on the *children* of HIV+ parents.

Cumulative factors: Many theoretical models of child mental health use a 'cumulative risk' approach (Rutter, 2000). This suggests that, whilst children can often cope with a single stressor, multiple stressors can interact to put children at risk of psychological distress. There is little available research to show whether this is true of AIDS-affected children, but a recent study demonstrates interactive and cumulative effects of AIDS-related stigma and under-nutrition on orphaned children (L Cluver & M Orkin, 2009). Those with enough to eat and no stigma had a 19% likelihood of clinical-level disorder, whilst those experiencing both stigma and hunger had an 83% likelihood (see Figure 4). Better understanding of cumulative factors that contribute to mental health problems among AIDS-affected children can guide the specific timing and focus of interventions.

Interventions: There are very few rigorous evaluations of intervention programmes designed to improve mental health amongst AIDS-affected children. In the US, Rotheram-Borus and her colleagues have reported that a group-based psychological intervention that targets HIV+ parents and their children has long-term positive effects on children's mental health (M. Rotheram-Borus et al., 2006). Similarly, a recent study (Kumakech, Cantor-Graae, & Maling, 2009) showed positive mental health effects of therapeutic groups for AIDS-

¹ Until recently, there were no validated measures of experience of AIDS-related stigma for uninfected children. A measure has been developed in the US (Mason, Berger, Ferrans, Sultzman, & Fendrich, 2010) and has been adapted and validated for Southern Africa.

orphaned children. Whilst most programmes use a counselling or support-group-based approach, to the best of our knowledge

[figure 4 about here]

there are no studies examining effects of reducing poverty and stigma, and supporting parenting for AIDS-sick parents, on children's mental health and wellbeing. However, non-HIV studies in other parts of the world suggest that these could have direct benefits on child emotional health (Aber et al., 2007). In other disadvantaged communities, carefully-planned short-term psychosocial interventions during pregnancy and the post-natal period can result in long-term mental health benefits to children (Richter et al., 2009). A number of trials in non-HIV contexts have shown that school-based interventions can also be effective at improving social-emotional development in high and low income countries, and have the advantage of being potentially scalable and feasible in some resource-poor settings (Baker-Henningham, Walker, Powell, & Meeks-Gardner, 2009). Similarly, studies of the effects of child-focused cash transfers in other poor communities show long-term educational benefits, although mental health benefits are not tested (Paxson & Schady, 2007). Finally, the provision of anti-retroviral medication to HIV+ parents has been shown to have effects on nutrition and growth of their uninfected children (Graff Zivin, Thirumurthy, & Goldstein, 2006), but effects on child mental health have not yet been examined. In the sub-Saharan African context of a generalised HIV epidemic with severe resource constraints, small-scale interventions may not be practical or may not have effects commensurate with the level of need. Policy-makers, and increasingly the research community, are accepting that interventions are not sustainable on a large scale unless they are based in existing structures such as NGOs, and make use of existing capacity. However, the vast majority of provision to

AIDS-affected children still lacks basic pre-and post-measurements of outcome, let alone well-controlled evaluations, or evaluation of effects of interventions on key developmental outcomes.

Summary

Whilst there has been a growth in studies from sub-Saharan Africa on the impacts of parental HIV on children, almost all these studies come from a small set of countries – South Africa, Zimbabwe and Uganda. There are substantial inadequacies in information from elsewhere in the region, as well as in areas of emerging epidemics such as India, China and Eastern Europe.

From the evidence we do have, it is clear that HIV affects different communities in different ways; however, the impact of parental death by AIDS on children's mental health and wellbeing appears remarkably consistent across cultures. Children orphaned by AIDS are clearly at increased risk of emotional problems such as depression, anxiety, and PTSD. However, whether these children are at greater risk than children orphaned by other means is still being investigated, although one large controlled study suggests that this is the case in South Africa (Cluver, Gardner, Operario et al). The risk of behavioural problems in AIDS-orphans is less clear and based largely on data obtained in the US. In contrast, very little is known about children living with HIV+ parents or guardians. Many of these children are likely to be 'young carers' who are potentially highly vulnerable. This is a group that clearly warrants further investigation. We also know that children who are themselves HIV-infected, may experience neurological difficulties, negative social effects (due to stigma associated with the disease), as well as emotional distress (perhaps related to disclosure).

At present the mechanisms through which familial HIV/AIDS impacts on children's mental health are not well understood. Studies suggest AIDS-related stigma, poverty, and caregiver illness may predict mental health outcomes; however further research is clearly

needed to document this conclusively. In addition to studying risks, research on protective factors and psychosocial assets can help inform interventions to promote resilience and build on the strengths of children, families and communities.

Additionally, the vast majority of intervention programmes aiming to improve psychological health amongst AIDS-affected children have not yet been empirically evaluated. This should be a high priority for future research. There are a large number of NGO-led interventions which could valuably be assessed which, if effective, could inform future programme design. Despite the extent and duration of the AIDS-epidemic, we are still desperately in need of research to guide social policy and programming for children orphaned by AIDS or living with AIDS-sick parents.

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Table 1: Number of people living with HIV/AIDS and adult prevalence rates in a sample of sub-Saharan African Countries

| Country | People living with HIV/AIDS | Adult (15-49) Prevalence |
|--------------|-----------------------------|--------------------------|
| Botswana | 300 000 | 23.9% |
| Kenya | 1.5 to 2 million | 7.1% to 8.5% |
| Lesotho | 270 000 | 23.2% |
| Malawi | 930 000 | 11.9% |
| Nigeria | 2.6 million | 3.1% |
| South Africa | 5.7 million | 18.1% |
| Swaziland | 190 000 | 26.1% |
| Uganda | 1 million | 6.7% |
| Zambia | 1.1 million | 15.2% |
| Zimbabwe | 1.3 million | 15.3% |

Note: statistics taken from UNAIDS (2008) report on the global AIDS epidemic (UNAIDS, 2008)

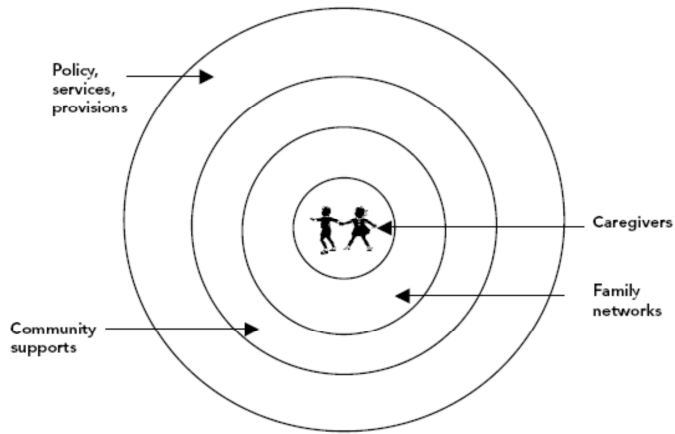


Figure 1. 'Circles of care' an adaptation of Bronfenbrenner's ecological model (taken from Richter, Foster & Sherr, 2006) (Richter et al., 2006).

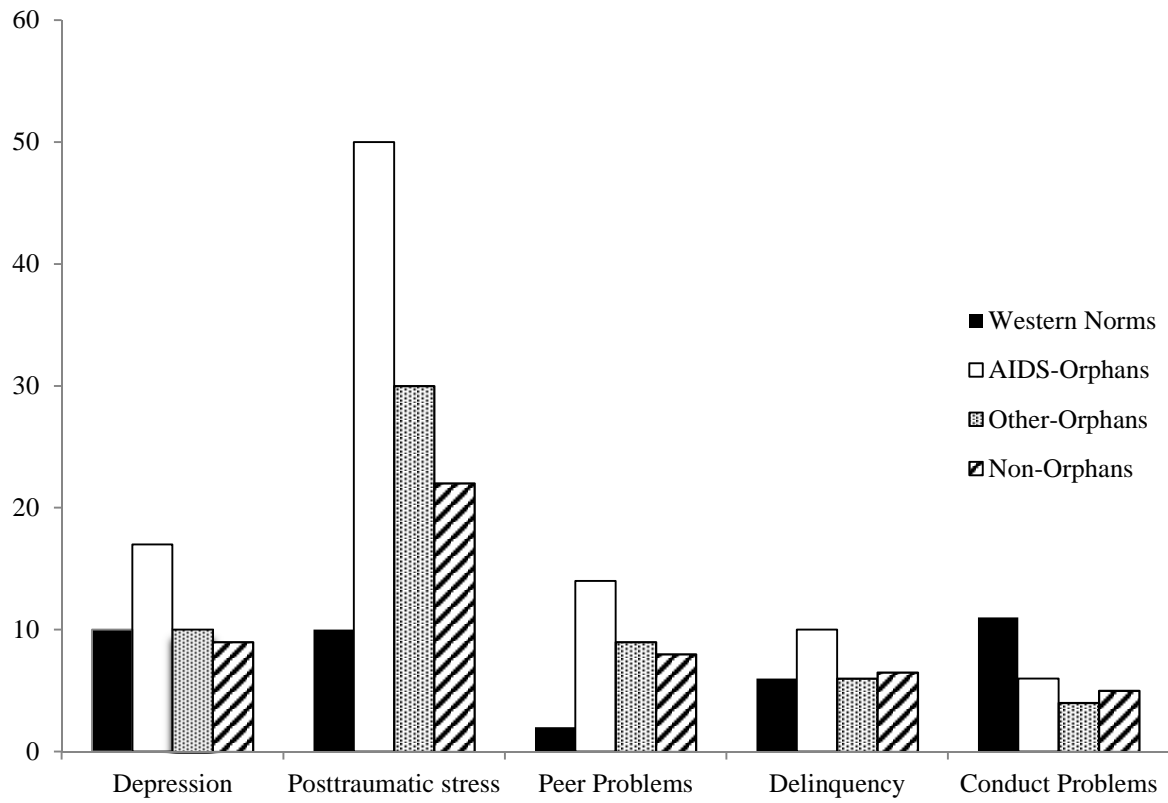
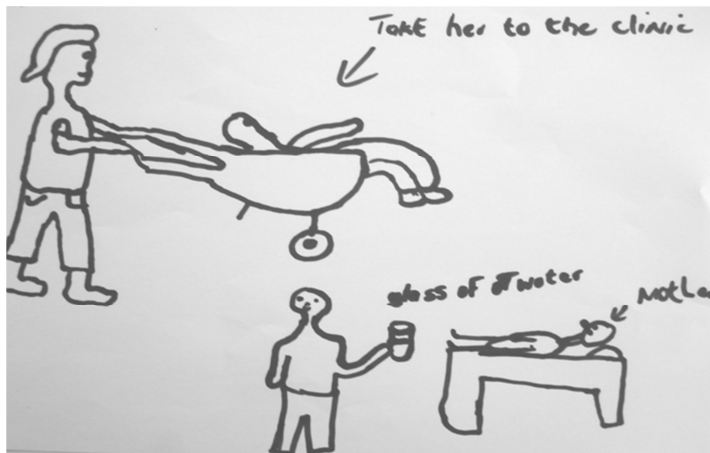


Figure 2. Proportions of children in range for clinical-level disorder in South Africa (Cluver et al., 2007)



'I take my mother to the clinic in a wheelbarrow. I bring her water when she is in bed' (Girl, 8, urban South Africa).

Figure 3. Picture and annotation by a young South African girl (L. Cluver & M. Orkin, 2009)

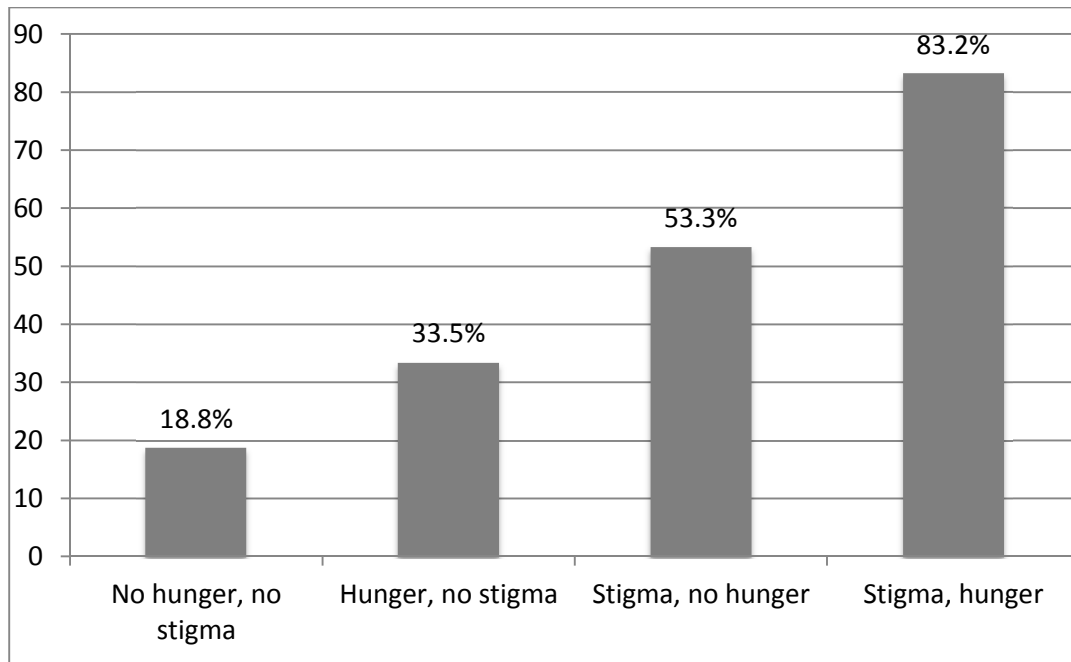


Figure 4. Clinical-level disorder amongst 1200 children in South Africa (L. Cluver & M. Orkin, 2009)