HIV and AIDS and Its Impact on Child Well-Being

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81.1 Introduction

HIV and AIDS remains a significant public health problem. Globally, an estimated 34 million people were living with HIV at the end of 2011 (UNAIDS 2012). Sub-Saharan Africa (SSA) remains the most severely affected region, accounting for 69 % of the people living with HIV worldwide, with nearly 1 in every 20 adults (4.9 %) infected (UNAIDS 2012). HIV incidence also remains unacceptably high: an estimated 2.5 million people (adults and children) acquired HIV infection in 2011 (UNAIDS 2012). Sub-Saharan Africa accounted for 71 % of the adults and children newly infected in 2011 (UNAIDS 2012). Further, an estimated 1.7 million people died from AIDS-related causes worldwide in 2011, with SSA accounting for 70 % of all the people dying from AIDS (UNAIDS 2012).

Children are disproportionately affected by HIV and AIDS. An estimated 3.4 million children were living with HIV at the end of 2011, 91 % of them in sub-Saharan Africa (WHO/UNAIDS/UNICEF 2011). In 2010, an estimated 250,000 children died from AIDS-related causes. In addition, an estimated 14.9 million children in SSA have lost one or both parents to AIDS. Many more children live with HIV-infected parents or primary caregivers. These children are also vulnerable and greatly affected by HIV and AIDS (UNICEF 2007; Atwani-Akwaraa et al. 2010; Daniel 2011).

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81.2 Children Living with HIV and AIDS

Efforts aimed at preventing HIV transmission are increasingly prioritizing the protection of children from acquiring the virus from mothers during the process of delivery and after birth (WHO 2006). Thus, considerable resources have been committed towards testing pregnant mothers to establish their sero-status and enrolling them on antiretroviral therapy (ART), if confirmed positive. This serves as a protective measure against the risk of transmitting the virus to the child, while at the same time benefiting the mother.

These developments notwithstanding more than 1,000 children are newly infected with HIV every day (WHO/UNAIDS/UNICEF 2011). According to the Joint United Nations Program on HIV and AIDS (UNAIDS), an estimated 330,000 children became newly infected with HIV in 2011, 90 % of them in sub-Saharan Africa. Although there has been significant scale-up of prevention of mother to child transmission (PMTCT) services across low- and middle-income countries since 2004, nine out of ten children infected with HIV acquire it from their HIV-infected mothers during pregnancy, birth, or breastfeeding (UNAIDS 2010).

HIV-infected children are affected by the AIDS epidemic in many ways. They experience a fourfold increase in mortality by 2 years of age compared to their HIV-negative counterparts (Taha et al. 1995; Villamor et al. 2005; Little et al. 2007). Studies also indicate that common childhood infections and illnesses are often more serious, recurrent, chronic, or difficult to treat among children living with HIV than those without (Gerson et al. 2001), and the stress of illness is felt by children regardless of their knowledge (or lack of knowledge) of their HIV sero-status. For example, symptoms common to many treatable conditions, such as recurrent fever, diarrhea, and generalized dermatitis, tend to be more persistent and severe and often do not respond as well to treatment in children living with HIV (Merchant and Lala 2012). These complications have implications for the status of children's health and quality of life (Brown et al. 2000; Rao et al. 2007; Kamau et al. 2012). For example, acute illness that results in hospitalizations frequently elicits anxiety, fear, and sadness in children living with HIV (Gerson et al. 2001; Rao et al. 2007).

Living with a life-threatening and stigmatizing illness is also difficult and creates great psychological distress for children with HIV (Domek 2006). Children living with HIV are often confronted with fears and thoughts about their own death, most of them are stigmatized and discriminated against, and many live in poor households – with HIV often perpetuating the vicious cycle of poverty (Domek 2006). There is also consistent evidence of cognitive difficulties for HIV-infected children (Sherr 2011).

81.2.1 HIV Treatment for HIV-Infected Children

HIV treatment for children slows the progress of HIV infection and allows infected children to live much longer, healthier lives. International guidelines therefore recommend that all HIV-infected children younger than 2 years start immediately

on antiretroviral therapy, whereas older children follow different guidelines based on their CD4 levels (WHO 2010). Research indicates that although the number of children receiving antiretroviral therapy (ART) has increased significantly in recent years, only a small proportion of the children in need of this therapy receive it. For instance, at the end of 2011, only 28 % of children eligible for ART were receiving treatment (UNAIDS 2012). In Uganda, out of an estimated 42,000 children in need of ART in 2009, only 32 % were receiving treatment. Depending on the age of the child when infected, death may occur within less than 1 year for children who do not have access to ART (Marston et al. 2011).

In resource-poor settings, HIV diagnosis in infancy is also difficult and often delayed, due to lack of low-cost diagnostic tests that allow for earlier identification of HIV infection in infants (Sutcliffe et al. 2008). While the World Health Organization (WHO) recommends that infants be tested within 2 months of birth, the proportion of infants tested within 2 months among 65 reporting low- and middle-income countries stood at 28 % in 2010 (WHO 2010). Delayed diagnosis of HIV among infants subsequently affects their early initiation on ART, which leads to increased HIV-related morbidity and mortality among children.

For children on ART, ensuring treatment success can be hard. Several challenges around ensuring that children living with HIV and AIDS are treated effectively have been identified, including the lack of child-friendly medication to treat the infection (Menson et al. 2006). This lack of appropriate treatment often results in treatment failures. Infants who are too young to swallow tablets ideally need to be provided with drugs that are more child-friendly such as syrups, powders, sprinkles, or "melts" or administered through more innovative methods, such as through a baby pacifier. However, these formulations are only slowly becoming available and are expensive. Unfortunately, many HIV medications have an unpleasant taste, especially in syrup and powder form. This can make it difficult for children to take their ARVs daily.

HIV-infected children on ART also suffer a range of drug side effects. Most of the side effects are mild. The most common side effects include gastrointestinal problems and skin rashes (Sutcliffe et al. 2008). Severe side effects have nonetheless been reported to occur in up to 10 % of children, and these often result into suspension of ART. Some moderate or severe side effects may require drug substitution or even the discontinuation of treatment (Sutcliffe et al. 2008).

Further, HIV in children poses a unique set of treatment-seeking and caregiving issues, including medication adherence, nutrition for HIV-infected children, and confidentiality, particularly regarding information sharing about HIV with infected children. Some of these are discussed in turn below.

81.2.2 Adherence to HIV Antiretroviral Therapy Among Children

Successful HIV and AIDS treatment outcomes largely depend on adherence to ART medication (Burns and Mofenson 1999; Haberer and Mellins 2009). Adherence is defined as taking medications correctly according to prescription. The optimal

level of adherence promoted to achieve treatment success is above 95 % (Simoni et al. 2006; Wandera et al. 2011). Poor adherence can lead to failure to reduce viral load, the evolution of drug resistance, and subsequent immunological and clinical failure (Descamps et al. 2000; Genberg et al. 2012). Caregivers are responsible for administering daily treatment when children are young. However, as children develop psychologically and socially, they are generally expected to begin taking responsibility for their own treatment.

Research indicates that sustaining adherence to ART medications represents a significant challenge for children receiving treatment and for their caregivers (Biadgilign et al. 2009; Yeap et al. 2010). A range of factors may affect ART adherence among children, including high/heavy pill burden, lack of the benefits of taking medication, treatment fatigue (Biadgilign et al. 2009), dietary restrictions/inadequate food and lack of nutritional support, and medication side effects (Bikaako-Kajura et al. 2006; Biadgilign et al. 2009; Haberer and Mellins 2009; Vreeman et al. 2010; Betancourt et al. 2012).

In addition, adherence may be affected by factors such as a child forgetting, refusing, or vomiting without re-dosing (Elise et al. 2005; Jooste et al. 2005), drug stock-outs, and delays in getting new prescriptions. Such delays are attributable to difficulties in making follow-up appointments due to long distances, family responsibilities, and the prohibitive cost of transportation (Lanièce et al. 2003; Nachega et al. 2004; Byakika-Tusiime et al. 2005; Bangsberg et al. 2006; Mukherjee et al. 2006). In a qualitative study in Uganda, barriers also included the child's and caregivers' attitudes towards antiretroviral therapy and the perceived benefit of the drug (Bikaako-Kajura et al. 2006).

Further, studies that have analyzed the rate of failure of antiretroviral treatment in children have also cited inadequate adherence due to incorrect dosing by caregivers (Jooste et al. 2005; Biadgilign et al. 2009). Incorrect dosing is mainly attributed to the complexity of dosing requirements (e.g., with food, on an empty stomach, not in combination with other medications), which complicates the regimen, making optimum compliance difficult.

In addition, the child's social context can also have dramatic effects on whether they adhere to ART, with adherence affected by factors such as the socioeconomic status of the caregiver, caregiver-child relationship, and whether or not a child's status has been disclosed (Bikaako-Kajura et al. 2006; Biadgilign et al. 2009; Haberer and Mellins 2009; Fenner et al. 2010). For example, a study in Uganda found that some caregivers decide not to disclose the HIV status of their children to school officials (Walakira et al. 2007). While this may shield the child from stigmatization, from both classmates and teachers, it can also lead to them missing drug doses during the school day (Domek 2006).

Conversely, the presence of follow-up counseling, improved health of the child, ART clinic and disclosure of HIV sero-status have been found to improve adherence to ART medication (Biadgilign et al. 2009). In a qualitative study in Uganda, a supportive relationship with an adult, such as a family member, health-care provider, or teacher, was also found to increase adherence (Bikaako-Kajura et al. 2006).

81.2.3 Complexities of Disclosure

One of the central questions of the landscape of pediatric HIV treatment is when and how to disclose HIV status to infected children (Gerson et al. 2001). Although the benefits of disclosure seem substantial (American Academy of Pediatrics 1999; Gerson et al. 2001; Abadía-Barrero and LaRusso 2006; Domek 2006), research to date finds extremely low rates of HIV disclosure to children (Armistead et al. 2001; Gerson et al. 2001; Lesch et al. 2007; Vaz et al. 2010; Vreeman et al. 2010; Biadgilign et al. 2011). Nondisclosure is more likely for HIV-infected patients who are asymptomatic compared to those who are symptomatic (Winchester et al. 2013).

Disclosure may be affected by contextual factors in the family and community (Biadgilign et al. 2011; Haberer et al. 2011; Mellins et al. 2004). Reasons for nondisclosure by caregivers to HIV-infected children vary across settings, but generally include factors related to the perceived readiness of the child and factors related to the readiness of the caregivers (Armistead et al. 2001; Biadgilign et al. 2011). Child-related factors include concerns for the child's emotional and mental health (Brown et al. 2000; Yeap et al. 2010) and the feeling that the child is too young, may not be able to keep the information private, and will disclose to others or that the child is not interested because they are not asking questions about their health (Lester et al. 2002; Dodds et al. 2003; Lesch et al. 2007). Caregiver factors include parental fears of rejection by the child or desire not to upset the child, parental sense of guilt or shame, the fear of parental disclosure linked to the child's infection, and the feeling of not knowing how to disclose (Domek 2006, 2010; Vreeman et al. 2010; Yeap et al. 2010). In addition, social norms, stigma, and the "cultural silence" that surround HIV may inhibit disclosure of a child's infection status (Daniel 2011).

In available literature, both negative and positive social, psychological, and behavioral outcomes of disclosure to children have been reported. The benefits of pediatric HIV disclosure can include high levels of medication adherence and ultimately improved medical outcomes (Bikaako-Kajura et al. 2006; Menon et al. 2007; Haberer et al. 2011), improved child mental health and well-being (Battles and Wiener 2002; Lam et al. 2007; Menon et al. 2007), and better psychosocial development (Domek 2006). Studies of children with life-threatening illnesses provide some evidence that diagnosis disclosure helps children cope with their illness (Gerson et al. 2001). Disclosure in a way that is appropriate to the child's cognitive development has been found to improve the child's psychological adjustment (Funck-Brentano et al. 1997; Brown et al. 2000). For example, Funck-Brentano et al. (1997) found that children who were aware of their HIV diagnosis had a better understanding of their medical condition and were better able to be supported in their coping efforts.

Conversely, nondisclosure or delayed disclosure has been linked to negative psychosocial outcomes, including emotional distress, sexual risk behavior, poorer medical outcomes, and even death for children (Ferris et al. 2007; Menon et al. 2007; Haberer et al. 2011). Nondisclosure also deprives HIV-infected children of potential help (Daniel 2011).

81.2.4 Nutrition for Children Living with HIV and AIDS

Many children living with HIV are at an increased risk for food insecurity and HIV-associated malnutrition, particularly in resource-limited settings (Taha et al. 1995; Chakraborty 2004; Villamor et al. 2005). Malnutrition increases the likelihood of child and infant death and is associated with more than half (54 %) of all childhood mortality in low- and middle-income countries (Pelletier et al. 1994).

Ideally, HIV-infected children who are symptomatic, or recovering from acute infections, need to consume 20–30 % more calories than other children (WHO 2010). In addition, HIV-infected children, like their adult counterparts, often experience a large increase in appetite when initiated on ARVs. However, like adults, many HIV-infected children live in poor households which can barely afford to meet their nutritional requirements. The failure to establish and maintain appropriate and adequate nutrition for HIV-infected children affects adherence to ART medication (Biadgilign et al. 2009; Haberer and Mellins 2009), influences the progression of HIV among children (Merchant and Lala 2012), and increases pediatric HIV-related morbidity and mortality.

81.2.5 Psychosocial Well-Being of Children Living with HIV

The psychological well-being of HIV-infected children is a growing area of concern. Studies show that children living with HIV experience more subjective distress than their HIV-negative peers (Brown et al. 2000; Cluver and Gardner 2007) and face multiple stressors related to HIV (Brown et al. 2000; Cluver and Gardner 2007; King et al. 2009). HIV-infected individuals (both adults and children) have to deal with much emotional pain and complex feelings of loneliness, guilt, anger, confusion, depression, and fear (Brown et al. 2000; Ruiz 2000; Battles and Wiener 2002). HIV-infected children can have clinical anxiety and depression as a result of "recurrent and cumulative" (Battles and Wiener 2002) losses. For example, some HIV-infected children may also experience the sickness and, in some cases, the death of their mother and/or their father. Such losses may affect the child psychologically, particularly if there is no one to support them in their bereavement (Rao et al. 2007) or to answer their questions.

81.3 Children Affected by HIV and AIDS

While in many countries the prevalence of HIV has decreased in the past decade, the number of children orphaned by AIDS continues to rise due to the time lag between HIV infection and HIV-related death (Salaam 2005). It is estimated that the number of children orphaned by AIDS increased from 10 million in 2001 to 16.6 million in 2009 (UNAIDS 2010). In sub-Saharan Africa, the hardest hit region by HIV in the world, the number of children under 18 years of age orphaned by AIDS was estimated to be 14.9 million by 2011, accounting for 30 % of the

children orphaned from all causes in the region and 80 % of children orphaned by AIDS worldwide (WHO/UNAIDS/UNICEF 2011). In some of the worst affected countries such as Uganda, out of an estimated 17.1 million children below the age of 18 years, 14–15 % (approximately 2.43 million) have been orphaned (Kalibala and Lynne 2010) due to HIV and AIDS.

While most studies examine only orphaned children – defined as those having lost one or both parents to AIDS – a number of studies note that living with an HIV-infected parent can also dramatically affect children's psychological adjustment, care, and outcome (Sherr et al. 2008). In addition, some studies have revealed the severe impact of parental HIV and AIDS on children prior to the death of an HIV-infected parent (Ainsworth et al. 2005). Therefore, in this section, children affected by HIV are defined as being either orphaned or made vulnerable (living with one or both HIV-infected parents) by HIV and AIDS under the age of 18 years. Orphans are further categorized as paternal, maternal, and double (loss of both parents to HIV and AIDS) orphans.

81.3.1 Care Arrangements for Children Orphaned by HIV and AIDS

Extended families care for the vast majority of orphans and vulnerable children in sub-Saharan Africa and in many countries assume responsibility for more than 90 % of all double orphans and single orphans not living with the surviving parent (UNICEF 2006). Studies show many of the families taking care of orphans are impoverished, often headed by grandparents, aunties and uncles, or remaining/surviving parent (Ansell and Blerk 2004; Monasch and Boerma 2004; Abebe and Aase 2007; Ssengonzi 2009). For example, in Uganda, 70 % of the families taking care of orphans are headed by poor, often elderly, caregivers (MGLSD 2004).

Studies show that orphans are likely to live in households with less favorable dependency ratios and greater experiences of financial hardship (Nyambedha et al. 2003; Monasch and Boerma 2004; Safman 2004; Oleke et al. 2005). Many extended family members of AIDS orphans have difficulty meeting the orphan's essential caregiving needs (Boris et al. 2008). For example, studies carried out in Uganda reveal that grandparents often take on the substantial responsibility of taking care of orphans, but monetary and other constraints do not allow them to live up to this expectation, and they have been unable to effectively address the basic needs of food, clothing, shelter, and health care (Manguyu 1991; Ntozi 1997).

Some studies also indicate that the drastic increase in the number of AIDS orphans, in combination with social and economic changes (Ntozi et al. 1999), has stretched the limits of traditional care arrangement for orphans (Foster and Germann 2002; Guest 2003; UNICEF 2003; Kaleeba 2004; Abebe and Aase 2007). These studies show that some families taking care of orphans are being stretched to the point of buckling with the absorption of additional children into their households.

Consequently, some orphaned children have no adults who are able to care for them. These children may end up living and working alone on the streets

(UNICEF 2006; Walakira 2012) or child-headed households (Child-headed households (CHHs) may be defined as households headed by a person who is under 18 years of age (Hosegood et al., 2007, p. 331; Foster and Williamson 2000; UNICEF 2006)). For example, in a recent survey of 668 children living and/or working on the street aged 11–17, more than half (55.2 %) of the children reported to be orphans. About 23 % of the children were double orphans, i.e., had lost both mother and father, while 21.5 % and 10.7 % of the children had lost their fathers and mothers, respectively (Walakira 2012). The lack of adult supervision, protection, or guidance often makes children in street situations vulnerable to a wide range of risks or hazards, including physical, sexual, and emotional violence (Thomas de Benitez 2011; Walakira 2012). For example, children in street situations face considerable stigma, which has implications for their psychological well-being (Jones et al. 2007; Kidd 2007). Many of them also experience multiple deprivations including lack of food, clothes, shelter, and education (Thomas de Benitez 2011; Walakira 2012).

Similarly, orphans in child-headed households can be expected to have greater needs and vulnerabilities than households headed by an adult. Children in these situations may be less able to earn sufficient money, protect themselves, deal with the legal system, or make good decisions (UNICEF 2006). For example, a situation analysis of orphans and other vulnerable children in Uganda reports that children within child-headed households (who benefit less from the guidance of adults) are more vulnerable to deprivation, abuse, violence, and risky sexual behaviors (Wakhweya et al. 2002). Similarly, Luzze and Ssedyabule (2004), in a quantitative study of 969 CHHs in one district in Uganda, found that orphans living in CHHs are poorer than other orphans, have lower school attendance, and poorer access to social services.

The erosion of the extended family to support orphans and vulnerable children has also been partly responsible for the growing number of children in institutional care, particularly orphanages. Numerous studies (Foster and Makufa 1996; Drew et al. 1998; UNICEF 2006; van Blerk and Ansell 2007; Sherr et al. 2008; Whetten et al. 2009) underline the need for efforts to keep children out of institutions, in preference for community-based care programs for orphan care focused on enabling extended families and communities to care for orphaned and vulnerable children. These studies reaffirm that institutional care for children should only be considered as a temporary option or a measure of last resort.

Care institutions are considered not to be an ideal environment in which to raise children (Save the Children 2009). Institutions generally lack the capacity to meet the physical and emotional needs of children; may lead to poor health, growth, and development; and cost more per child than community care (Foster and Makufa 1996; Subbarao et al. 2001; Shetty and Powell 2003). For example, studies show that children enrolled in care institutions may experience shocking and sometimes deadly level of abuse, neglect, and gratuitous cruelty (Walakira and Ddumba-Nyanzi 2012), and children in family-based foster care report better health outcomes than their counterparts in orphanages (Whetten et al. 2009).

81.4 Survival and Health of Children Orphaned by AIDS

Children affected by AIDS suffer multiple deprivations and are more likely to report financial difficulties (Heymann et al. 2007). Studies indicate that orphaned children, compared to non-orphaned children, are more likely to lack food at home; lack money for school fees, books, and uniform; and often go to bed hungry (Ntozi 1997; Nyambedha et al. 2003; Sherr 2011). Such multiple deprivations potentially have far-reaching implications for child survival, growth, and development. Although the extended family might alleviate orphans' plight, it is unrealistic to assume that the children can escape from poverty without massive support from external sources (Bhargava and Bigombe 2003).

In addition, orphans may be denied the love, nurturing, and protection of their biological parents that play such a critical role in early life and development (UNICEF 2006). There is evidence that orphans may experience varying degrees of discrimination and other forms of injustices within foster households. Several studies document how orphaned children may have to do a disproportionate amount of household chores, may receive less food and clothing, and may be punished more harshly than the children of their new caregiver (Deacon and Stephney 2007; Madhavan 2004; van Blerk and Ansell 2007; Daniel 2011). For example, in a study by World Vision, community leaders in Uganda reported that corporal punishment was more severe and common against orphans compared to other children in the household who were more closely related to adult caregivers or to the head of the household (World Vision 2005). The study also revealed that orphans who were taken in by extended family members were frequently subjected to sexual violence from uncles, stepfathers, and cousins (World Vision 2005).

Some studies also indicate that while extended families assume substantial responsibility of caring for orphaned children, in many cases there is some degree of reciprocity in the care and support relationship. It is not uncommon for adults (extended family or others) who care for children not their own to expect some sort of compensation or exchange. Madhavan's (2004) literature review elucidates how fostering arrangements in Africa were historically devised to benefit both biological and foster parents.

81.4.1 Physical Health and Health-Care Access

Mixed results about physical health and health-care access have been reported among orphans as compared with non-orphans (Crampin et al. 2003; Lindblade et al. 2003; Nyambedha et al. 2003; Masmas et al. 2004; Sarker et al. 2005). Some studies have found orphan status to be a critical predictor of poor health outcomes among children (Miller et al. 2007; Watts et al. 2007). For example, in a study in Zimbabwe, Watts and colleagues found that orphans and vulnerable children (OVC) were much more likely to suffer malnutrition and ill health than non-orphans and that the difference could not be explained by differences in poverty (Watts et al. 2007). Also, in a study in Uganda, illness was reported more

often for orphans than non-orphans (Sarker et al. 2005). In contrast, Kidman et al. (2010), in examining the impact of AIDS in the family and community on child health in Malawi, found that for a range of physical health indicators, orphaned children were no worse off than non-orphaned children, though children living with ill parents were significantly more likely to suffer serious morbidity. Similarly, research in Kenya found that the health status of orphans under five living in their communities was similar to that of non-orphans (Lindblade et al. 2003).

While several studies report diminished access to health care for orphans compared to non-orphans (Ainsworth and Semali 2000; Miller et al. 2007), some studies have found no discrimination by caregivers in seeking treatment for orphans compared to other children (Sarker et al. 2005).

81.4.2 Nutritional Outcomes

Evidence on orphan-based disparities in nutritional status is also mixed. Some studies indicate that orphans are more likely to suffer malnutrition and stunting or growth failure. Specifically, orphan-based differences in nutritional status among children under 4 year olds were found in studies from Western and Eastern Kenya (Lindblade et al. 2003; Bloss et al. 2004), Botswana (Miller 2005), and Tanzania (Ainsworth and Semali 2000). In a study of households in the poor suburbs of Dar Es Salaam, Tanzania, it was found that orphans were more likely to go to bed hungry than non-orphans (Makame et al. 2002). In Malawi, households with more than one orphan were much more likely to report food insecurity with moderate to severe hunger than households with no orphans. The data suggest that while households can manage to absorb one orphan without significant impact, they cannot continue to care for additional orphans without affecting their food security (Rivers et al. 2006).

In contrast, research in northern Malawi (Crampin et al. 2003), Uganda (Sarker et al. 2005), Guinea Bissau (Masmas et al. 2004), and analysis of national survey data on children ages 12–59 months in 40 countries (Monasch and Boerma 2004) found no differences in the nutritional status of orphans and non-orphans.

81.4.3 Psychological Well-Being

The psychological and emotional well-being of children orphaned and made more vulnerable by AIDS is threatened by a number of different pressures. The death of a parent during childhood is traumatic, with a profound impact on a child's psychosocial adjustment. AIDS orphans experience grief at the loss of their parents and may experience considerable stigma and discrimination. Stigma may exacerbate the effects of bereavement and hinder psychosocial adjustment (Deacon and Stephney 2007; Makame et al. 2002). In most cases, stigmatization prevents affected children from having normal interpersonal relationships with others. In addition, the material, health, and education impacts occasioned by a child's

orphan status also threaten the psychological and emotional well-being of the affected child.

AIDS orphans have markedly increased internalizing problems and higher levels of depression, anxiety, fear, anger, loneliness, social withdrawal, and hopelessness (Sengendo and Nambi 1997; Makame, et al. 2002; Atwine et al. 2005; Cluver and Gardner 2007). For example, in one study in Uganda, higher depression scores were reported among orphans compared to non-orphans (Sengendo and Nambi 1997). Maternal orphans and those in child-headed households were significantly more depressed than paternal orphans, and children living with grandparents were less depressed than those living with other relatives (Sengendo and Nambi 1997). Depressed children had more physical complaints and lower self-esteem and were more likely to be overactive, involved in fights, and refuse to go to school. Depressed children also appeared miserable, unhappy, tearful, or distressed (Sengendo and Nambi 1997).

Another study carried in Uganda also documented higher levels of anxiety, depression, and anger, along with inactivity, feelings of hopelessness and despair, and suicidal ideation among children orphaned by AIDS (Atwine et al. 2005). In this study, 12 % of orphans affirmed a wish that they were dead, while only 3 % of non-orphans expressed such feelings.

81.4.4 Sexual Health and High-Risk Activities

Research indicates that orphans are at an increased risk of HIV infection (Gregson et al. 2005; UNICEF 2005; Thurman et al. 2006; Birdthistle et al. 2009). Orphans are more likely than non-orphaned children to engage in sex at an earlier age (Foster and Williamson 2000; Gregson et al. 2005) and to be sexually exploited or abused (Foster and Williamson 2000; UNICEF 2005). For example, one study in Uganda, among orphans participating in a service provision program, documented early age of sexual intercourse (Sharpe et al. 1993). A population-based study in Zimbabwe also found earlier sexual intercourse among adolescent female maternal orphans compared to their non-orphaned peers; the same pattern was not found among male orphans, though the male sample was limited to adolescents age 17–18 (Gregson et al. 2005). Thurman et al. (2006), utilizing data from a population-based survey of 1694 South African adolescents, ages 14-18, also found both male and female orphans significantly more likely to have engaged in sex as compared to non-orphans (49 % vs. 39 %). Among the sexually active youth, orphans reported younger age of sexual intercourse with 23 % of orphans having had sex by age 13 or younger compared to 15 % of non-orphans (Thurman et al. 2006).

Earlier sex debut among orphans could be due to depression, hopelessness (Atwine et al. 2005), lack of education, and/or lack of adult influence (Gregson et al. 2005). Research also indicates that the trauma of losing a parent, growing up in a distressed home, or with lower quality care may drive affected orphans into sexual activity to fulfill emotional needs (Miller 2007). Further, poverty and financial desperation may also drive orphans into exchanging sex for money or

goods and other exploitative situations. For example, numerous studies in Uganda cite orphanhood as one of the main reason for children's involvement in commercial sex work (Kasirye 2002; ILO/IPEC 2004; Walakira 2006; UYDEL and Acting for Life 2011). Involvement in commercial sex work (CSW) exposes these children to HIV and other sexually transmitted infections (STIs) and unwanted pregnancy (ILO/IPEC 2004; Walakira 2006). Commercial sexual exploitation is also associated with increased involvement in delinquent activities, increased rates of alcohol and substance abuse (Kasirye 2002), and exposes children to other forms of abuse and violence at the hands of their clients, such as rape, physical assault, and use of "objects" for sexual satisfaction (Walakira 2006).

81.4.5 Educational Outcomes

Education is universally recognized to be essential for child development and has far-reaching impact on societies (Bredie and Beeharry 1998; Stiglitz 2005; UNICEF 2009). HIV and AIDS however has enormous impact on children's educational outcomes. Most of the existing studies show educational disadvantages among children affected by AIDS in various educational outcomes, including school enrollment and attendance, school behavior and performance, school completion, and educational attainment (Guo et al. 2012). The effects of HIV and AIDS on children's education is potentially moderated or mediated by a number of individual and contextual factors, including gender of child, pattern of parental loss (maternal vs. paternal vs. dual), living arrangement (relationship with caregivers, gender of the household head), and household poverty (Guo et al. 2012).

Several studies have found that orphans are less likely to be enrolled in school or attend school (Kamali et al. 1996; Konde-lule et al. 1996; Case et al. 2004; Monasch and Boerma 2004; Nyamukapa and Gregson 2005; Case and Ardington 2006). For example, using national representative data (23 Multiple Indicator Cluster Surveys (MICS) and 17 Demographic Health Surveys) from 40 countries in sub-Saharan Africa, one study found that orphans were approximately 13 % less likely to attend school than non-orphans (Monasch and Boerma 2004). Another study in Kenya utilizing 5 year longitudinal data revealed a substantial and significant impact of parental death on orphan's primary school enrollment and attendance (Evans and Miguel 2007). Compared with non-orphans and single orphans (i.e., children who lost one parent to AIDS), double orphans were found to have significantly lower educational enrollment and attendance, especially in rural Africa (Case et al. 2004; Kobiane et al. 2005; Birdthistle et al. 2009). Low school enrollment and attendance among orphans could be the result of household inability to meet the costs associated with schooling, increased household need for income generation or domestic labor, intra-household stigmatization, and other reasons related to the parental sickness or loss.

However, several other studies did not find an independent effect of orphanhood on school enrollment or attendance after controlling for other factors (Sharma 2006; Kurzinger et al. 2008; Birdthistle et al. 2009; Oladokun et al. 2009). These factors

included age, gender, education (grade level), and religion of the child, living arrangement (i.e., whether the child was living with his/her own family), relationship between the child and the household head, household child/adult ratio (i.e., number of children aged under 18 years to number of adults, an indication of childcare burden), and school fee assistance to families (Sharma 2006; Kurzinger et al. 2008; Birdthistle et al. 2009).

Studies also indicate that orphans are less likely than non-orphans to be at the age-appropriate grade level, due to the interruption of parental illness and death (Bicego et al. 2003; Ainsworth et al. 2005; Kasirye and Hisali 2010). Younger children and double orphans were the most affected groups in terms of schooling gap (Bicego et al. 2003; Ainsworth et al. 2005). Households affected by AIDS often delayed school enrollment of younger children, while trying to maintain the enrollment of older children if possible. Double orphans often experienced multiple interruptions of parental illness and death and therefore were more likely to fall below their appropriate grade (Bicego et al. 2003; Ainsworth et al. 2005).

81.5 Children Living with HIV-Infected Parents

The expanding access to ART has improved the well-being of people living with HIV (PLHIV) and remarkably reduced the morbidity and mortality due to HIV and AIDS (Vittinghoff et al. 1999; UNAIDS 2010, 2012; Obua et al. 2011). Nonetheless a countless number of children whose parents are infected with HIV experience the prolonged illness and eventual death of their parents from AIDS-related infections (Daniel 2011). Living with an HIV-infected parent can dramatically affect children's psychological adjustment, care, and development outcomes (Sherr et al. 2008).

Children living with HIV-infected parents may experience an increased responsibility of caregiving in family (Zhang et al. 2009). Skovdal and Ogutu underline some of the duties involved with chronic care of adults affected by HIV and AIDS (Skovdal and Ogutu 2009; Skovdal 2010). This includes direct care activities, such as taking on considerable nursing duties (Skovdal and Ogutu 2009), or indirect activities, such as overseeing even younger siblings, preparing food, cleaning, and other household chores. Such caregiving may end up jeopardizing their daily life such as school attendance (Robson et al. 2006), socializing, or play activities. Parental or caregivers' illness may also lead to a reduction in household income and food production and depletion of savings due to expenditure on health services (van Blerk and Ansell 2007). In the absence of working adults in their households, children may be obliged to try and earn some cash and produce food to sustain their household (Skovdal and Ogutu 2009; Skovdal 2010). Consequently, children may be forced to drop out of school or put their education on hold.

Children with HIV-infected parents are also at increased risk of poor health outcomes. Such children will be more exposed to TB and other opportunistic infections associated with AIDS (Daniel 2011). In addition, they experience complex problems specific to their psychosocial well-being as a result of their parents' HIV sero-status (Bhargava and Bigombe 2003; Bhargava 2005;

Bauman et al. 2006). Studies show that such children, facing the potential of losing parents infected with HIV, are at the same or higher risk as AIDS orphans for poor psychosocial adjustment (Fang et al. 2009), suggesting that children living with HIV-infected parents are at particular risk of psychological stress. The context in which these children live (e.g., uncertainty regarding parent health status or death, being potentially isolated from others due to parental AIDS-related illness) may contribute to such stress (Fang et al. 2009).

81.6 Summary

The impact of HIV and AIDS on children remains wide ranging. HIV and AIDS negatively impact the quality of care, socialization, health, and emotional and cognitive development of affected children. Children may lose one or both parents and other family members or become infected with HIV. Apart from the physical and psychosocial stress associated with the onset of the disease itself and the experience of loss of loved ones, children affected by HIV and AIDS may additionally be subjected to the burden of caring for others, stigma, discrimination, exploitation, abuse, financial hardships and are less likely to attend school.

Children living with HIV and AIDS are at increased risk of mortality and morbidity and experience psychological distress as a result of their status. The physical well-being of HIV-infected children also depends largely on the HIV-related treatment, care, and support available to them. Without treatment, more than one-third of these children do not survive their first birthday. While the number of children accessing ART has increased significantly in recent years, only a small proportion of the children in need of this therapy receive it. In addition, for many HIV-infected children, ART initiation is often delayed and ensuring treatment success often daunting: low-cost diagnostics tests that allow for identification of HIV infection in infants, pediatric drug formulations, and assays for monitoring response to therapy (particularly HIV-1 viral load) are not widely available in many poor-resource settings. Further, while ART for children is important for their medical prognosis and life expectancy, it also poses a unique set of social consequences and treatmentseeking issues that have implications for children's well-being such as caregiving, medication adherence, nutrition for HIV-infected children, and sharing of information about HIV with infected children.

The experience of children affected by HIV (i.e., those who have lost one or both parents to HIV and those living with HIV-infected parents) vary significantly across families, communities, and countries. Numerous studies, however, indicate that many children affected by HIV experience physical deprivation such as a lack of basic needs (such as food, shelter, education, and medical care) and social disruption, are at higher risk of missing out on schooling, live in households with less food security, suffer anxiety and depression, and are at higher risk of exposure to HIV. The impact of HIV on children's well-being is mediated or influenced by a complex mix of variables, including gender and age of affected children, pattern of parental loss (maternal vs. paternal vs. dual), relationship with caregivers, the

social economic status (SES) of their household, gender of the household head, and an array of other factors. In addition, HIV-infected orphans or vulnerable have unique challenges not faced by uninfected children orphaned by HIV and AIDS. These challenges, however, need further exploration.

Over the last two decades, local, national, and international efforts have been undertaken in different settings to address vulnerabilities of children affected by HIV and AIDS, particularly through a range of social protection programs (including education support, e.g., provision of uniforms, economic strengthening for vulnerable households, material aid in the form food). In addition, considerable progress has been made in providing access to ART for children infected by HIV and AIDS. However, in terms of psychosocial support, there is still much to be done. More exploration is also required regarding risk and resilience factors, both individual and contextual, affecting psychosocial functioning, to inform future intervention efforts and public policy regarding the care for children affected by HIV and AIDS.

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