Growing Up in the Context of High HIV Prevalence: Adult Death and Illness, Family Living Arrangements, and Children's Lives

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The HIV/AIDS epidemic in Southern Africa is one the most pressing problems facing the world today. HIV/AIDS-related illness and death are reorganizing families and households throughout the region. The well-being of children is of particular concern due to the scale of parental death. Using the Lesotho Demographic and Health Survey (Lesotho DHS) and over 100 in-depth interviews with caregivers and children, we depict the lives of children in Lesotho, a country in which 40% of children lose at least one parent to AIDS and other causes by age 16. Using DHS data we detail children's exposure to adult death and illness and embed this experience in the broader context of children's family living arrangements. Using in-depth interviews with caregivers, we elaborate on the circumstances surrounding parent presence and absence. Finally, we analyze interviews carried out with children themselves to learn what children say about HIV/AIDS, and to situate the epidemic in their lives.

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Introduction

Worldwide more than 65 million people have been infected with HIV and 25 million have died from AIDS (UNAIDS 2006). While no region of the world has been untouched by the epidemic, sub-Saharan Africa is by far the most affected region—with only about 1/10 of the world's population, but nearly 2/3 of the world's HIV cases (UNAIDS 2006). Within sub-Saharan Africa the prevalence of HIV varies significantly. In Southern Africa, where the epidemic is most extensive, adult HIV prevalence rates now range from 19 to 33% (UNAIDS 2006); consequently, the effects of HIV are particularly pervasive in this region.

The high prevalence of HIV among adults in sub-Saharan Africa has contributed to widespread concern for children. To date, social science research related to children and HIV/AIDS in sub-Saharan Africa has focused primarily on the consequences of parental death for children. Parental death, particularly maternal death, has been found to be detrimental to children's schooling outcomes (Bicego et al. 2003; Case et al. 2004; Nyamukapa and Gregson 2005; Case and Ardington 2006; Evans and Miguel 2007). In addition, orphans have been found to live in poorer households than non-orphans (Andrews et al. 2006; Miller et al. 2007), and longitudinal research suggests that paternal death likely has causal negative economic consequences for children's households (Case et al. 2006). Loss of a parent is also associated with negative psychosocial outcomes (Sengendo and Nambi 1997; Makame et al. 2002; Atwine et al. 2005), negative health outcomes (Miller et al. 2007) and increased child mobility (Ford and Hosegood 2005; Ansell and van Blerk 2004).

As many have noted, however, despite the significance of parental death, orphan[1] children are not the only children affected in settings with a generalized HIV epidemic (Ainsworth and Filmer 2006; Skinner et al. 2006; Meintjes and Giese 2006). HIV/AIDS illness and death can affect children, orphaned and not, through decreased household income, increased household expenses, increased caregiving demands, and changes in household composition (UNICEF 2004; United Nations 2004). Such household level factors can be compounded by community and state level changes. As the working aged population disproportionately dies, local poverty can intensify. In addition, resources that governments may have used to support institutions that serve children directly may be redirected toward the growing need to fund AIDS initiatives. As a result, all children in HIV/AIDS affected settings are at risk of reductions in health and nutrition, decreased schooling, greater demands for their labor, and increased social isolation. These circumstances lead us to explore and describe the situation of children living in the midst of a generalized HIV epidemic.

In this paper we build on the existing literature by elaborating children's experience with adult death and HIV infection in a southern African country with a generalized HIV epidemic and high levels of HIV infection. Drawing on nationally representative survey data and semi-structured interviews with children and caregivers in two communities in Lesotho, the goal of this paper is to describe what it is like to be a child growing up in a setting with high HIV prevalence. We detail children's direct exposure to parental death, as well as their indirect exposure through living with children who have experienced parental death. Significantly, we situate parental death in the broader context of children's living arrangements, and especially parental presence and absence. Then, because children can be affected by illness as well as

[1] Consistent with standard practice, we use the term orphan to refer to any child with one or more deceased parents (UNAIDS and UNICEF 2003).

death, we detail children's exposure to HIV infected adults in their households. Finally, we turn to the in-depth interviews with children and their caregivers to learn what they say about HIV and AIDS, and to situate their experience of the epidemic in the broader context of their daily lives.

While we focus on children's lives in the midst of an HIV epidemic, it is important to note that in our data we do not have information on, nor do we discuss in detail, children who are infected with HIV. HIV-positive young children contract HIV almost exclusively through mother-to-child HIV transmission during pregnancy, birth, or breastfeeding (De Cock et al. 2000). Without antiretroviral treatment to prevent maternal transmission, mother-to-child HIV transmission rates range from 15% to 45%, and vary substantially depending on a number of factors including breastfeeding length and intensity (De Cock et al. 2000). Rates of antiretroviral treatment to prevent maternal transmission are low in the region, and in Lesotho were estimated at 5.1% in 2005 (UNAIDS 2006). The rates of treatment for HIV infected infants are also low (Lamptey et al. 2006). In the absence of treatment, infants infected maternally with HIV can expect to live less than 5 years (Taha et al. 2000; Newell et al. 2004). High mortality rates for HIV-positive infants means that very few children in the region are HIV-positive between infancy and adolescence. However, once older children become sexually active, they are again at risk of contracting HIV.

Setting

Lesotho is an appropriate setting for this analysis. In Lesotho, an adult HIV prevalence rate of 23% (UNAIDS 2006) has contributed to a situation in which approximately 97,000 children under age 18 have lost at least one parent. Nearly two thirds of these parental deaths are

attributed to AIDS (UNAIDS 2006). Although access to HIV treatment is increasing (National AIDS Commission, Lesotho 2006), treatment rates have been low in recent years—estimated at 14% in 2005 (UNAIDS 2006). Thus, the consequences of HIV illness and death will continue to affect the children of Lesotho for the foreseeable future. HIV has also contributed to a shrinking of the total population size. Estimated at 2.2 million in 2003 (Ministry of Health and Social Welfare 2005), preliminary results from the 2006 Census reveal that the current population of Lesotho is now 1.8 million people (Bureau of Statistics, Lesotho 2007). The high prevalence of HIV at the population level suggests that HIV will have consequences for all children in Lesotho—not just those who have lost a parent.

The HIV epidemic in Lesotho takes place against a backdrop of widespread poverty. More than half of the country's population lives on less than $2 per day (UNAIDS 2006). Lesotho is highly rural, with approximately 75% of households located in rural areas (Bureau of Statistics, Lesotho 2007). Running water is also scarce—about half of urban households and 2% of rural households had water piped directly to their yard or house in 2004.[2] Despite considerable poverty, school enrollment among children is high, with 85% of girls and 78% of boys age 6-17 enrolled in school in 2004 (Ministry of Health and Social Welfare 2005).

Data

To examine children's experiences of growing up amidst high HIV prevalence from multiple vantage points, we integrate two complementary sources of data. We use the 2004 Lesotho Demographic and Health Survey (Lesotho DHS) to provide population level estimates. The Lesotho DHS includes a nationally representative sample of more than 9,000 households

[2] Approximately 37% of rural households and 76% of urban households had access to a water source within 15 minutes of their home.

across the country of Lesotho, including approximately 15,000 children in 6,500 households.

We use the Lesotho DHS household questionnaire to determine the household composition, parent vital status, parent residence status, and HIV status of household members for all children considered usual residents of a household. Given that children's needs and experiences vary significantly over the life course, we present descriptive statistics by age. We focus on children less than seventeen because the rate at which children leave home and form their own households increases in the late teen years, which complicates the interpretation of household composition.

To contextualize these survey-based descriptions of children's experiences with adult death and illness, we analyze in-depth interviews conducted with children, their caregivers, and others familiar with children's lives. The data come from the 2004 Lesotho Children's Project — an ethnographic data collection effort that included participant observation as well as semi structured in-depth interviews with caregivers, children, and key informants. Interviews took place in a village about one hour from the capital city that had a relatively high level of services (which we refer to as a "town-village") and a set of small associated rural villages that were accessible by a two hour walk from the town village, that relied on the main town-village for schools and services (which we refer to as a "rural-village").

The goal of the Lesotho Children's Project was to understand better family reorganization in the context of HIV/AIDS and its implications for children's care and outcomes. The in-depth interviews were organized around 74 focal children ages 0-14 who were selected to assure variation along three axes—community context (town-village versus rural-village); family circumstance (socioeconomic status); and child characteristics (residence with at least one biological parent versus residence with no biological parent). Interviews were conducted with

the primary caregiver of each focal child. Focal children age seven and older were interviewed directly, resulting in 35 focal-child interviews. In addition, 14 key informants (village chiefs, social workers, police officers, teachers, and others) were interviewed. In the results reported in this paper, we draw primarily on material from the child and caregiver interviews. See Table 1 for a summary of focal child attributes.

Children's Experience of Parental Death

Data from the 2004 Lesotho DHS indicate that, overall, 28% of children less than seventeen years old have lost at least one parent to death. However, experience of parental death becomes more likely as children age. Figure 1 summarizes children's experience of parental death by age, distinguishing between maternal and paternal death. In 2004, 32% of children had experienced the death of at least one parent by the time they were ten years old, and a full 41% had experienced the death of a parent by the time they were 16 years old. Children were more likely to experience paternal death than maternal death, with 34% of sixteen year olds having lost a father compared with 16% who had lost a mother. In addition, evidence suggests that orphan prevalence in 2004 was rising rather than declining. In 2001, just three years prior, inter-censal data from the Lesotho Demographic Survey indicate that smaller percentages of children had experienced parental death at almost every age.[3]

Figure 1 about here

The widespread experience of parental death among children is mirrored in patterns observed at the household level. In addition, household patterns reveal additional children who may not have experienced parental death directly, but who may live with other children who

[3] The 2001 Lesotho Demographic Survey is a nationally representative household based survey of ~16000 households in Lesotho. The survey was designed to provide basic population measures for Lesotho midway between the 1996 and 2006 censuses.

have. In 2004, some 37% of households with children less than seventeen years old included at least one orphan. Among these households, 23% included only orphans while 14% included both orphans and non-orphans. Overall, while 28% of children were orphans in 2004, another 11% of children lived with children who had a parent who had died. Figure 2 shows the percentage of orphan and non-orphan children who lived in households with only orphans, only non-orphans, or in blended orphan-non-orphan households by age. This figure indicates that although older children are more likely to experience parental death, younger children are more likely to live with a child who has experienced parental death. Thus, even though parental death is less common among younger children, preschool children are likely to live with children who have lost at least one parent. Some 17% of children 0 to 5 years who were non-orphans lived in a household with at least one orphan.

The experience of children in blended households is important to consider. For example, households that contain both orphans and non-orphans are larger than other households (Parker and Goldberg 2007), and subsequently both orphan and non-orphan children living in these households may face resource dilution as resources are spread among a larger number of household members. Higher numbers of children in these households also means that older orphan and non-orphan children in such households may have increased caregiving responsibilities.[4]

Figure 2 about here

Figures 3 and 4 situate children's experience of death in the larger context of children's living arrangements. These figures show that children's experience of parental absence for

[4] Further research is needed to explain the circumstances that lead to blended orphan/non-orphan households, as these circumstances are likely to affect the experiences of the children in such households. For example, it may be that households with young children readily take in older orphan children because they can help care for younger children.

reasons not precipitated by parental death is substantial. Figure 3 shows mother presence and household affiliation for children 0-16 years. While at the time of birth nearly all children live with a mother, by the end of their pre-school years, less than two-thirds do so. Mother co-residence continues to decrease as children age so that by the time they are 16 years old, about half of children live with a mother. When children do not live with a mother, most often their mother is not affiliated with their household. However, about 5% of children have mothers who are absent household members, or migrants. By the time they are ten, however, children are more likely to have a mother who has died than a mother who is away but part of the household. In sum, while a substantial percentage of children have experienced maternal death, children are more likely at every age to have mothers away for other reasons.

Figures 3 and 4 about here

Figure 4 highlights the connections children have to fathers in Lesotho. Overall, about a quarter of children have experienced paternal death. Among those who have not, the majority do not live with a father. During the preschool years about 35% of children have a father present in the household; during the teen years about 25% live with a father. Roughly 20% of children have fathers who are absent household members. At least as many children, however, have fathers who are not household members. By the time they are sixteen, children are more likely to have a father who has died than a father who is present in the household.

Figure 5 summarizes the likelihood that a child lives with any parent by age. At birth, fewer than 5% of children live without a mother or father. By age 7, this proportion has increased to about 30%, and by age 16 it reaches approximately 40%. Among children who live with at least one parent, at all ages children are slightly more likely to live with a mother than with a mother and father. When no mother is present, very few children live with a father.

Figure 5 about here

With whom do children without a mother or father present live? As shown in Figure 6, it depends to some extent on age. About three-quarters of preschool age children who do not live with their parents live with grandparents. Among older children, grandparent co-residence remains substantial, but over one-third live with other relatives. It is relatively uncommon for children of any age to live with adult non-relatives only, though the likelihood of doing so increases with age. About 10% of 11-14 year olds and nearly 25% of 16 year olds that are not living with a parent are living with an adult non-relative. The data also confirm that some children, albeit a small proportion, live in child-only households. Although there may be some adult involvement in these households, child-only households are characterized by no adult household member 17 years or older co-residing as a usual resident. On average, 1% of all children live in child-only households, with the likelihood increasing with age so that by age 16, 3.5% of 16 year old children live in such households.

Figure 6 about here

The figures above underscore that both parental death *and* parental absence are prevalent in Lesotho. Caregivers, in their interviews, detailed the reasons parents and children do not co-reside and the types of connections children have to absent parents. These include the importance of limited job opportunities and the need for parents to migrate for work. Although many types of formal and informal sector activities are sought by men and women, for decades many men have worked in mining jobs in South Africa. Often, those away working or looking for work continue to share household membership in their children's households. If they are successful at finding work, these parents can play a vital role in household survival. Unfortunately, many absent parents are looking for work rather than working.

> Do you see [the situation] as worthwhile that Pali (focal child) is here and his father is far away [working in the mines]?
> **Even if it is not worthwhile nothing can be done since he [the child] needs clothing and food.**
> (Mother of 19 month old boy)

Another reason parents and children do not co-reside is that the absent parent does not belong to the child's household. Caregivers explained that such arrangements can result when pregnancies occur outside of marriage. At the time of birth, the new child of a young unmarried woman can be claimed by its maternal grandmother.

> So how come you are the one responsible for Sebina (focal child)?
> **She is considered my child because she was made outside marriage.**
> (Maternal Grandmother of 10 year old girl)

Caregivers explained that in such situations the child would not have a father.

> Who is his father?
> **His mother wasn't married so he has no father.**
> (Maternal Aunt of 6 year old boy)

Caregivers noted that relationship instability also leads parents and children to live in different households. Relationship dissolution, including separation and divorce, can create distant relationships between the absent parent (most often the father) and the children. Occasionally, other relatives, such as grandparents, take over the care of children in times of parental conflict and instability.

Finally, children in this setting are mobile, and may divide their time between multiple households. In particular, children of school age may live in one place while school is in session and another during school breaks. They may not live with parents in both locations, but may maintain high levels of contact with them throughout the year. In other situations, children may

move in with grandparents to keep them company ("remove boredom") or help them with domestic chores. On occasion, caregivers also spoke of children being sent to live with others to reduce the "luggage" of parents with many children.

These relatively high rates of parental absence and migration are relevant to consider in thinking through the effects of the HIV/AIDS epidemic on children's lives. The emotional impact of parental death may be less for children who did not co-reside or had limited contact with their parent before his or her death.[5] On the other hand, if the absent parent was contributing resources to the child's household, the economic effects of his or her death might be great, and, given the high rates of rural unemployment, perhaps even greater than if the parent was co-resident with the child. Furthermore, because migration has been linked to HIV risk (Quinn 1994; Perrin et al. 2003; Lurie 2006), parental and other adult migration may actually increase children's exposure to an HIV-positive parent or household member. Finally, HIV/AIDS may itself contribute to increased parental co-residence if migrant parents who are too sick to work return to their homes of origin for care (Knodel et al. 2001).

Children's Experience of HIV in Their Households

Thus far we have largely focused on describing and contextualizing children's direct and indirect experiences with adult death. Many children are also affected by living with HIV-infected household members, some of whom may be ill. HIV-positive adults may or may not show external signs of illness; however, HIV prevalence in children's households is a useful proxy for considering children's exposure to illness as a consequence of HIV.[6] Living with an HIV-positive adult may affect children's daily lives in a very significant way, as they may be

[5] Indeed, one caregiver of an orphan child suggested that this was the case for the orphan in her care.
[6] Also, in the absence of widespread treatment, the presence of an HIV-positive adult foreshadows a child's exposure to illness and death within the household.

called on to care for a sick adult, take on additional domestic chores, or care for other young children in the household (Robson et al. 2006). Children may also experience reduced school attendance and enrollment in the months prior to the death of an adult in the household, perhaps as a consequence of increased caring needs (Ainsworth et al. 2005; Yamano and Jayne 2005).

A number of recent Demographic and Health Surveys have included HIV testing. The Lesotho DHS included HIV testing of men 15-59 and women 15-49 in all households selected for male interviews (every second household). While 16.6% of age eligible men and 12% of age eligible women in the Lesotho DHS were excluded from testing because they refused consent, an analysis of non-response bias concluded that the selectivity of refusals did not significantly affect prevalence estimates (Ministry of Health and Social Welfare 2005). Other research has also asserted the validity of individual HIV status in DHS data (for example, see Bongaarts 2007). The household based collection strategy of the DHS allows us to link HIV status to individuals within households and thereby determine children's exposure to HIV-positive parents and other adults in their households.

Table 2 summarizes children's experience of living in households with HIV-positive parents and other adults. Because estimates are based on living arrangements, and living arrangements vary substantially by child age, we present statistics by child age group. Among children who live with mothers, over one-quarter live with a mother who is HIV-positive. Similarly, among children who live with fathers, about one-quarter live with an HIV infected father. Further, if we consider all adults in a child's household, over one-third of children live in a household in which at least one adult member tested positive for HIV. Thus, while a large number of children are affected by adult death, it is important to also recognize the extent to which children may be experiencing adult illness related to HIV, or to which they may be likely

to experience adult illness or death in the future. Despite these high HIV prevalence rates among adults in households with children, low voluntary counseling and testing (VCT) rates in Lesotho at the time means that it is likely that many of the adults who tested positive were not aware of their HIV status.[7]

Table 2 about here

Children's Perspectives on HIV/AIDS

We now turn to the words of the children themselves. What do they say about HIV/AIDS? The in-depth interviews conducted with children age 7 to 14 were structured primarily to learn about children's daily lives in the context of the epidemic. Due to the potential sensitivity of the topic, and the young age of many of the children, most were not asked directly about HIV/AIDS. However, of the five older children asked directly about their knowledge of the disease, only one reported having heard of HIV/AIDS, which she had learned about in school. Others denied hearing or knowing of HIV, and some even expressed an aversion to knowing about it, although this response could be in part because they associated "knowing HIV" with having HIV. Below are some illustrative responses:

> Do you know something about HIV/AIDS?
> **I know nothing about HIV/AIDS.**
> Have you heard of it?
> **I haven't heard of it.**
> What about at school?
> **We have never been told of HIV/AIDS**
> (Girl, age 14)

> Do you know something about HIV/AIDS and TB?
> **I know nothing and I don't want to learn about it.**
> (Boy, age 14)

Given the pervasiveness of illness and death in children's lives, it was also notable how little the

[7] In the DHS, HIV test results were not made available to the respondents; however respondents were given information on where to go for VCT should they want to learn their HIV status.

children brought up the disease. None of the children spontaneously mentioned HIV/AIDS during their interviews.

In contrast to the children's interviews, the caregiver interviews contained more direct questions related to HIV/AIDS. Caregiver reports on what they had said to the children in their care about HIV help put the children's lack of mention of HIV in context. In many cases, caregivers expressed reluctance to discuss HIV with their children.

Caregivers provided a number of explanations for not talking about HIV/AIDS with the children in their care. Some caregivers explained that their children were too young. Teenage years (13 to 15) were most commonly cited as the ideal ages for talking with children about HIV/AIDS, although ages as young as six were mentioned. Some caregivers stated more generally that children should not learn about the disease until they are old enough to have "full and clear understanding."

Additionally, a number of caregivers admitted being too shy to talk to their children about HIV/AIDS. Several also felt that they could not teach children about HIV because they knew little about it themselves. At the same time, all of the caregivers who discussed the issue indicated that they wanted their children to learn about HIV eventually. Yet when asked where children should learn or who should teach them, many caregivers deferred to schools, peers, and AIDS educators, citing their own shyness and lack of knowledge. Indeed some caregivers reported that their children had already heard about HIV on the radio or were learning about it in school. Here a mother and grandmother describe their hesitancy to discuss HIV/AIDS with the children in their care:

> Do you know if there's someone who once talked to him about HIV/AIDS?
> **I don't know.**
> Is there something he knows about AIDS?

He knows nothing about it.
Would you like him to learn about it one day?
Yes I'd like him to learn about it.
Who'd tell him about that?
His sister will tell him. I fear AIDS issues.
Does it mean you won't tell your child about it?
Even in a single day, I'm shy to talk about it.
(Mother of 11 year old boy)

Do you know if there's something she knows about HIV/AIDS?
She knows nothing about it.
Do you think you'll ever teach her about HIV/AIDS?
What can I teach her about it because I already know nothing about it?
(Grandmother of 3 year old girl)

Both children's disinclination to talk about HIV and caregivers' own aversions to talking to their children about HIV are likely reflective to some extent of the stigma still associated with the disease. However, not all caregivers were reluctant to talk directly about HIV with their children. Some had spoken to their children themselves about the disease, or, in the case of caregivers of very young children, said they were planning to do so when the child was older.

Also relevant to this topic is the place of HIV in the range of dangers caregivers talk about with their children. The children were asked in their interviews about dangers they had been warned about by their caregivers. Here many issues surfaced; however, HIV was not among them. Children mainly reported that their caregivers had told them to avoid dams and walking at night. They described the latter as putting them at risk of kidnapping, murder, and rape. They also reported being told not to walk on the road due to the risk of being hit by a car. Children also said that they were supposed to avoid behaviors such as drinking alcohol, using drugs, and stealing. Some girls reported they had been warned in general about boys. Below is an illustrative quote:

Were you told to beware of dangerous things?
Yes, I was told that.

Who told you that?
'Me 'Malineo (the child's grandmother) told me that.
What were you told to stay away from?
I should not love and run after boys.
Why?
She has never told me the reason.
(Girl, age 11)

It is possible that such warnings related to relationships and sex may be indirect attempts to protect the children from HIV. However, the children did not indicate that their caregivers explicitly referenced HIV/AIDS in these discussions.

Although the children did not mention HIV spontaneously in the course of their interviews, some did make references to deaths around them and the role of death in their lives. For example, two older children made comments that referenced the possibility of dying young:

Do you like school?
Yes.
Where do you want to stop?
Form E[8] and go to the university if I am still alive. (laughter)
(Girl, age 13)

What do you think of school?
I think of passing all the subjects so that I can also have a brighter future if ever I'm still alive.
(Girl, age15)

Both children had lost fathers, which may have made them particularly aware of their own mortality.

Children who had lost a parent usually referred to that parent's death in the course of their interviews, although none attributed the death to AIDS, even when caregivers had indicated AIDS as a cause of death. Other references to death were more indirect – such as the mention of seeing parents or other relatives during funerals. Overall, however, mentions of death were

[8] Form E is the final year of high school. Schooling in Lesotho consists of 7 years of primary school (Standards 1-7), followed by 5 years of secondary school (Forms A-E).

relatively uncommon, considering the frequency with which children in Lesotho are exposed to death in their families.

Children's Perspectives on their Daily Lives

To round out our understanding of what it is like to be a child growing up in a setting with high HIV prevalence, it is useful to hear what the children themselves emphasized about the reality of their daily lives. If the children did not talk about HIV/AIDS during their interviews, what did they talk about? Primarily, the children focused on their regular routines and day-to-day activities. These most frequently included play, school, and chores—activities that likely would have been salient to children in Lesotho before the epidemic, as well. The children also spoke of hardships, but here, too, focused on things that affected them directly and on a daily basis.

Many children described play and friends as a source of joy in their lives, and several reported being happiest when playing and spending time with friends and family. For example, an 11 year old boy described some things that made him happy:

> Which people make you happy?
> **My brothers and sisters.**
> What do they do to make you happy?
> **They play with me.**
> Which games?
> **Marbles and football.**
> If you were told to do whatever you like for the whole day, what would you do?
> **I'd like to play marbles and football for the whole day.**

The children spoke of school as another primary activity in their lives. All but one of the children interviewed attended school, and many said that going to school was something that made them happy. Beyond enjoying their daily experiences at school (for example, spending

time with their teachers and their friends), they linked schooling with opportunity and with their future standard of living. Illustrative are the words of an 11 year old girl: "I think of attending [school] because it is very important in one's life…After finishing school, one gets a job and finds a better way of living."

In addition to playing and school, children mentioned household chores as an important part of their daily routines, and most children reported being responsible for some chores. Typical household chores included cooking, cleaning, watching younger children, collecting water or firewood, working in the garden or the field, and looking after animals. The substance and quantity of chores varied substantially among children, as did the children's attitudes toward doing them.

Several children also mentioned working outside of their households, and sometimes received payment for this work in food or cash. However, the children did not speak of being overly burdened by such tasks, and indeed did not appear to spend a substantial amount of time on this outside work. Some children spoke of helping neighbors outside their household without expecting to be compensated for their efforts.

In line with the children's tendency to focus on their day to day activities, the children's references to adversity also revolved around issues that affected them directly. The most frequently mentioned problem was resource constraint. The children's examples of resource constraint focused on its concrete and immediate impacts on their regular routines; for example, their ability to attend school, or to have enough to eat.

Consistent with the children's emphasis on schooling as one of the most important components of their daily lives, they frequently mentioned schooling as an area in which they felt resource constraint. Some of the children mentioned inconsistent school attendance due to

familial needs for their labor, family difficulties in consistently paying their school fees, or a lack of shoes and/or uniforms. For example, a 14 year old boy in the rural area spoke of responsibility for his family's animals as a barrier to his school attendance:

> Do you always go to school?
> **I sometimes miss it.**
> For what reasons?
> **When there's no one looking after the animals.**

Additionally, some children articulated concerns about school completion. For example, when asked how long they would attend school, some anticipated that their caregivers would not be able to afford their schooling past a certain point. A 14 year old girl in her sixth year of primary school described why she did not think she would attend school for more than another year or two:

> For how long do you think you'll stay at school?
> **I'll complete my Standard 7.**[9]
> Why?
> **Because there's no money that'll be used to pay my school fees if I continue with my studies.**

In addition, the children reported relying on multiple sources (including parents, uncles/aunts, grandparents, employers, and siblings) for school fees, uniforms, books, and other supplies, highlighting the vulnerability of their schooling to deaths of working adults at home and in their social networks.

The children also frequently mentioned food scarcity as a constraint they faced. For example, when asked what they would like to change about their lives and what they would like their futures to be like, a number of children spoke of wanting to be free of food security issues. Common themes were not having enough food, having to ask others for food, or being limited to a narrow range of foods. An eight year old spoke of wanting a future in which she would not

[9] The final (seventh) year of primary school.

have to rely on the generosity of others for food provision:

> What would you like to have in life?
> **I'd like to have a very jolly life.**
> With what?
> **With everything I need–especially money to buy groceries so that we can't [don't have to] ask other people for maize flour.**

Overall, children expressed varying levels of satisfaction with their current lives. Some, such as this 11 year old, spoke of unhappiness resulting from resource constraint:

> How is your life now?
> **It's very bitter.**
> What makes it bitter?
> **…we sometimes have no food in the house.**

Others acknowledged difficulties while at the same time reporting an overall contentment with their lives:

> How would you like your life to be like tomorrow?
> **I want to live like now.**
> Do you have everything you need now?
> **I don't have everything I need, but I'm still satisfied.**
> (Boy, age 13)

Still others spoke of their lives in unqualified positive terms. For example, a 10-year-old echoed the sentiments of many when she said that she would like to remain in her village in the future, explaining "My stay is very jolly here".

Conclusion

In southern Africa, where more than one in five adults is infected with HIV, the consequences of the epidemic are widespread. Given the scale of parental illness and death, the well-being of children is of particular concern. A significant body of research has considered the relationship between parental death and child outcomes, particularly in terms of schooling. In

this paper we attempt to portray a broader picture of what it is like for children—orphan and non-orphan—to grow up in the midst of a generalized HIV epidemic, and to contextualize adult death and HIV illness in children's daily lives.

In Lesotho, a full 41% of children experience parental death by the age of 16. Adult death also likely influences the lives of those non-orphan children who co-reside with orphans. . Though the rates of parental death appear to have increased in recent years, it is, however, important to note that mortality rates are high in general in this region, and one out of three of these deaths can be attributed to causes other than AIDS (UNAIDS 2006). Moreover, even in this context of high levels of parental death, children in Lesotho continue to be more likely to live in a household without a parent due to parental *absence* than to live in a household without a parent because that parent is dead. While migration for work is common and contributes to parental absence, especially among men, most absent parents are not actually members of their children's households. Absence due to migration and relationship instability also characterized the region before the onset of the HIV epidemic (Murray 1981). Parent/child separation has also been noted among South African children of migrant parents as a consequence of strict residency rules under apartheid (Madhavan 2004); indeed, child living arrangements vary greatly within sub-Saharan Africa, and many children spend part or all of their childhoods apart from their parents (Isiugo-Abanihe, 1985; Lloyd and Desai, 1992; Madhavan, 2004).

Children's experiences of parental death and absence in Lesotho vary by age, as do their non-parental living arrangements. Older children are most likely to live without one or both of their parents, due to migration, lack of household affiliation, or death. They are also most likely to be living with distant adult relatives, no adult relatives, or no adult at all, and such living situations may be negatively related to their schooling outcomes (Shapiro and Tambashe, 2001;

Case et al., 2004; Ainsworth et al., 2005; Nyamukapa and Gregson, 2005). Nonetheless, younger children are also exposed to significant levels of illness and death in their households. Preschool children are more likely than older children to be non-orphans living with orphan children in the household. They are also as likely as older children to be living with an HIV-positive household member. Indeed, while most preschoolers are living with at least one parent, at least a quarter of these parents are HIV-positive. In the absence of widespread treatment, the presence of an HIV-positive parent or adult in a child's household foreshadows that child's exposure to illness and death in the future.

Despite the pervasiveness of adult illness and death in children's lives in Lesotho, the children we interviewed spoke infrequently about HIV or AIDS. Given their age range (7-14 years), most experienced little risk of contracting HIV/AIDS themselves. However, the children did not express worry about HIV affecting their parents or other relatives, either. Their interviews emphasized typical routine childhood activities such as going to school, playing, and doing chores. Their silence regarding HIV likely reflects ongoing stigma surrounding the disease. It may also reflect a sense that resource scarcity more immediately shapes their everyday experiences of childhood. Nonetheless, the poverty that touches their lives on a daily basis is likely exacerbated by the epidemic around them. For example, the specific material constraints children spoke of may increase in intensity as the amount of adult illness and death in their networks increases.[10] This suggests the continuing relevance of programs that support school attendance and provide basic nutrition for all children in need.

The situation of children in Lesotho is likely similar to children in the other southern African countries of Botswana, Namibia, South Africa and Swaziland, where HIV prevalence

[10] Along these lines, caretakers of orphans in rural Kenya cited schooling and food as the main problems of the orphans in their care (Nyambedha et al. 2003).

rates are also high—estimated in 2005 at 24, 20, 19, and 33% respectively (UNAIDS 2006). However, differences in treatment availability, and community, national, and external sources of support suggest that the situation of children may vary significantly within the region. For example, in Botswana, an estimated 85% of HIV infected adults received ART treatment in 2005, compared to only 14% in Lesotho, 21% in South Africa, 31% in Swaziland and 35% in Namibia (UNAIDS 2006). Higher treatment levels indicate that fewer children will experience the illness or death of an important adult in their social network. Differences in historical and cultural context, living arrangement patterns, and child rearing practices would also be expected to influence the consequences of the HIV epidemic on children's lives (Madhavan 2004; Oleke et al. 2005).

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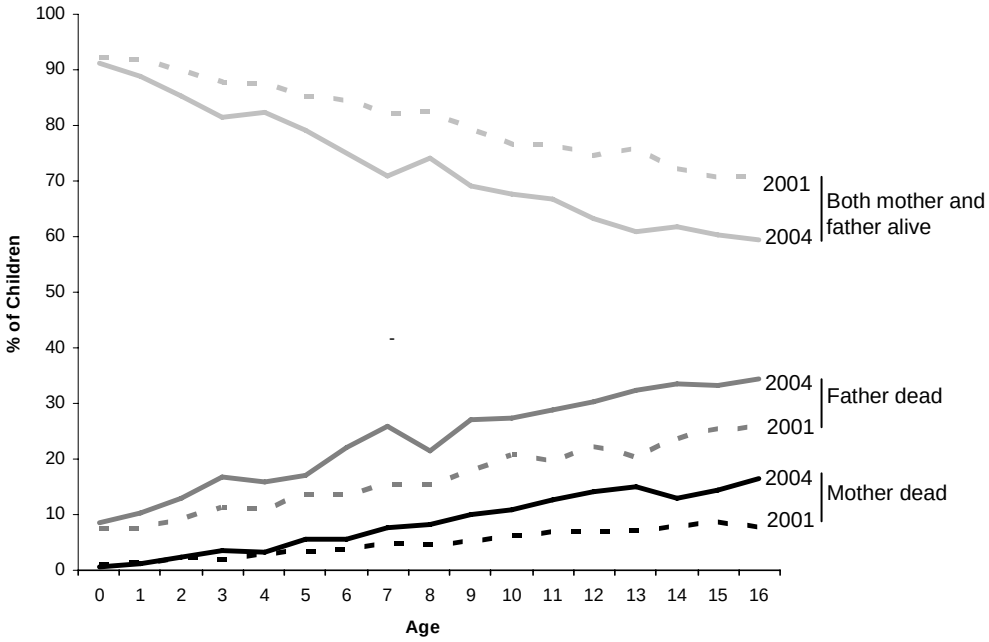
Figures and Tables

Figure 1. Orphan Status of Children 0-16 in Lesotho by Age, 2001 and 2004



Sources: 2001 Lesotho Demographic Survey; n=31,167
2004 Lesotho DHS; n=15,116

Figure 2. Children's Household Experience by Child Age, Child Orphan Status, and Orphan Composition of the Household

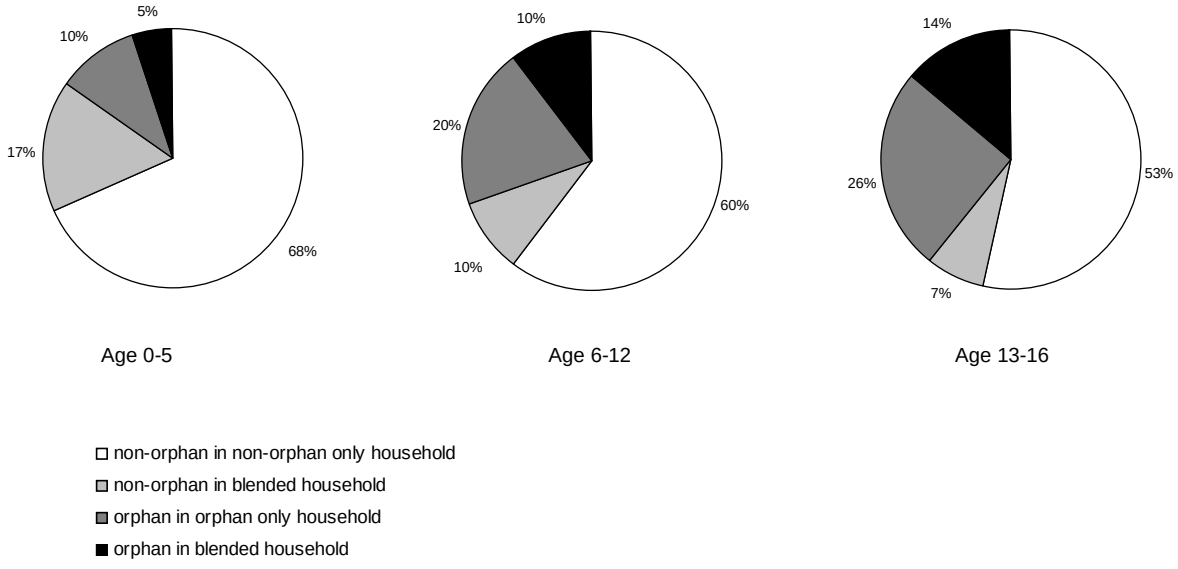
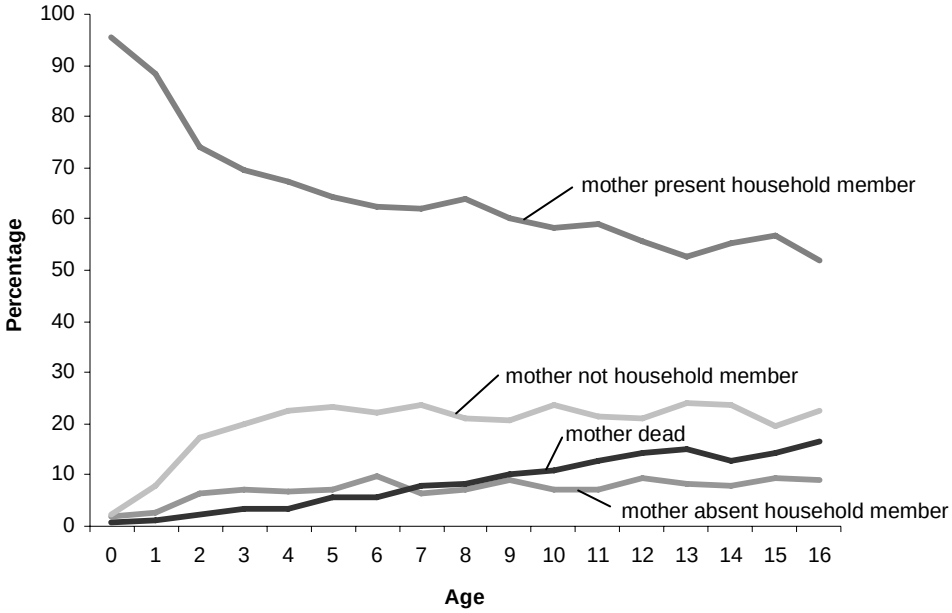
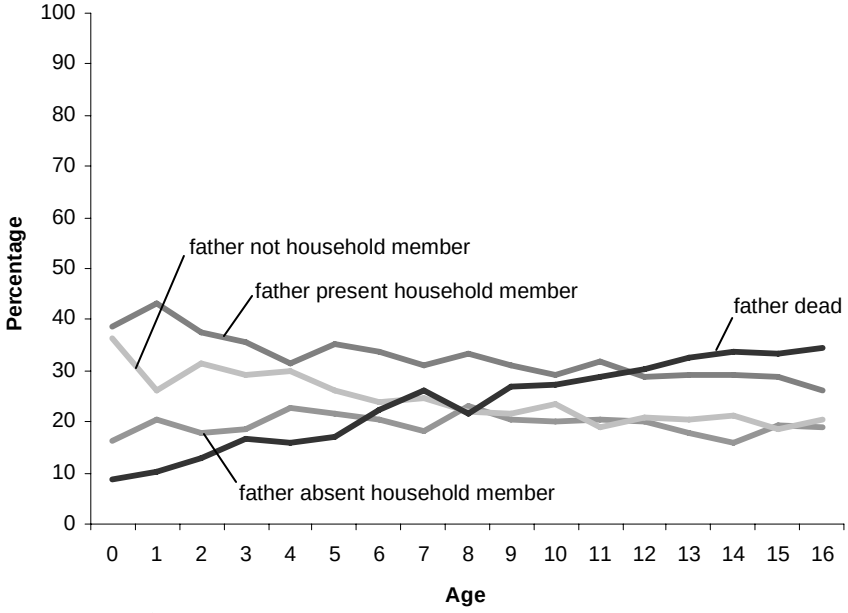


Figure 3. **Mother** Presence and Household Affiliation for Children 0-16 in Lesotho by Age, 2004



n=15,116
Source: 2004 Lesotho DHS

Figure 4. **Father** Presence and Household Affiliation for Children 0-16 in Lesotho by Age, 2004



n=15,116
Source: 2004 Lesotho DHS

Figure 5. Combined Mother and Father Presence among Children 0-16 in Lesotho by Age, 2004

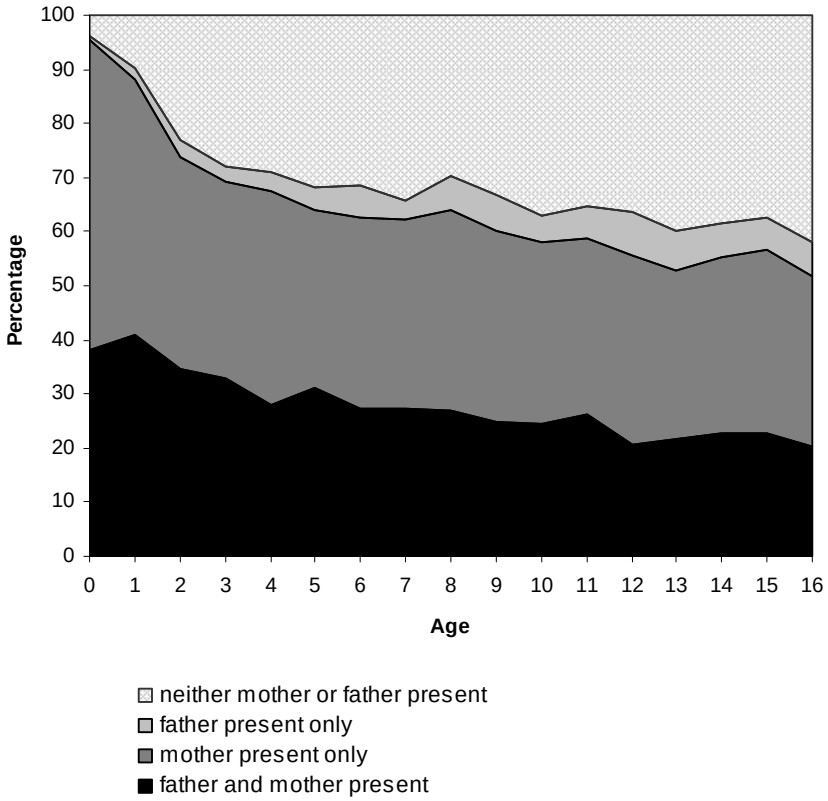


Figure 6. Presence of Relatives in Household among Children 0-16 Not Living with Parents in Lesotho by Age, 2004

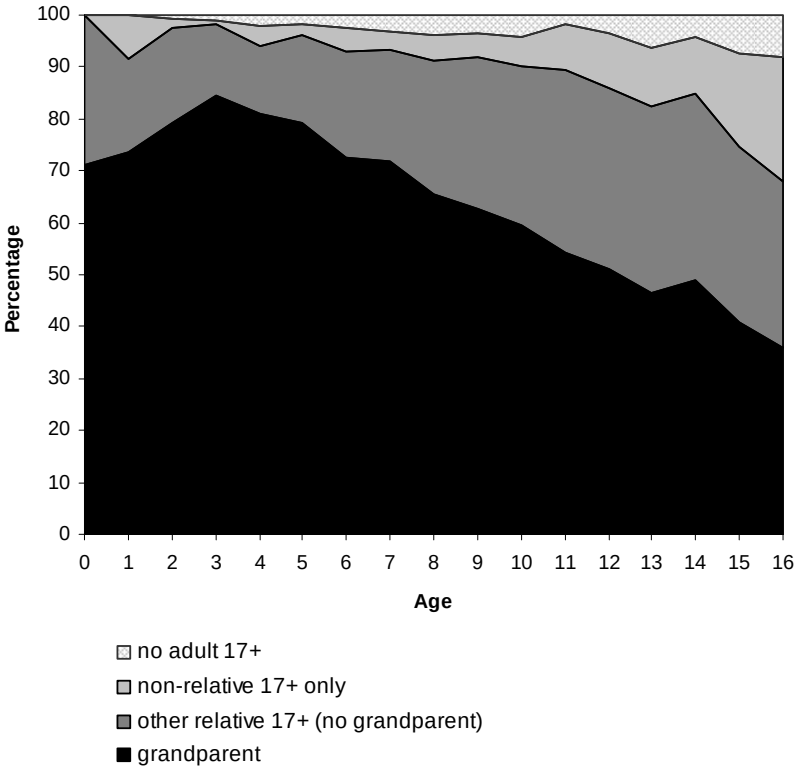


Table 1. Characteristics of All Focal Children and Interviewed Children

	all focal children (n=73)	interviewed focal children[1] (n=35)
Parent Status		
Mother present	42	17
Mother absent but affiliated w/child	17	5
Mother absent not affiliated w/child	7	8
Mother dead	6	4
Mother status unknown	1	1
Father present	21	9
Father absent but affiliated w/child	21	6
Father absent not affiliated w/child	20	11
Father dead	5	5
Father status unknown	6	4
Child Age		
Mean age	7	11
Child Sex		
Male	34	13
Female	39	22
Caregiver Type		
Mother	38	16
Father	4	2
Maternal Grandmother	13	7
Paternal Grandmother	5	2
Maternal Grandfather	1	0
Aunt	6	4
Other Relative	5	3
Non Relative	1	1
Household Location		
Main village (more urban)	39	21
Cluster of villages (more rural)	34	14
Household SES		
Low[2]	43	21
Medium	15	7
Medium/High	7	3
High	8	4

[1]Interviewed children are a subset of the focal children, including all children old enough to be interviewed (age 7-14). In five cases a sibling of the primary focal child was interviewed. In one case a co-resident cousin was interviewed.

[2]All households in the cluster of villages (more rural location) had low SES.

Source: Lesotho Children's Project 2003-2004

Table 2. HIV Prevalence among Parents and Adult Household Members 17+ of Children 0-16 in Lesotho, 2004

	Child Age		
	0-5	6-12	13-16
	%	%	%
% children living with mothers	78	63	55
% children living with mothers who are eligible for HIV testing[1]	99	90	78
% children living with mothers who had blood taken[2]	85	83	81
% children living with HIV+ mothers[3]	**25**	**30**	**27**
% children living with fathers	38	30	27
% children living with fathers who are eligible for HIV testing[1]	96	90	81
% children living with fathers who had blood taken[2]	69	67	66
% children living with HIV+ fathers[3]	**28**	**29**	**21**
% children living with adult 17+ eligible for HIV testing	94	89	86
% living with adult 17+ who had blood taken[2]	89	87	84
% living with HIV+ adult 17+[3]	**35**	**36**	**35**

[1] Of children living with mother/father.

[2] Of children living with mother/father/adult 17+ who was eligible for HIV testing.

[3] Of children living with mother/father/adult 17+ who had a successful blood test result.

Sample: Children 0-16 in households selected for HIV testing.

Note: Men 15-59 and women 15-49 in selected households were eligible for testing. Only those age 17+ are included as adults. Weighted by household weight.

Source: 2004 Lesotho DHS.