# An Integrated Literature Review of the Impact of Parental HIV/AIDS Deaths

on African Children and Families

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A project presented to the faculty at

University of North Carolina at Chapel Hill

In fulfillment of the requirements for

Undergraduate Honors.

Date Completed: July 27, 2007.

Honors Advisor Approval:

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#### Abstract

There are 14 million children in Africa who have lost one or both parents to HIV/AIDS. By the year 2010, African children orphaned by AIDS will number 25 million, accounting for 25% of all children in some nations. These children experience negative social forces such as discrimination and stigma, even in their own families. Economic forces, including property grabbing, may leave them impoverished and unable to afford an education. The child's grief response may be hindered by a misunderstanding of childhood grief as well as the difficulty of the environment in which the child must try to grieve. This paper is an integrated literature review regarding the social and economic impact of HIV/AIDS parental bereavement on children and their families and how this environment affects the grief response of children. The literature shows that AIDS-bereaved children are vulnerable to behavioral and psychological problems including depression as children and adults. While some economic and psychosocial interventions exist to combat this negative impact, more programs and more research are needed.

An Integrated Literature Review of the Impact of Parental HIV/AIDS Deaths
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For twenty-five years, HIV/AIDS has spread across the globe and now infects 40 million people worldwide. Despite efforts to bring attention and resources to the HIV/AIDS crisis, the number of people living with and dying from HIV/AIDS continues to rise (Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Children's Fund (UNICEF), and the United States Agency for International Development, 2002). In Africa 2.1 million people died of AIDS in 2006, most of whom left behind children (UNAIDS et al., 2002; World Bank, 2002). Currently there are 14 million African children orphaned by HIV/AIDS. That number will rise to 20 million in 2010 accounting for up to 25% of the children in some nations (UNICEF, 2003).

This paper is an integrated literature review of the impact on African children of HIV/AIDS-related parental bereavement. These children experience negative social forces such as discrimination and stigma, even in their own families. Economic forces, including property grabbing, may leave them impoverished and unable to afford an education. In accordance with cumulative risk research, this paper argues that this adverse socioeconomic effect puts the child at risk for behavioral and psychological problems, both as children and adults (Appleyard, Egeland, Van Dulmen, & Sroufe, 2004). Worden's (1996) tasks of childhood grief provide the framework to examine how these negative forces as well as cultural views on childhood grief may lead to complicated grief and future problems for these vulnerable children

The ultimate goal of this endeavor is to provide an evidence-based foundation for the design of community-based interventions to aid parentally bereaved children in Cameroon. The Republic of Cameroon is a Central African nation of 18 million residents. Five percent of Cameroonian adults are infected with HIV/AIDS and the prevalence is as high as 9 percent in some regions (UNAIDS & World Health Organization (WHO), 2006, p. 28). In 2003 (the last year of available data) there were 240,000 HIV/AIDS orphans in Cameroon, up over 70% from 2001 (United Nations Common Database, 2007) and the numbers are expected to continue to rise. A Cameroonian community palliative care nurse who works with people dying of AIDS wants to expand the scope of his program to include bereavement services to help the children and their families deal with their grief. It is hoped that this research will aid in future and ongoing interventions.

#### **Definition of Terms**

Throughout this paper the terms "orphan" and "adoption" are used. In keeping with the vast majority of the literature reviewed, "orphans" includes children younger than 15 who have lost one or both parents (Foster, 2000, UNAIDS, 2003). "Double orphan" refers to a child under fifteen years old who has lost both parents (UNICEF et al., 2003).

The term "adoption" refers to the taking in of these children into new households with new guardians. The practice of adoption in sub-Saharan Africa differs from adoption practiced in the United States. In Africa, children are almost always adopted by a relative. A close family friend or neighbor may also adopt a child who loses his parents. Rarely is a child adopted by strangers. When a family adopts a child, formal

papers of adoption are rarely filed. The adoption arrangement is not necessarily final as children often move to the home of another relative several times before reaching adulthood and independence. As such, the system may be called "fostering" instead of adoption. This paper uses the terms interchangeably as does most of the literature reviewed.

#### Method

The research method was to conduct and analyze a literature review of the impact on African children and families of HIV/AIDS associated parental bereavement. The first search was conducted using CINAHL and ISI Web of Science. The search terms "AIDS" and "orphans" were used in CINAHL. ISI Web of Knowledge was searched using the terms "psychosocial distress, children, AIDS." The cited references of pertinent articles were also included in the review when they were electronically accessible. This search included all articles added to the database before June 2007 and after 1999.

The second search was conducted using CINAHL and employed the terms "child" and "bereavement" as well as "child" and "complicated grief. Literature added to the database before June 2007 and after 2002 were included and relevant references were included when relevant and accessible. Anecdotal literature regarding interventions to help these children as well as research on interventions and their effect was included.

Overall, articles published earlier than 1999 were only included when they present a relevant point that is not contradicted or does not exist in more current literature or to inform general concepts. The focus was on research conducted in sub-Saharan Africa except where research in Africa was lacking or to inform general concepts such as

the grief process of children. The literature on children who are themselves infected with HIV/AIDS was not included as this research is sparse, complicated, and outside the scope of this paper.

## **Findings**

The literature was read, synthesized, and organized conceptually into three major sections: social impact, economic impact, and impact on the grief response.

## Social Impact

The Extended Family Safety Net

Traditionally in sub-Saharan Africa, the extended family cares for all of the children. In fact, in some African languages, there is no word for aunt or uncle (Foster, 2000; Monash & Boerma, 2004). Instead aunts are "junior" or "senior mothers" and uncles are "junior" or "senior fathers," depending upon their age in relation to the parent (Chirwa, 2002; Foster, 2000; Mann, 2004; Monasch & Boerma, 2004). In rural areas, three or four generations of an entire extended family may live on contiguous, inherited, ancestral lands. Their neighbors are more distant relatives that make up the clan. The clan and family cooperate to achieve social and economic stability in times of prosperity and poverty (Foster, 2000; Monasch & Boerma, 2004). When a woman marries, her husband pays a bride wealth to her family, and she effectively becomes part of the family and clan of her husband. She leaves her family and joins them on their clan land (Nyambedha, Wandibba, & Aagaard-Hansen, 2002).

When children of the family lose their parents, the extended family, and particularly the siblings of the deceased, are expected to care for the bereaved children.

Most African cultures are patrilineal in which case the siblings of the father care for the

6

children. More rarely, cultures are matrilineal and the mother's siblings are responsible for care (Mann, 2004; Mendenhall, 2007). Currently, over 90% of double orphans are cared for within extended families (Ainsworth, Beegle, & Koda, 2005; Bicego, Rutstein, & Johnson, 2003; Monasch & Boerma, 2004). Foster relationships within extended families consist of complex and reciprocal relationships of care. Children are cared for in homes of relatives and may travel between several homes. They may receive financial and emotional support from a variety of family members over great geographical distances, particularly if the family is spread out in urban centers rather than living on ancestral land (Abebe & Asase, 2007; Ayieko, 2000; Foster & Williamson, 2000).

With the advent of the AIDS epidemic and rise in the number of orphans, in addition to other ongoing forces such as poverty, urbanization, and westernization, there has been much debate about whether or not the extended family is able to continue to absorb and care for these children (Abebe & Asase, 2007; Ayieko, 2000; Chirwa, 2002; Foster, 2000; George, Oudenhoven, & Wazir, 2003; Nyambedha et al., 2002; UNICEF, 2003). With paternal aunts and uncles unable, unwilling, or unavailable to take on this role, the most likely caregiver of an orphaned child is now a grandmother (Ainsworth et al., 2005; Ayieko, 2000; UNICEF, 2003). Unfortunately, in countries made up largely of subsistence farmers and day laborers, the elderly grandparents are unlikely to have economic resources, retirement savings, or pensions (Ayieko, 2000).

The maternal side of the family may care for children when paternal relatives are not available. Traditionally in patrilineal societies, allowing maternal relatives to care for orphaned children was considered shameful. However, with the high demand for care of orphans, some paternal relatives have had to let maternal relatives care for these

children. In some situations, no one is able or willing to care for the children. In these cases the children may become domestic works or live together in child-headed households. Child-headed households may receive some support from relatives. Other children may migrate to cities to live with relatives, work in the informal sector, beg, or work in the sex trade (Ayieko, 2000; Evans, 2005; Foster, 2000; Nyambedha et al., 2002; Oleke, Blystad, & Rekdal, 2005; UNICEF, 2003).

## Exclusion and Stigma

Even when extended family networks care for children, they may be shunned and discriminated against, creating an adverse situation (Abebe & Asase, 2007; Cluver & Gardner, 2007; Family Health International (FHI), 2003; Mann, 2004). Adopted children often claim that aunts, uncles and step-parents favor their biological children over the adopted children, making the adopted children work too hard, acting unfairly mean to the child, withholding the best food, and forcing the child to stay home from school (Cluver & Gardner, 2007; Horizons Project, 2003; Mann, 2004; Strode & Grant, 2001; UNAIDS, 2001). They may also tell the child, "This is not your home," or, "if you want new things, you will have to go to the cemetery and ask your own parents" (UNAIDS, 2001). The reports of these children are corroborated by other adults in the child's life such as teachers and social workers (Cluver & Gardner, 2007).

This maltreatment can be very detrimental to a child. Of the adverse events that can lead a child to psychological and emotional stress, parental maltreatment seems to have an especially deleterious effect, putting the child at risk for psychological and behavioral problems (Appleyard et al., 2004; Cicchetti & Toth, 2000).

Other children are cast out of the family entirely. This may occur because the children are thought to be cursed or infected (Ayieko, 2000). Even before the child's mother dies, he may be cast out from the family upon his father's death, particularly if his mother refused to be "inherited." Traditionally, the brother of the deceased had the right and duty to marry his brother's widow, giving him the responsibility of caring for and feeding her and the children. If the man is already married, she may still become his wife in many polygamous tribes (Mendenhall, 2007; Nyambedha et al., 2002; Oleke et al., 2005). Sometimes, the brother says he will not marry her but still "cleanses" her by having sex with her. If she refuses either marriage or sex, she and her children may be shunned by the clan and forced from their home and land (Luginaah, Elkins, Maticka-Tyndale, Landry, & Mathui, 2005).

Besides familial discrimination, children may also be discriminated against in wider society. They may be gossiped about, ignored and excluded, or have derogatory terms shouted at them (Cluver & Gardner, 2007). They may many not be allowed to play with other children and may be banned from the home of some relatives (Strode & Grant, 2001). Children may think of themselves as unwanted or cursed and their parents may be considered sinners for contracting the disease. (Ayieko, 2000; Chirwa, 2002; Strode & Grant, 2001). Other factors that can lead to ridicule include an inability to maintain clean, intact clothes and a clean habitus (Cluver & Gardner, 2007). Children must deal with this adverse social impact while also suffering economically.

Economic Impact

*Impoverishment* 

Extended families who experience a parental bereavement due to HIV/AIDS are at great risk of impoverishment. Even before the HIV/AIDS infection, the family was probably poor as impoverished families are disproportionately infected (Oni, Obi, Okorie, Thabede, & Jordan, 2002). As the parent becomes sicker, the family begins to sell off assets in order to afford medical care as well as the parent's unemployment. By the time the parent dies and is buried, the family may have sold off most or all of its means of production and may have gone into debt. Other family members may have quit their jobs or left school in order to care for the sick, further depleting resources. Surviving children must be cared for but there may be no inheritance or insurance from which to support them (Ayieko, 2000; Foster, 2002; Oni et al., 2002; UNAIDS, 2001). The household that receives the children are likely to be headed by poor, single or widowed, older women (Andrews, Skinner, & Zuma, 2006; Nyamukapa, Foster, & Gregson, 2003; Oni et al., 2002; Orner, 2002; UNICEF, 2003), each of which are risk factors for extreme poverty (Nyamukapa et al., 2003). Up to half of the parent(s) who foster these children may be infected with HIV, leading to high medical bills, missed work, and further orphaning of the child (Horizons Project, 2003). Furthermore, these new children may represent the second or third time that this household has had to take in foster children. As would be expected, after the arrival of the newest children, the foster household is even more likely to become food insecure and adults may have to curtail other community and family responsibilities (Bhargava, 2005; Miller, Gruskin, Subramanian, Rajaraman, Heymann, 2006, 2006; Schroeder & Nichola, 2006) as new children to care for means less time to work, more mouths to feed, more childcare to

secure, more medical costs, and more homework help needed (Heymann, Earle, Rajaraman, Miller, & Bogen, 2007; Luginaah et al., 2005).

This impoverishment combined with social impacts or orphanhood are evident in the health of these children. Orphaned children are more likely to become HIV-infected than their non-orphan counterparts (Gregson et al., 2005; Mann, 2004). Furthermore, while in some places children orphaned by AIDS may not be more likely to be stunted or malnourished (Crampin et al., 2003), in other places they are at greater risk. They are more likely to have diarrheal or respiratory illnesses, stunting, and malnutrition. When controlling for poverty, the children are still more likely to have diarrheal illnesses, chronic malnutrition, and lack of medical treatment than their non-orphan counterparts (Watts et al., 2007). In fact, orphaned children have a higher mortality at two years old, even when controlling for HIV infection (Masmas et al., 2004). It seems that a complicated combination of social and economic impacts put these children at greater health risk.

# Property Grabbing

While many extended families try to care for the bereaved children as best they can, other extended families fail to act in the financial interest of the children. Upon the death of the child's father, whether or not the wife agrees to be "inherited" or "cleansed" she and her children may be denied access to family land and resources. If the mother also dies, the children may have no one to defend them. The extended family may seize the property and other material possessions, leaving the woman and her children destitute and landless, a practice called "property grabbing" documented in various African nations. If both parents die, the in-laws may take the land and home from the children

and cast the children off the land, abdicating their traditional duties (Nyambedha et al., 2002; Mendenhall, 2007). Many, if not all, modern African nations have laws against property grabbing, protecting the right of the widow and/or children to inherit property with or without a will. However, property grabbing still occurs as these laws often remain unknown and unenforced (Chirwa, 2002; Mendenhall, 2007).

Even if the widow and children are given access to land, they may not be able to inherit money. When a pension or savings account is left, it may be very difficult for the widow and/or children to access. Because many Africans consider it taboo to talk about an impending death, financial arrangements and a written will are usually not made (Ayieko, 2000; Horizons Project, 2003; Mendenhall, 2007; Oleke, Blystad, Flykesnes, Tumwine, 2007). Other barriers include their low level of education, their inability to hire a lawyer, lack of awareness about inheritance laws, and the corruption of the financial and government sectors. Moreover, the couple may have had only a common law marriage with no official marriage certificate creating a further barrier to their claims (Ayieko, 2000).

Children who lose both parents may face further difficulties inheriting property. They may not know where the money is kept, who is going to care for them, where the family land is (as clan land may be divided up in a patchwork manner), and how to run the family business or farm. If the woman or children try to legally regain the land, they may not be able to prove that her husband owned the land as they may never have held a deed or certificate to the property (Ayieko, 2000).

Education

The child may also face economic difficulties surrounding his education. When a parent falls sick with AIDS complications, the child may have to leave school. His withdrawal avoids education-associated costs in order to afford increased medical expenses. His presence at home allows him to care for an ailing parent and contribute economically (Oni, Obi, Okorie, Thabede, & Jordan, 2002). Once one or both parent dies, the child may be withdrawn from school permanently (Ainsworth et al., 2005; Case & Ardington, 2006) as orphans are enrolled in school at lower rates than non-orphans (Andrews et al., 2006; Bhargava, 2005). In fact, some African adults and children take it as a given that if your parents die before you complete school, you must leave school and do housework, find odd jobs, accomplish agricultural and informal work, or care for sick, young, or old family members. (Abebe & Asase, 2007; Ayieko, 2000; Bhargava, 2005; Foster, 2000; Mann, 2004; Robson, 2004; Robson, Ansell, Huber, Gould & van Blerk, 2006; UNAIDS, 2001). These chores may be new and difficult for the child (Nyambedha et al., 2002; UNAIDS, 2001). Other orphaned children are loaned out as domestic workers in exchange for money paid to the family (Foster, 2000; FHI, 2003; UNAIDS, 2001). While some families force their new charges to work, other families have no other option because they cannot afford the school fees and uniforms for all of the children in which case they must choose whom to send to school (Abebe & Asase, 2007, Ainsworth et al., 2005; Ansell & Young, 2004; Aspaas, 1999; Ayieko, 2000; FHI, 2003; Nyamukapa et al., 2003; Nyamukapa & Gregson, 2005; Rotheram-Borus, Lee, Lin, Lester, 2004; UNICEF, 2003).

Their lack of enrollment in school causes psychological distress as children often associate school with the possibility of being able to care for themselves and their

siblings as they enter adulthood (Cluver & Gardner, 2007). Their absence from school also eliminates an important source of psychosocial support. African children who lose parents to HIV/AIDS cite "hanging out with friends" as a way for them to cope with their grief (FHI, 2003; Horizons Project, 2005; UNAIDS, 2001). The children are also removed from teachers and other caring adults, in whom they report being able to confide (Cluver & Gardner, 2007; Foster, 2002). They may also be separated from their siblings into separate adoptive households (Townsend & Dawes, 2004). Finally, their presence in the workforce may also make them feel different from other children and alone—they do not have time to "be a child" or play with friends (Cluver & Gardner, 2007; Nyamukapa et al., 2002; UNAIDS, 2001).

Even when orphaned children are enrolled in school, they are not necessarily able to take advantage of their enrollment. Bereaved African children are less likely to do their homework, study, or read, because of chores at home, engaging in economic activities before or after school and lack of lighting after dark. They are also more likely to not have food to eat before or during school, to go to bed hungry, and are sometimes forced into transactional sex in order to pay school fees. When they do attend school they were less alert, less focused on their studies, non-assertive, and un-involved in activities (Nyambedha et al., 2002; Oleke et al., 2007). Their preoccupation with their hunger, their history of abuse, and the problems they face at home may isolate them from their peers and harm them emotionally (Cluver & Gardner, 2007; Dowdney, 2000). Their inability to be successful in school can lead them to feel hopeless for the future (Cluver & Gardner, 2007; Horizons Project, 2003).

Impact on the Child's Grief Response

While normal grief reactions differ from child to child in relation to culture, experience, religion, personality, and stage of development, all children grieve (Boyd-Franklin, Steiner, & Boland, 1995). Besides the loss of the parent, they may also be grieving the loss of their home and land, their potential separation from their siblings, and the loss of the future they expected to have. Normal childhood grief response includes sadness, fear, depression, anger, frustration, fear, guilt, and somatic complaints such as stomach aches and headaches. Some children seem to regress in development for a time. Transitional objects such as a blanket or doll, imaginary friends, or fantasies that the person is still alive are also normal parts of childhood grief (Kirwin & Hamrin, 2005).

For some children, their grief response becomes complicated. Almost half of all children experienced complicated grief emotional disturbances one year after the death of a parent, and emotional disturbances for up to two years (Black, 1992; Dowdney, Wilson, Maughan, Allerton, Schofield, & Skuse, 1999). Symptoms can include overwhelming guilt, depression, suicidal ideation, anxiety, post-traumatic stress disorder, hallucinations an severe psychomotor retardation. As adults they may experience depression and other mental health issues (APA, 2000; Dowdney, 2000; Fombonne, Wostear, Cooper, Harrington, & Rutter, 2001; Kirwin & Hamrin, 2005; McClatchey & Vonk, 2005; UNAIDS et al., 2002).

To avoid the risk of complicated grief and sequale, children must successfully accomplish several tasks of grief. Worden's (1996) framework includes six tasks that

build on each other. Children who complete these tasks of grief successfully are said to have a normal grief response and are at less risk of mental health problems.

The primary task of childhood grief is to understand the death through receiving adequate, accurate, age-appropriate, and clear information (Baker, 1992, Worden, 1996). Phrases that may be confusing such as "She went to sleep," should be avoided (Bernes, 2004). Young children in particular may have difficulty understanding the concept of death. Without information, children tend to fill the gaps in knowledge for themselves. This "magical thinking" may lead them to imagine horrible ideas about the death that may be worse than the reality (Baker, 1992; Worden, 1996). While trying to understand and accept the death, children may keep some emotional distance between themselves and the emotions surrounding the loss to lessen the blow (Baker, 1992; Bernes, 2004). They may be sad or may be seen playing happily and seem to understand the death at one point, and then later ask when the deceased parent will be returning. These responses are normal and children should be supported throughout the process (Baker, 1992). Without this first task, the child will be unable to accomplish any of the other tasks of grieving and will experience complicated grief and a potential for future psychological and emotional problems (Baker, 1992).

For parentally bereaved children in Africa, these tasks may be very difficult. In many cases, children are shielded from the parental death and ensuing mourning.

Despite the fact that a child may have nursed his parent throughout her illness, he may not be allowed to visit her in the hospital when she is dying (FHI, 2003). Often, the child may not attend the funeral and may be sent to stay with a relative or friend far away while the adults mourn. When the child returns, he may be told that the parent is gone,

but will return later. This leaves the child sad and wondering why his parents have not returned. However, the child may find out about his parents' death in a more traumatic way without a loving caregiver to explain what happened, answer questions, and comfort the child (FHI, 2003; UNAIDS, 2001).

Despite this lack of communication, African children usually express a desire to have an adult talk to them honestly about the situation (FHI, 2003; Mann, 2004; UNAIDS et al., 2002; Wood, Chase, Aggleton, 2006). Talking about the death allows the child to confirm what he is feeling and ask questions in a safe environment (Horizons Project, 2003; Wood et al., 2006).

The second task it to have their fears and anxieties addressed. Children may fear their own death or the death of the remaining caregiver or parent. The remaining parent or caregiver should assure the child that they will take care of the child and are not sick. The child should also be reassured that he is healthy and very unlikely to die (Baker, 1992; Worden, 1996). However, African AIDS-bereaved children and their families may not have this luxury. If one parent dies of AIDS, the other parent has a high probability of also dying of AIDS, making these children double orphans, a very vulnerable group (UNICEF, 2003). Those who are willing to adopt these children are more likely to be HIV-infected themselves (Horizons Project, 2003). with the weakening of the extended family system, property grabbing, and poverty, fears of vulnerability may be well-grounded. Without the knowledge that they will have enough money for the basics of life such as food, shelter, and clothing, children's grief may become complicated. They may focus on how things were when they had parents and not be able to finish processing their grief. (Worden, 1996). One way to deal with this problem

may be to develop a detailed succession plan before the parent's death. Those who are asked to care for a child before the parent's death are more likely to adopt the child (Horizons Project, 2003; Mendenhall, 2007).

The third task is to realize that they are not to blame for the death of their parent. Children may believe that they caused the death through thinking bad thoughts or misbehaving and may feel very guilty for years (Baker, 1992; FHI, 2003; Worden, 1996). Anecdotes of children who believe that they directly caused the death of their parent can be found in both the American and African literature (see for example FHI, 2003 and Carney, 2003). Telling the child the cause of death, or at least explaining that the child is not at fault would be more helpful.

The fourth task is being listened to and understood. Adults should listen to these children and ask them about their fears and worries. For example, a child may be worried about what happened to the body after death and may need age-appropriate information (Worden, 1996). However, if caregivers do not know that the child is worried about this, they will not be able to address these worries. Through talking, asking the children to draw pictures, playing games, reading and discussing storybooks that deal with death and other therapeutic techniques, adults can understand children's feelings and take note of and correct any misinformation that the child believes (Baker,1992; Bernes, 2004; Carney, 2004; Worden, 1996). This communication also helps address the aforementioned tasks of grief such as realizing they are not to blame.

The fifth and sixth task are to have their feelings validated and to deal with their overwhelming feelings of sadness, guilt, anger, anxiety, and loss. They will need the help of caregivers around them to do this. They should not feel alone and isolated.

Assurance of the normalcy of their emotions may relieve the child's fears and anxiety (Baker, 1992; Worden, 1996). During this task they may be able to resolve anger at the perceived abandonment of the parent as they secure their own identity and begin to establish new relationships with the people in their lives (Baker, 1992). Their relationship with the deceased will be consolidated and reestablished in a new way. They will focus on the memory of the parent and perhaps use a transitional object or piece of memorabilia to consolidate the memory. They may also view their parent as "watching over" them (Carney, 04).

#### Conclusion

AIDS-bereaved children must deal with a web of social and economic forces impacting their ability to survive and flourish. Cumulative risk research has established that the combination of several risk factors, such as child maltreatment, neglect, family disruption, poverty, , low social status, large family size, foster placement, low maternal education, single parenthood, and stressful live events can lead children to behavioral problems in adolescence and put the child's future position in society at risk. Each added factor multiplies the chance of negative outcome (Appleyard et al., 2004; Haine, Wolchik, Sandler, Millsap, & Ayers, 2006; Jones, Forehand, Brody, & Armistead, 2002; Rutter, 1979; Sameroff, 2000).

The fact that these children are still grieving when they have to face these adverse social and economic forces only complicated matters. African bereaved children report feeling guilty, sad, worried, stressed, lonely, isolated, depressed, angry, anxious and overwhelmed (Atwine, Cantor-Graae, Bajunirwe, 2005; Horizons Project, 2005). They are more likely than their non-bereaved counterparts to view themselves as friendless,

have difficulty concentration, have nightmares, and display symptoms of post-traumatic stress disorder (Culver, 2003). They may believe that they are cursed (Ayieko, 2000). In Dar es Saalam, thirty-four percent of children orphaned by AIDS reported suicidal ideation within the last year (Makame, Ani, & Grantham-McGregor, 2002).

It is important to note that while all bereaved children display some type of grief, boys and girls may present differently. Girls are more likely to internalize their feelings and have somatic complaints such as headaches and stomach aches and to be socially maladjusted (Bhargava, 2005; Horizons Project, 2005; Makame et al., 2002) while boys are more likely to externalize their feelings and behave poorly (Ayieko, 2000). This difference holds true across cultures and cause of parental death (Reinherz, Giaconia, Carmola-Hauf, Wasserman, & Silverman, 1999). This may be due to the fact that they have taken the loss of the parent hard, have greater home responsibilities and less opportunity for schooling or are more likely to reveal these feelings to researchers (Bhargava, 2005).

Interventions and Programs to Help Children orphaned by HIV/AIDS

Given the complexity of the difficulty that these children face and the variety of contexts and cultures in which they live, different types of interventions and programs exist. They include socioeconomic and psychological support. Some programs also try to impact the culture by seeking to change inheritance and succession practices.

Economic Support

Some interventions support children by providing economic means to extended families. One approach is micro-enterprise. These small business loans have proven an effective means of aiding families and orphans throughout the world, including

sub-Saharan Africa and in families affected by AIDS and caring for orphans (Parker, & Singh, & Hattel, 2000; Sherer, Bronson, Teter, & Wykoff, 2004; Snodgrass & Sebstad, 2002). Usually, these programs create groups of about 20 women who are guided in their business endeavors. One or more of them are given a small loan of about \$100 at a low interest rate. Once they pay it back, another woman from the group is given the loan. Program staff provide technical support. The woman also help each other and hold each other accountable to repay the loan since the next woman cannot receive the loan until the other person pays it back. Interest paid back is used to fund staff. These programs have shown high rates of return of money, usually higher than 95% and provided economic increase in families and communities without further infusion of money (Sherer et al., 2004; Snodgrass et al., 2002). While these programs are sometimes only financial, other programs include health education or other services (Sherer et al., 2004).

Other than micro-entrprise, approaches vary. Some have called for government subsidies to families caring for foster children or free education for all children (Bhargava & Bigombe, 2003). Others rely on financial support from NGO's (Abebe & Asase, 2007) or loans for vocational programs (Bhargava & Bigombe, 2003). Some programs provide food, schooling, income-generating activities, micro-loans, and widow support (Beard, 2005). By supporting widows and/or orphans and their extended families, the children will be provided for. There is clear evidence that despite some abusive extended families, for the most part, when families have more money, they use it to feed, clothe, and educate the children of the home (Ainsworth et al., 2005; Bhargava, 2005).

Children express a strong preference to live with relatives that are emotionally supportive even if they are poorer than other relatives. This usually means that they are choosing to live with a poor grandmother over a financially stable aunt and uncle. Enabling grandmothers and others to afford schooling and other needs may allow children to live in the home that is most responsive to their emotional needs (Ansell & Young, 2004; Mann, 2004).

Children overwhelming agreed that paying their school fees is the best way to help them (FHI, 2003). School fees are also cited by foster parents as the most pressing unmet need (UNICEF, 2003)

Community Capacity Building

Community-based care is often preferred by Africans and is thought to be the most culturally appropriate way to care for children as it keeps them in their clan and village (Beard, 2005). Charities and government agencies or helpful community members may step in to organize community support for children. This support may include orphan committees who are made aware of orphaned children in the community, volunteers to visit child-headed households, and community and school gardens to grow food and teach agricultural skills (Chirwa, 2002; Kidman et al., 2007; White, 2002). Day care programs and helpful neighbors may also allow adoptive parents to work or care for sick family members. Some programs include counseling.

Allowing more access to education can also help children have hope for the future. Radio-based schools, free primary education, and inexpensive or free private, community schools, may help more children obtain an education. Remedial school for

those who had to leave school earlier may also be beneficial (Beard, 2005; Gilborn, 2002).

The community can also be aided by training caring adults, such as teachers and nurses, to recognize children with complicated grief who need intervention (Auman, 2007; Pillay & Lockhart, 1997; Wood et al., 2006). In some places, community-based interventions like these are already reaching thousands of orphaned children (Foster, 2002).

## Psychosocial Interventions

Despite the great need for mental health services, it is largely unavailable in these resource-poor settings (Atwine, et al., 2005; Foster, 2002). Nevertheless, some psychosocial interventions exist. These include counseling, leadership opportunities, self-discovery, trust-building activities, support groups, recreation, and bonding with other orphaned children. This programming may also incorporate meals, therapeutic play, therapeutic art, and mutual support. The goal is to help children build self-efficacy and interpersonal skills while working through their guilt and grief. Such interventions can help orphans accomplish the tasks of grief (UNAIDS, 2001).

Psychosocial support programs may help children accomplish their grief tasks and discover an improved sense of identity and purpose. Furthermore, preliminary research also suggests that these programs provide increased self-confidence and coping skills (Atwine et al., 2005; Horizons Project, 2005, UNAIDS, 2001, Wood et al., 2006). In fact, support groups were found to be associated with positive self-concept, (Atwine at al., 2005). Addressing these needs may help limit future emotional problems (UNAIDS, 2001).

Using children's storybooks is another intervention that has been used in both Africa and the United States. (Bernes, 2004; Corney, 2004; UNAIDS, 2001). can deal directly with stories of grief at the loss of a parent or grandparent, or they can be more general stories to generate conversation about sickness, feeling sad, feeling alone, etc. These books help children learn more about death, dying, and grieving. They are used as an optional component of support groups as well as in one-on-one therapeutic interactions with a child. A skilled adult can be trained to use the stories to help validate and normalize a child's grief reaction, support constructive coping strategies, reinforce creativity and problem solving, and decrease any feelings of isolation (Bernes, 2004). The characters, story, and situation of the story can allow the child to understand and process what happened in the story and to share feelings and reactions to the book through identifying with the characters, releasing pent-up emotions within a safe environment, and developing insight into his grief response. An adult can ask the child (or children) questions like, "The child thinks it is his fault that his mother died. Do you ever feel like that?" "What will happen to the characters next?" or "Are you like any of the characters?" (Bernes, 2004; UNAIDS, 2001). Talking about the book can also be a safe way for the child to discuss his emotions while keeping a safe distance from his own grief (Bernes, 2004). Activity books, such as workbooks and coloring books, can also be helpful. In these books the therapeutic questions are already written in the book (Carney, 2004).

Another new practice that may help orphaned and soon to be orphaned children are memory boxes. Memory boxes were introduced by the National Community of Women Living with AIDS in Kampala, Uganda. These memory boxes serve as a

reminder of the parent and of the child's life when the parent was living. The memory box is constructed by the family while the parent is still alive. It includes an interview with the parent either as a tape recording or written transcript. It also includes family photographs and may also include other memorabilia such as a cloth worn by the parent (Denis & Makiwane, 2003). Instead of using a box, a memory book may be written. Pages include "Family Tree," "Information About your Father," and "Family Traditions and Special Events" (UNAIDS, 2001). Besides serving as a tool for remembering after the parent dies, the creation of the memory box creates a space and opportunity for the parent to talk to the child about the parent's life, sickness, and eventual death and to allow the child to ask questions. Parents may use this time to disclose their HIV status to their children and to make plans for the children's future (Denis & Makiwane, 2003; UNAIDS, 2001).

These memory boxes may be particularly important to children who are victims of property grabbing or who face a distant migration to be placed with relatives. Children who lose (or never had) pictures of their parents or lose all of their parents' possessions and their childhood home may express worry over forgetting their parents. They may also be saddened by forgetting what their parents looked like. Children and parents who make memory boxes report that they are aided by the experience (FHI, 2003).

Memories are important to a grieving child because they allow the child to maintain a feeling of connectedness with the deceased parent. The preparation of the box allows for a time of intense bonding and reminiscing, solidifying the child's attachment to and memory of the parent. Memorializing rituals, discussing contact with other family members, and sharing stories allow the child to identify with the good

characteristics of the parent and solidify the parent-child bond that will help the child remember and cherish their lost parent (Bernes, 2004; Saldinger & Cain, 2004). These interventions may be especially important when a parent dies from AIDS as the other parent is at a high risk of also dying. Once both parents die, the children may not have other adults that help them to maintain their memories of their parent. When preparing a memory box is not possible or the parent finds the process to painful, children often assign other objects, such as a gift from the parent, as a memory object that connects them to their lost parent (Saldinger & Cain, 2004)

## Changing Inheritance Practices & Culture

## Succession Planning

Because some cultural inheritance practices can be detrimental to widows and orphans as discussed above, some programs try to change these practices. Succession planning is when a parent or guardian plans what will happen to the parent's children and property upon his death. Succession planning programs can be a difficult and technical endeavor that demands a high level of technical expertise to implement. Interventions include writing wills to protect the children from property grabbing relatives and determining a future guardian for the children. Legal aid may also be provided when wills and laws are ignored. Besides being a practical help, the process of planning for this succession may lead the parent to disclose their HIV status and health condition to their children, allowing their children to accept the disease, ask questions, and discuss what will happen to the child after the parent dies. This may help avoid some traumatic experiences later (Wood, et al., 2006; Horizons Project, 2003; UNAIDS, 2001).

Will writing is central to succession planning. However, written wills are not a traditional aspect of society in many African cultures. Wills are often thought to be bad luck and hasten death. If someone speaks of his imminent death, he may be accused of being involved in sorcery. Because of these influences, most parents do not write wills. When someone dies without a written will, law usually dictates that a child or spouse inherit at least some of the property and money. However, these laws are often unknown and un-enforced. Small-scale projects have shown that with encouragement and education parents have been willing to write wills which can allow for the protection of their children and widow. Unfortunately, even when a family has a written will, this property may still taken by relatives leaving the intended heirs impoverished. Increasing awareness of laws and providing legal aid to children may help decrease the vulnerability and poverty of these orphans (Horizons Project, 2003; Mendenahll, 2007). Succession planning may be implemented as part of a support group, women's club, or in conjunction with bereavement services associated with end-of-life care (UNAIDS, 2001; Horizons Project, 2003). These programs may be able to help children feel that they will be loved and cared for after their parent dies. As such, it may help children process and move past their grief.

## Non-kin Adoption & Orphanages

With the increasing stress on the extended family, some are looking to western-style, non-kin adoption to support orphaned children. While non-kin adoptive parents are rare, there is some evidence that the practice is increasing. In urban areas, where relatives may live far away and rarely visit, non-kin adoption is more prevalent (Foster & Williamson, 2000; Miller et al., 2006). Non-relatives who foster children are

usually socially close to the deceased parents. They are also likely to have been asked to be the guardian before the death of the parent (Howard et al., 2006; Horizons Project, 2005; Abebe & Asase, 2007), yet parents still rarely name a guardian before their deaths (Ayieko, 2000; Horizons Project, 2003).

Part of the reason that non-kin adoption does not have widespread support, is that the way adoption is practiced in many parts of Africa may be bad for children. Children who are adopted by non-relatives are the least likely children to be enrolled in school (Case, Paxson, & Ableidinger, 2002). They may live as maids, nannies, or farmhands in their adoptive home (Nyambedha et al., 2002).

Western-style adoption in which a non-relative adopts an orphaned child and then raises that child as she would raise her own child, is still—rare in Africa. Resistance to the idea of adoption within these nations and even stronger resistance to the idea of these children being adopted into homes in other nations is one barrier (Freeman & Nkomo, 2006). Despite the increased conversation about the possibility of international adoption, many are still against it and consider it to be culturally inappropriate (see for example Roby & Shaw, 2006).

Orphanages or other institutional care for children are considered to be only a last resort. While little quantitative evidence exists on institutional care for African children, most practitioners agree that institutional care is not good for children and that children should remain in community and family settings, even if that sometimes mean that the children live alone in a child-headed household (UNAIDS, 2004). Authors cite the cost of institutional care, lack of individual attention, and cultural inappropriateness (UNAIDS, 2004).

#### Discussion

#### Limitations

There are several limitations to this research. The first is that the researcher does not read French and therefore could not include research written in this language.

Because large parts of Africa (and in particular Cameroon) are Francophone, this limits the potential body of literature. Second, this paper looked at general impacts on children throughout sub-Saharan Africa and included research from many different nations.

However, Africa is a very large and extremely diverse place. In Cameroon alone there are 200 different people groups and languages. Each people group may have very different cultural perceptions of childhood grief and very different inheritance and child care practices. This paper painted a general picture of some of the impacts on these children. This impact is not uniform across families, people groups, or nations.

Similarly, there may be specific issues within certain nations or people groups that are overlooked in the literature. Finally, much of the research included on the grief response of children was specific to children in industrialized nations and focused mainly on children who lost one parent.

## The Need for Further Research

While there is abundant research examining the economic and social problems that orphaned African children face, the research into their psychological needs and grief response is limited. Despite these difficulties, small-scale community-based interventions have been shown to mitigate children's risk. However, good empirical studies into social and economic interventions and their effectiveness is limited. Robust studies on psychosocial interventions and their outcomes are nonexistent. Instead, most

research into psychosocial programming merely describes programs already in place and cites only anecdotal evidence.

There is even less research regarding the grief response or psychological stress that make these children particularly vulnerable to psychological and behavioral problems. Most of the literature that does exist regarding children bereaved by HIV/AIDS deals only with the grief of children in the United States or other industrialized countries (see for example Boyd-Franklin, Steiner, & Boland, 1995 and Rotheram-Borus et al., 2004) despite the large and ever growing number of children orphaned by HIV/AIDS in Africa.

While Western literature can be used to inform general concepts related to childhood grief, it fails to take into account the realities of AIDS in Sub-Saharan Africa. Africa also has more poorly developed welfare systems and safety nets leaving these children little psychosocial support.

And while both industrialized and developing countries report stigma (Mizota, Ozawa, Yamazaki, Inoue, 2005). even the stigma is different since in industrialized nations AIDS is often associated with injecting drug users and homosexuality while in Africa, AIDS is generally associated with extramarital sex (Mizota, Ozawa, Yamazaki, & Inoue 2005; UNAIDS, 2001).

Furthermore, most of the research into children's grief and resulting psychological distress focused on surviving parents as opposed to surviving aunts, uncles, grandmothers, and other potential foster parents. While it is unclear how much the literature is directly relevant and more research is needed.

Recommended Interventions for the Republic of Cameroon

Several interventions may prove helpful in the palliative care program in Cameroon mentioned above. First, before the death of the parent succession planning and memory box workshops should be offered to each family. Making the memory box can help the child and parent bond. It can also create a space for the child to ask questions about his parents and her impending death. Succession planning and will writing can help ensure that the child finds a caregiver. These early interventions may help prevent abandonment.

Once a new caregiver is established, nurses at the palliative care program could talk to the caregivers, either informally or in workshops, about childhood grief response. This sensitization may prevent maltreatment of the child and may give the guardian tools to help the child overcome emotional and psychological problems associated with complicated grief.

Counseling and support groups may also be a successful intervention. Nurses at the palliative care center can be trained to run support groups for children and their families who come into contact with the palliative care services. Once a support group has met and been established, nurses may be able to train volunteers to start another support group. While some volunteers may be adults who have lost a spouse, older children whose parents have died may also become support group leaders. This would allow the support group to be self-replicating and may provide important leadership skills to the spouse or child.

Family and community-based programs may help parentally bereaved children.

Social interventions can help decrease the risk of abandonment. Economic support can

help the child stay in school and stay healthy. Supporting children and families in their grief response can contribute to strong families and well-adjusted children.

# Acknowledgments

The author wishes to acknowledge, George Mbeng, a nurse in Cameroon who has developed a palliative care program for those dying of HIV/AIDS. His current plan, to establish a bereavement service, was the impetus to write this paper. It is hoped that this review of the relevant literature regarding children who are orphaned as a result of the HIV/AIDS epidemic in Africa will be useful to inform and guide the development of bereavement services for HIV/AIDS orphans and their families. She also wishes to thank Dr. Margaret Miles for her invaluable help in preparing this paper.

Finally, she would like to acknowledge and thank her wonderful husband, Eric Stortz, without whose help and encouragement she never would have finished this paper.

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