HIV and AIDS: the impact on the mental health of children & caregivers:
In what ways can the scientific mind and new mindsets improve the response to this neglected aspect of the pandemic?

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Introduction

The purpose of this paper is to increase the attention of scientific minds ---researchers, policy makers and program designers---to improve the response to the mental health needs of millions of children worldwide, affected by HIV and AIDS. The children I refer to are themselves HIV-negative, but their lives have been forever changed by the AIDS epidemic due to the illness of their caregivers and the ultimate loss of one or both parents, as well as teachers or other important persons in their lives who die of the disease. The mental health and survival of these children is affected by the mental health of their caregivers, who, if depressed, are less able to provide the emotional bonding and stimulation so necessary for a child’s development. Because these children are orphans, they are often further isolated through stigma and discrimination. Poverty, displacement from family and community and trauma from emotional, physical, and sexual abuse can all exacerbate the impact on their mental health.

The sheer magnitude of the numbers of young people who are affected by HIV/AIDS is almost too staggering to comprehend. An estimated 14 million children living today have lost one or both parents to AIDS. Eighty percent, or 11 million of these children, live in Sub-Saharan Africa (WHO). Other regions of the world have seen great losses as well. There are an estimated 1.8 million children who have lost at least one parent to AIDS living in South and Southeast Asia (WHO).

The numbers, each of which represents a heartrending story, are growing (WHO). Epidemiologists project that 44 million children in the 34 hardest hit countries will have lost parents to AIDS by 2010 (USAID). Some estimate that in the next 25 years, up to 20% of the children under 15 in Sub-Saharan Africa (SSA) will have lost a parent, as compared with 2% before the epidemic (World Bank).
Over the past two decades, the predominant mindsets that have responded to the epidemic have been based on the sciences of:

- public health and social science—understanding the patterns of the disease and methods for prevention;
- medicine and pharmacology---striving to find methods of testing and treatment;
- economics—analyzing the impact on human and social capital and the implications for economic development and failure of specific industries;
- education, communications and the social sciences---through designing prevention strategies; and
- basic enumeration and shelter for orphans and vulnerable children—counting the number affected and finding ways to provide for basic survival: shelter, food, and adequate caregivers.

The material needs of children orphaned by AIDS are so great that sometimes these obscure or delay realization of the tremendous mental health and psychological needs of these children, even by those who care about them most. For example, HIV-positive parents interviewed for a study in Uganda mainly expressed concern about their children’s future economic situation. Only 10% reported they were worried about their children’s emotional well-being.” (World Bank). Yet inadequate attention to the mental health and psycho-social needs of the children and caregivers can contribute to failure of every other response. Children who are depressed, listless, angry, or despairing are less likely to thrive in other aspects of life. The health and mental health of ill or depressed caregivers, unable to provide basic nurturing and stimulation, can have a profound impact on children’s developing brains—their cognitive, emotional, and social development. The mindset for funding and conducting research on policy and program design in the mental health and psycho-social arena has been under-developed and even neglected in the global response to HIV and AIDS.

Concentrating on those children who are HIV-negative, but profoundly affected by HIV and AIDS through the chronic illness or loss of parents or other significant caregivers, this paper: 1) reviews the major mental health and other factors affecting these children; 2) discusses strategies for coping with loss and grief and to foster resiliency and protection; and 3) suggests areas to consider for future advocacy, research and practice.
Changing Life Circumstances of Children Orphaned by AIDS

“It was hard to stay with my uncle as he was a cruel man. He had many children and he favored them when we shared food and gifts and I was overlooked like a slave. The other children didn’t do any work, just me.

---Mpando, (quoted in Ansell & Young)

Children orphaned by AIDS face an increase in poverty, malnutrition, household responsibility and vulnerability to abuse, child labor, sexual risk, stigma and isolation. Moreover, studies show that they have less access than other children to food, health services, school opportunities, material goods, protection and love.

Losing a parent to AIDS diminishes the child’s position in the family. Traditionally, the death of the father deprives children of income and male authority; the death of the mother deprives the child of emotional and mental security. If the child is taken into the extended family, he or she can be in a weak and tenuous position due to scarce resources and the primary position of existing offspring. Orphans can lose their inheritance or suffer malnutrition in a family already struggling to feed its own members.

Children orphaned by AIDS in SSA tend to be marginalized in the school environment, and they often drop out. A school headmaster quoted in one study observed, “You can tell the orphans: their clothes are worn out, they are dirty, and their hair is not combed” (Foster & Makufa). Some students leave because of stigma and discrimination, others because they cannot pay the fees. Still others leave because they must become caregivers or breadwinners. According to a study in Kenya, 52% of children orphaned by AIDS were not in school, compared to 2% of children in the rest of the population. In Mozambique, only 24 % of children whose parents had died were attending school compared to 68% of those with parents still living. (Brown et al.). Staying in school is one means children may have to overcome their persistent poverty. Even for those who remain in school, school performance studies provide some indication of the debilitating impact of grief and depression on young people’s ability to carry out normal school tasks (World Youth Report).
The physical needs, emotional deprivation and financial desperation of children orphaned by AIDS make them easy prey for exploitation and abuse. They often live on the street, where they are used as cheap labor by day and as sex workers by night. This deadly pattern exposes them to HIV and AIDS, thereby repeating the cycle (Hunter & Williamson).

Mental Health and Psycho-Social Issues of Children Orphaned by AIDS

The mental health and psycho-social issues of children whose parents have died of AIDS tend to be under-examined and under-treated in light of demands for basic survival. Yet HIV and AIDS affect children’s mental health in many ways. Children’s psychological vulnerability begins long before the death of a parent. One of the single most important factors in children’s mental health is the mental health of their parents. Unsurprisingly, depression is very common among mothers who have HIV and AIDS; one study found a 38% prevalence rate of depression among infected mothers (Baingana et al.).

Most research to date on the psycho-social effects of parental AIDS and death on children has been conducted in Zimbabwe, Uganda, Zambia, Kenya, and Tanzania (Mailutha & Belfer). Studies have identified significantly higher rates of depression, anxiety, survivor guilt, loneliness, isolation, low self-esteem, and disruptive, antisocial high-risk behaviors among children orphaned by AIDS compared to other children. Other researchers have noted a general emotional imbalance in children orphaned by AIDS, marked by anxiety, depression, and grief (World Bank).

For many of these children, the trauma from the death of a parent recurs and the risk to mental health may be additive. Children “become parentless multiple times” because their caregivers keep dying of the disease. Other beloved figures get sick and die. In Malawi and Zambia, for instance, up to 30% of teachers are infected with HIV (Acklin).

Few studies have yet captured the complicated ways in which children are affected by losing parents and other important adults in their lives to AIDS. Orphan hood is “compounded and buffered by numbers of pathways,” according to Isolde Birdthistle.
Descriptive studies do not measure how common are the psycho-social patterns identified or whether the documented reactions are specifically attributable to losing a parent to AIDS or to the many other risk factors these children face.

Some comparative research of psycho-social problems has been conducted. In Uganda, researchers investigated the nature of emotional problems of school-sponsored orphans. In comparing the feelings of children orphaned by AIDS to feelings of non-orphans, investigators found that non-orphans showed more optimism: they expected to live longer and they imagined themselves staying in school, working, and wanting children. The children orphaned by AIDS were significantly less able to envision a future (Sengendo & Namib).

A study in Tanzania found “substantial evidence of reduced well-being, with most orphans showing psychological impairment.” Orphans were three times more likely than non-orphans to contemplate suicide. The researchers also found that orphans, and particularly female orphans, had more internalizing problems than non-orphans. These problems included depression, anxiety and low self-esteem (Makeme et al.). Yet few studies have been conducted that identify what differs in the grief process when the death is AIDS-associated and whether the research on bereavement can be generalized to AIDS (Siegel & Gorey). And little is known about children’s perceptions of death and loss, and how they interpret the scale and never-ending prevalence of the pandemic that surrounds them, as opposed to living through a one-time event of poignant loss.

**Effects on Neurobiological Development**

Children who lack a secure attachment because of the depression, unavailability or death of a parent or caregiver live in chronic stress, which can weaken the immune system. Moreover, the absence of a loving and attentive caregiver has been shown to alter the development of the brain. Depressed mothers often cannot respond to their children with emotional nurturing and stimulation. According to Sue Gerhardt, author of *Why Love Matters*, “after nearly four decades of research into the cellular and molecular bases of brain development, there is one unassailable conclusion: the developing child’s
environment plays a large role in shaping his or her brain circuitry and subsequent behavioral performance.” Current neurobiology suggests that children are most vulnerable to adversity when their brains are most plastic and developing most rapidly.

At birth, an infant’s primitive emotional reactions are already organized by parts of the brain, primarily the almond-shaped amygdala. The prefrontal cortex, which plays a major role in directing and modifying people’s more primitive reactions like anger or fear, develops during the first 18 months of life. The development of this part of the prefrontal cortex, which relates to thought, language, reasoning and perception, is not automatic; it is dependent upon the child’s environment and it develops only in response to experiences the child has with other people. Positive interactions-- smiles, games, especially touch-- generate connections in the prefrontal cortex, which help to manage the more impulsive reactions of the amygdala. In simplest terms, the pre-frontal cortex helps to calibrate our emotional lives. When developed positively, it enables us to develop deep human relationships, to think and to feel.

Inadequate development of this part of the brain, on the other hand, causes many of human beings’ ills: anxiety, depression, and other forms of mental illness. Lack of stimulation and neglect can short-circuit developing connections within the brain and decrease its size. Too much stress in the absence of a calming, soothing parental figure hinders the child from developing a biological mechanism to regulate his feelings. The classic studies of Harlow in the 1950’s so clearly demonstrated the needs of primates and infants for contact comfort and its soothing effect. Gerhardt concludes, “Our earliest experiences are not simply laid down as memories or influences; they are translated into precise physiological patterns of response in the brain that then set the neurological rules for how we deal with our feelings and those of other people for the rest of our lives” (Gerhardt).

What are the implications of this science for how care is provided for millions of young children, whose parents may be ill or dead, in their most formative years?
Strategies to Promote Resiliency and Coping

For adults and caregivers

The scale of the epidemic and the cultural and economic context in resource-poor countries demand new and bold strategies, different from Western clinical models. New strategies, which can be delivered to vast numbers of people through existing systems (schools, clinics, religious institutions) and by ‘trained’ peer lay persons, are needed. Community and voluntary supplementary support can provide basic contact comfort and stimulation for children when ill or depressed mothers are unable to do so. In addition, the research underscores other important strategies, such as: pre-planning for the child’s care while the parent is still alive; involving the orphans themselves in moves toward a solution; and, whenever possible, having the child remain with the surviving family or extended family in the community. Other strategies address ways to handle migration that can reduce stress and maximize the effectiveness of relocation, if necessary.

Given the critical care giving role of parents and grandparents, who may also be grieving the loss of their adult child(ren), more strategies are needed to address these adult family members’ grief and depression. The clinic or community setting, where parents seek testing and care, as well as workplaces or village gathering sites provide potential locales for addressing caregivers’ own mental health to mitigate the impact on the child. Strengthening the counseling component for loss and depression to equip parents with the comfort and skills to talk with their children about their illness or impending death could begin a supportive grieving process for the child. Parents need skills and support to disclose their status and prepare their children.

There are not enough trained professionals to provide the emotional support needed by children orphaned by AIDS. Much more use must be made of peer, lay groups for group counseling and support. A randomized control trial with adults in Uganda, for example, showed that group interpersonal therapy was highly efficacious in reducing and dysfunction in adult men and women (Bolton et al.). A new mindset is needed, which
moves beyond the narrow sphere of using credentialed professionals to one that respects the abilities of lay people to provide counseling and support.

A few studies suggest that the condition of living in poverty is the major factor in depression, more so than illness. Attending to the economic and basic survival needs, along with emotional and mental health, may be beneficial. Studies of orphan support models in Zambia and Uganda conclude that economically empowering guardians is a more effective strategy than just reaching out to the orphaned children. If caregivers are to be trained in income-generating activities, participant guardians with potential economic abilities can be selected for training, while those who lack these skills can be assigned specific duties within their capacity in an integrated orphan management program (Ayieko).

For children who are HIV negative

Knowing how children conceptualize their experience should help guide strategies to communicate with them. What can be learned from the literature about how children understand death and handle grief? Research indicates that children have at least a shadowy conception of death by age 3. Representations of grief in children under 3 include crying, regressive behaviors, excessive fear, and clinging. From ages 3-5, children realize death occurs, but they may imagine it as reversible and partial. Indeed, they fear separation from others more than they fear death. Sometime between ages 6 and 10, children realize that death is both final and universal (Mailutha & Belfer).

Many parents dying of AIDS choose not to talk about their illness and impending death because they fear harming their children. Some parents report that trying to decide whether or not to disclose their HIV diagnosis to their children is as emotionally charged as learning of the diagnosis itself (Wiener). In Shona culture in Zimbabwe, children are kept from participating in funerals. Nevertheless, they are aware of what is happening, but lack the skills to understand it (Foster & Makufa). “Children are fantastic observers but poor interpreters,” according to Karimi Mailutha and Myron L. Belfer. In the absence of clear communication about the losses they are experiencing, children construct their
own meaning of the terrible things happening in their lives. They often blame themselves, especially if they tend to lose one parent, one caregiver, one teacher after another.

Talking about AIDS and death can help both children and their parents. One study investigated the reactions of parents who chose to disclose their HIV status to their children and those who did not because of fear their children would be psychologically harmed. The study showed that those parents who chose not to reveal their illness were more depressed than those who did. None of the parents who spoke honestly with their children about their disease and inevitable death regretted having done so (Wiener). Talking about the disease can also encourage parents to plan for their children’s future care. Research in Kenya showed that only 3.7% of parents infected with HIV currently had such a plan (Hunter). Children seem to fare better, even considering the wide variation in cultural behaviors around death, when the truth is presented honestly to them. Researchers in Kenya reported that when caregivers told children their parents had died instead of that they “went to church,” the children’s night terrors waned (Ready to Learn).

Low-cost strategies can be implemented to help children deal with their depression and grief. For instance, journal writing, creating storyboards, art therapy and expressive drama have been shown to help children cope with depression, stress and trauma in circumstances where resources are scarce and long-term psychological counseling is unavailable. Volunteers, using locally available materials, can put such programs in place and sustain them (Ready to Learn).

The Memory Book Project, developed in the United Kingdom and first used in Uganda, has been used in several areas of SSA for parents and children to deal with AIDS and death. Parents are encouraged to create books that include pictures and descriptions of family history, thoughts, feelings, and messages for the future. Creating and passing on Memory Books helps parents prepare for their deaths and reassures children that their parents and families love them (Baingana).
Teachers and health workers can be trained to provide support and counseling for children of parents who are ill or dying from AIDS. Teachers can learn to recognize children who need special support, to encourage interactions between orphans and other students, and to use activities like art and storytelling, encouraging children to express their emotions. For example, a new regional campaign launched by EDC’s Health and Human Development Programs and UNESCO Caribbean encourages leaders in the education sector to help counter the impact of HIV and AIDS (Vince Whitman). The approach encompasses policies to reduce stigma and discrimination, teacher training, steps toward a healthy physical and psycho-social school environment, and counseling services. This initiative calls on the education sector to move beyond its traditional focus on academics and to plan such strategies for the growing number of children and families affected by AIDS in that region.

Other strategies are known to strengthen the psycho-social response of children orphaned by AIDS. Some of these concern children’s placement after the death of their parent(s). Research has shown that orphans experience less trauma if they are cared for by members of their extended family. Informal, non-institutional care by a member of the extended family is overwhelmingly preferable to institutional care. This finding appears to be true across cultures. In most African countries, families do not cease to exist when parents die, as most people live in communities of extended families in rural areas. A study of children orphaned by AIDS in Thailand posits that the extended family may be even more important in Southeast Asia than in SSA and suggests that the grandmother is an especially critical family member to serve as her orphaned grandchild’s caregiver (Safman).

A study of resiliency factors among 8-10 year old children from Zimbabwe concluded that six traits seem to be linked to resiliency in children orphaned by AIDS: 1) a willingness to accept surrogate caregivers, 2) an open definition of family, 3) a developmental age consistent with or greater than chronological age, 4) interpersonal relationships based on reality, 5) positive perception of home life and family life relations, and 6) a perception of warmth and nurturance and the stability from the overall
environment (Williams). Considering these six factors is important for designing programs that help children cope with losses due to AIDS.

Attending to the mental health needs of children and all caregivers –parents, grandparents, extended family and surrogates -- should start at the earliest possible intervention point, diagnosis of the disease in the child’s parent. Joining the scientific mindsets of clinical medicine even more intensively with psychiatry, psychology, counseling, and faith-based spiritual support can enable programs to assess and minimize the impact on caregivers and children early in the process.

**Highlights of Important Initiatives that Address Children’s Mental Health**

A few examples follow of current efforts recognized for addressing the psycho-social needs of children orphaned by AIDS. The *Regional Psychosocial Support Initiative for Children Affected by AIDS* (REPSSI) is an initiative of the Salvation Army in Switzerland, Terre des Hommes, the Southern African AIDS Training Program, and the International HIV and AIDS Alliance. The initiative is intended to build resilience in children as well as in their caregivers and the community. REPSSI has worked to provide 250,000 children with psychosocial support during the past 5 years (at [www.repssi.org](http://www.repssi.org)).

*The Uganda Women’s Effort to Save Orphans* (UWSO) is a nonprofit, interdenominational development agency to improve the quality of life of needy orphans by empowering local communities to meet children’s needs in a sustainable manner. More than 15,000 women across Uganda have stepped forward to help foster orphans, monitor the situation of orphans in the villages, and lobby for orphan support, protection, and advancement (at [www.uweso.com](http://www.uweso.com)).

*The Families, Orphans, Children Under Stress* (FOCUS) program through the Family AIDS Caring Trust in Mutare, Zimbabwe, covers the domain of psycho-social effects of AIDS on children. Program planners advocate for donor support of community-based initiatives that are cost-effective (Mailutha & Belfer).
Future Directions to Consider

Advocacy and Policy

• Physical and mental health are inextricably linked. AIDS advocacy must address the important role of mental health, heretofore neglected. Policy makers and program planners must elevate attention to this link and consider ways to strengthen the mental health component. On a January 2005 trip to a township in Cape Town, Doctors without Borders and community grassroots organizations noted how the availability of antiretroviral drugs gave hope and motivation to parents. Though no empirical studies had yet been conducted of the impact of treatment on prevention, it was the providers’ observation that the treatment and therefore hope for survival improved so people’s quality of life that it improved prevention and protection.

• At a recent international AIDS conference, sponsored by The University of the West Indies in Barbados, a 16-year old girl from Miami, who had been HIV positive since birth, participated on a panel of Persons Living with HIV and AIDS. For the first time, she publicly disclosed her status before an audience of 300 people. She also admitted that she had stopped taking her medication. Her physician, present in the audience, felt compelled to comment that to resume her treatment, the young woman needed to find some purpose to her life. Clearly, this sixteen year-old was depressed and discouraged. Even when treatment may be available, the scientific mind must deal with emotional health to ensure that a person is motivated to comply with the treatment regimen and that the treatment’s potential is truly realized. But who will be the advocates for greater attention to the mental health component -- the persons living with AIDS, the mental health professionals, the counselors, the religious community, or the children themselves?

• To date only a small portion of global AIDS funding has been allocated to address the psycho-social needs of children orphaned by AIDS. The increasing numbers of infants, children and youth, whose lives are forever changed by loss, call for a
multi sectoral response from government agencies. At present 39% of countries have no policy for providing support to children orphaned by AIDS and fewer than 5% of these children receive any publicly funded services (UNAIDS). Policies guiding the response to children who are affected must elevate the importance of resources for the mental health component.

Research and Practice

- The impact on a child of the parent’s chronic illness from AIDS and death needs greater understanding. What are children’s perceptions of loss and death from HIV and AIDS as compared to deaths from other causes? How does AIDS prevalence in the community affect children? What can the mental health and social science disciplines contribute to our understanding of how to strengthen a coping response and provide interventions to reach masses of people at critical developmental stages? What are the mental health needs of the ill parent, and how can interventions mitigate the depth of their own depression and sadness to enhance care giving and planning for their children?

- How do the scientific minds of the medical, psychiatric, psychology, counseling and religious communities and the systems in which they work view the mental health and psycho-social component? What will it take for various systems to develop a shared mindset that envisions ways to cooperate in meeting the mental health needs of children affected by AIDS?

- What can various systems really do? For those orphans who can continue schooling, what coping mechanisms, supported through life skills or other bereavement and group support sessions, can be valuable? In systems already besieged, how can the school as a community and teachers respond to the needs of staff, parents and the children in their care?

- Coping is not only an individual but a community issue. With so many people affected, what types of interventions can make a difference at the community level?
• Prospective, longitudinal studies are needed to assess children’s psycho-social strategies at various stages and to investigate if and how short-term distress leads to long-term outcomes (Wild) and what might be critical stages for intervention?
• Research should be conducted to identify protective factors that facilitate resilience. How can findings from such work as the Zambia resilience study be translated into the design of interventions? Research should address the impact of HIV and AIDS on psycho-social life of children in different contexts—e.g., urban vs. rural and in different countries.

Key to intervening with the children who are affected by HIV and AIDS is locating and identifying them. The World Bank proposes several strategies: tracing orphans who have migrated and who have left their original caregivers, and sampling broader populations, including children who are institutionalized, who live on the street, and who live in households headed by adolescents.

The psycho-social needs and mental health of children is an area in need of greater attention. By placing a higher priority on these advocacy, policy and research questions, the field can move toward strengthening the response to the circumstances of these children at many levels. Addressing the psycho-social impact of HIV and AIDS on children—even in the context of the many other problems and risks—can ultimately reduce the severity of the epidemic and promote the stability of families and communities. The scientific mindset allows us to apply the joint perspectives of our various disciplines to find solutions to complex problems. Few other problems on earth are more worthy of our attention.
References


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Education Development Center, Inc (EDC) is an international non-governmental organization with headquarters in Boston, MA, USA, and offices in more than 25 countries worldwide. EDC applies research and education strategies to address societal challenges in health, education and social justice. With close to 1000 staff, (550 in the U.S and 400 worldwide), EDC carries out work in such fields as early childhood, special education, math, science and technology, adult literacy, youth employment and health promotion and disease prevention.

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