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AIDS and Trauma:
Adults, Children and Orphans

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1. Introduction

Though HIV/AIDS has become more of a chronically-managed illness in the most well-off of places, it is still a devastating disease that spreads rapidly and silently. Biomedical and behavioral research conducted over the last 25 years has taught us a tremendous amount about HIV: the people it infects, the way it infects and the damage it reaps. While some of this research is headline news, particularly those discoveries that lead us closer to a vaccine or other biomedical prophylaxis like microbicides, and to a lesser extent behavioral research that teaches us about effective prevention efforts, what are infrequently discussed but are no less important are the very substantial effects that trauma has on those infected and affected by HIV. We have found that there are higher rates of past and current trauma in adults infected by HIV than in the general population and subsequently these adults often have higher rates of substance abuse and other high risk activities. In children orphaned and otherwise affected by AIDS, we see they suffer not just the loss of a parent, but also significant emotional wounds that require specific treatments to heal. HIV is more than a virus; it is a disease that exploits already present vulnerabilities like poverty and goes on to wreak havoc on all levels of society. In this chapter, we will talk about trauma and its relationship to HIV in both adults and children. We will use fictitious case studies starting in childhood and moving through adulthood to explicate the complicated life stories, specifically the significant role trauma plays in the lives of people who are affected by HIV.

1.1 Orphans and culture and how AIDS has changed orphanhood

Orphans have been a part of the fabric of all cultures for time immemorial. Parents die at all times of a child's lifespan, from childbirth through the teenage years. AIDS has not created the experience of orphanhood but it has exacerbated the situation in many countries. Today, one hundred and forty-three million children are estimated to have lost one or both parents, fifteen million of these to AIDS (United Nations Children's Fund [UNICEF], 2009). Millions more have been abandoned by their parents. While Africa is most often referenced when discussing the orphan burden with respect to HIV/AIDS, South and Southeast Asian countries are caring for 67.5 million orphans alone (UNICEF, 2009). In both Africa and Asia, high mortality among young parents from conditions such as malaria, tuberculosis, HIV/AIDS, pregnancy complications, injuries, and natural disasters are responsible for the

large and increasing number of orphans (World Health Organization [WHO], 2007). Most children in less wealthy nations are orphaned not at birth but at older ages (Norwegian UN Association, 2009; UNICEF, 2009; Zuberi et al., 2005); 36% of all orphans and 29% of double orphans are aged 6-11; almost half of single orphans and nearly two-thirds of double orphans are aged 12-17 (UNICEF, 2006).

Traditionally, cultures all over the world have long had their own unique ways to manage their populations of orphans. Eastern Europe is known for its past history of the institutionalization of children; Western Europe after World War I and II also dealt with orphaning through institutionalization; the United States used institutions and then later foster care became more popular. In many parts of Africa, extended family members are expected to absorb their brother or sister's children into their own families; neighbors or even whole villages tacitly and implicitly agree to care communally for the young members of a household that is suddenly parentless. Even today, many non-governmental organizations (NGOs) and other organizations working to care for orphans and vulnerable children (OVCs) use traditional African village culture as a model and point of reference for setting up care systems all over the world, particularly in Sub-Saharan Africa. Indeed, there have always been ways and means to care for orphans in their own societies, by their own societies.

The difference today is the sheer number of orphans that the HIV pandemic has created, with the most dramatic increases in orphaned children occurring in Sub-Saharan Africa and in Southeast Asia. With the virus killing off men and women of reproductive age the fastest – in some countries up to 40% of the men and women in this age group are infected - the number of children with one or both parents dead has increased exponentially in the last 20 years and has thereby overwhelmed these traditional mechanisms (Ntozi et al., 1999; Nyambehdha et al., 2006; Joint United Nations Programme on HIV and AIDS [UNAIDS] et al., 2004). This orphan epidemic of sorts has has left entire communities with sometimes thousands of children they are unable to clothe, educate or even feed. In some cases children are heading up their own households. HIV/AIDS has made desperate a generation of children who were already vulnerable from poverty. This is a crisis by any definition.

However, before we go too much further into the traumatic experiences that concern children infected and affected by HIV/AIDS, it is also important that we recognize how HIV/AIDS has changed the way we *talk* about orphanhood and orphans, perhaps in a way that does not serve them. According to Helen Meintjes and Sonja Giese at the University of Cape Town, from the time the epidemic first started killing off men and women of reproductive age, the NGO and aid community started referring to children who experienced the death of a parent from the disease as 'AIDS orphans.' This change was significant because typically a child was not labeled an 'orphan' in most parts of the world unless he/she lost both of his/her parents. This is still true today when one is *not* speaking in terms of HIV; the loss of one parent is no less a hardship but a child is not called an orphan. Yet, in the context of HIV/AIDS, losing one parent makes you an orphan according to the international aid community. While the attention and subsequent resources the focus on orphans has brought to countries with the most 'orphans' have no doubt been materially and instrumentally helpful to children who are most certainly in need, it is naïve to believe that focusing on what these children have lost, rather than what they still have – which in *many* situations is another biological parent – has some kind of cultural or at the very least semantic repercussion (Meintjes & Giese, 2008). Further, a child must be identified as an orphan – as someone who has lost something vital and makes him/her the target of aid – in

order to receive this aid. How does that affect the recipients, particularly in cultures where the word 'orphan' means more than being without parents: it means you are without care or without love, and is necessarily associated with pity? Does this definition bring to the child its own kind of stigma and therefore *more* suffering instead of less? We do not have answers to these questions, but feel they are, at the very least, important to consider in the context of how we understand and digest the world of 'HIV and orphanhood.' In addition, it is important to note that it is those who have lost both parents who are truly the most vulnerable, and according to the Positive Outcomes For Orphans (POFO) data[1], children who have lost one parent show similar rates of trauma to those who have lost *neither*. We are not the first to point out that we are not the first to point out, that the very thing that makes children *most* vulnerable is not their orphanhood but poverty, to which children, not just orphans, are subject.

Regardless of the language of the international community there is no question that any child who experiences the death of a parent experiences a profound loss.

1.2 Traumatic grief

While the death of a parent at any age is upsetting and painful, even as adults we mourn the loss of a parent in ways specific to the relationship that we do not experience when mourning the death of a friend or even a spouse. For children, the loss of a parent has a particular gravity, by nature definition children do not have the developmental distance from their parents *as their own person* to mourn their passing separate from themselves, since they are by nature dependent on them (Brown et al., 2008). In other words, children are connected to their parents in ways that tie directly to their identification of self; children self-identify through their parents and only learn to separate their identities in their adolescence. So losing a parent during any developmental stage, but particularly for younger children, has a specific weight that is qualitatively different than any other kind of loss one can experience.

All children naturally grieve the loss of their parent(s), and this is very healthy. However, the profound nature of losing a parent, perhaps in the context of other environments that make a child more vulnerable, can bring about a specific kind of grief called 'Childhood Traumatic Grief (CTG)' that researchers and professionals have only in the last decade or so really started to strongly define and parse out from post-traumatic stress disorder (PTSD) or other symptoms of normal grieving following a traumatic experience such as the death of a loved one. The definition of CTG is distinct from depression and PTSD and understood as occurring following a loved one's death and the subsequent natural/normal grieving of the child is interrupted/disturbed by the development of trauma symptoms, which can include intrusive thoughts, intense and prolonged longing for the deceased, and, in school-aged children, inability to concentrate (J. Cohen et al., 2006).

Other research suggests that children who have lost a parent to AIDS face increased burdens related to emotional and psychological well-being. In his Ghanaian study (2009), Doku's findings support the mounting evidence which tells us that children orphaned by AIDS show more problems with their peer relationships when compared to other children their age (Ntozi et al., 1999; Nyambehdha et al., 2006; Cluver et al., 2008). Dowdney explains that

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[1] Positive Outcomes For Orphans is a longitudinal research study following orphaned and abandoned children in 5 less wealthy nations funded by the NIH.
http://globalhealth.duke.edu/dghi-fieldwork/open-projects/pofo

that the death of a parent under any circumstances, regardless of the additional burden of a stigmatizing illness, is grounds for increased risk of depression and anxiety. She further suggests that one in five children who experience parental death will "likely develop a psychological disorder" (Dowdney, 2000). Dysphoria and depression are the most widely reported of psychological problems in children following parental death (Dowdney, 2000). Severe depression is a potential issue, but is infrequently found in the literature on childhood bereavement. However, it is important to remember that depression and anxiety are associated with suicidal ideation. The type of despair that can accompany the loss one feels with the death of a parent, when unchecked and unmonitored, particularly in the wake of a stigmatizing illness where there is little to no community supporting that child, is a sobering picture.

There are other behavioral and emotional issues that are potential risks with parental death such as anxiety, temper tantrums, hyperactivity, withdrawal and other kinds of somatizing disorders (stomachaches) but in the case of children orphaned by AIDS, it is difficult to tease out causal variables (AIDS, AIDS orphanhood, orphanhood alone) due to the complexity of challenges when a parent is lost to a stigmatizing illness. There is varying evidence related to whether expected death (long illness preceding death) further complicates or ameliorates the grieving process. Likely there are many mediating and moderating factors, such as the way death is dealt with in the family, the way the illness/death is viewed in the community (stigma), any planning that is done ahead of time, and how much the child is included in these decisions and discussions. Indeed, these are not symptoms unique to children who have been orphaned, but it is necessary to understand the full complexity these children are facing when they lose their parents to HIV/AIDS and why they may be more vulnerable to trauma and traumatic experience.

1.3 HIV-related risk-taking behaviors as it relates to trauma in children

Sexual risk behaviors, and other HIV risk behaviours are of particular concern when discussing the health of OVCs. Studies found orphans to be more sexually active than non-orphans (Kang et al., 2008; Nyamukapa et al., 2008; Palermo & Peterman, 2009; Thurman et al., 2006); and to have higher rates of sexual risk-taking and reported forced sex (Birdthistle et al., 2008). Other research, including pilot study research conducted by these authors, finds orphaned girls more likely to go into sex work and, conversely, sex workers in low and middle income countries (LMICs) to be highly likely to have been orphaned and abandoned children (OAC) (Mangoma et al., 2008). The small, qualitative pilot study was not meant to demonstrate causality but to explore the relationship between OAC and sex work. Qualitative interviews were conducted with 25 female sex workers in Hyderabad, India. Our research team and outreach workers visited 'hot spots' (railway stations and bus stops known as areas where sex workers find customers) and sex workers' homes. While not part of the inclusion criteria for the study, it was notable that 16 of the 25 women (64%) were found to have been either single or double orphans.

Human and animal studies demonstrate that greater stress results in increased propensity for drug and alcohol use (Gordon, 2002). The biological response to early life stress modifies neurodevelopment in permanent ways; these neuroadaptations occur within the same neuronal systems that comprise the drug, sex and risk-taking/gambling reward circuit (Adinoff, 2004; Gordon, 2002). Children who have experienced trauma and chronic stress

are more likely to be biologically predisposed to gravitate to drug and alcohol use and risky sexual activity (Adinoff, 2004; Gordon, 2002). Our team's adult HIV studies have demonstrated strong relationships between childhood trauma and adult drug and alcohol use, as well as high-risk sexual activity (Leserman et al., 2005; Mugavero et al., 2007; Pence et al., 2008; K. Whetten et al., 2005). Baseline data from the POFO study indicate ongoing traumatic experiences of OAC (K. Whetten et al., 2011); in the 36 month follow-up, some OAC reported illicit drug use and having been drunk.

1.4 Post-traumatic stress disorder and trauma in children

There is ample evidence associating PTSD with trauma exposure in children, with documented and well-researched examples such as bearing witness to neighborhood or familial violence, war, and/or natural disasters. A plethora of research exists examining the effect of all sorts of traumatic events: following the terrorist attack of September 11th in the United States, post-conflict research in Bosnia-Herzegovnia, Croatia, Cambodia, Algeria and Palestine; victims of both community and personal violence (rape or physical assault); and victims of natural disaster, etc. all documenting rates of PTSD and the effects of traumatic events (Calderoni et al., 2006; Dobricki et al., 2010; Hoven et al., 2005; Klaric et al., 2007; Loncar et al., 2006). However, there are remarkably few articles in the literature examining PTSD among orphans, given the sheer number of orphans and the simple vulnerability of the population. There are some studies that have identified trauma and PTSD as significant factors in the life of a child orphaned by HIV. In her South African study of over 1,000 children ages 10-19, Cluver found that AIDS-orphaned children reported high levels of symptoms of PTSD when controlling for age, migration (moving between homes), household size, and gender. This same study revealed higher levels of other psychological distress among children who were orphaned by AIDS, when compared to children orphaned by other causes and non-orphans. The POFO study also found that in addition to losing 1 or both parents, 98% of the sample of 1,258 children experienced at least 1 more traumatic event and more than half (55%) experienced 4 or more traumatic events. While this study did not diagnose PTSD, the sheer fact of having experienced what have been scientifically proven as potentially traumatic events is ominous, never mind *four* such events.

What may be even more important, particularly as we try to intervene on the behalf of children who have experienced trauma and those who have been diagnosed with PTSD is that children who have already experienced one trauma are at an increased risk of experiencing more traumas. Simply put, trauma begets trauma; this is terrifying because we do know that children who experience trauma and/or have experienced PTSD are more vulnerable in their adult lives to psychological problems like depression and anxiety, as well as an increased risk for contracting HIV and other STDs (K. Whetten et al., 2008; Whitmire et al., 1999) than children who have not experienced trauma/do not have PTSD. A 2009 review of all published psychosocial interventions for children orphaned by or vulnerable from HIV/AIDS, defined psychosocial intervention as including "…psychological therapy, psychosocial support and/or care, medical interventions and social interventions…" with liberal inclusion criteria "..Randomised controlled trials, crossover trials, cluster-randomised trials and factorial trials were eligible for inclusion. If no controlled trials were found, data from well-designed non-randomised intervention studies (such as before and after studies), cohort, and case-control observational studies were considered for inclusion. Studies which included male and female children under the age of 18 years of age, either orphaned due to AIDS (one or more parents died of HIV related-illness or AIDS), or vulnerable children (one

or more parents living with HIV or AIDS)…", turned up exactly ZERO tested, evidenced-based interventions available to these children who are in such desperate need and in a clear and present danger (King et al., 2002). In other words, it is documented that there are children in need of help, yet there is little evidence that the 'help' on the ground is based on empirical research.

Currently, these authors are aware of a few pilot studies that are using Judith Cohen's manualized Cognitive-Based Therapy (CBT) to address traumatic grief in children who have been orphaned and early analysis is showing real promise.

2. Joshua – A case study: Father dying of AIDS and the effects of the children to be orphaned

In order to really elucidate the series of challenges and hardships the children who are orphaned by AIDS come to face, we will provide a 'case study' of an orphan and his family: a fictitious orphan who is really a composite of orphans who have been orphaned by AIDS who we have known over the years through our research or intervention work.

Joshua was nine, living in a Sub-Saharan country with his elder sister and two younger brothers. Joshua's father was a farmer and while they were by no means rich, they had two solid meals a day and they were happy. Two years before, Joshua's father fell ill with what everyone told him was malaria. After a few weeks Joshua knew that it wasn't malaria because his father was not getting better. At first his father went to the hospital but after a week the family could no longer afford to pay the doctors, and nor could his mother take the time to bring meals to the hospital, so he was moved home. Though initially he was well enough to do some work, ultimately he became bedridden. Joshua began to notice that their meals were getting smaller and sometimes his mother would not eat at all. One day he overheard his aunties and mother talking about the cost of his father's medication and he understood he would need to work as the man of the household and cease going to school.

HIV/AIDS has infected men and women of reproductive age all over the world, particularly in Sub-Saharan Africa, and these are the breadwinners and caretakers of the household. In households that are managing but live on the margins of poverty, one illness can be the difference between eating and not eating or education and no education for the children of that household. Numerous programs have sought to aid the hardest hit countries and populations by providing life-extending medications, and while these programs have been life saving for many, there are still millions of eligible infected individuals who are unable to access the medications for a plethora of reasons: transportation, inability to leave work or family (lack of time), and concern about stigma. Sometimes parents must sacrifice their children's school fees to pay for these medications. In other cases, children leave school in order to make money to supplement the cost spent on medications. Similar circumstances arise when a family member is hospitalized. Furthermore, it is not unusual for hospitals in less wealthy nations to supply only medical care but not food or drink. As a result, this burden to feed the patient falls to the family which can turn into a full-time job, especially for those families who live far distances from the hospital.

Joshua continued to rise with the sun and to help his mother and sister with the morning chores, but then he would go to the fields to work. Upon returning home he would eat and then sit with his father, who appeared to be losing weight by the day and began to cough often. After several months had passed, in the middle of the night he heard his mother's sobs and then the sobs of the neighboring women. His father had passed on in the night. A funeral followed in two days time and it seemed as

though not everyone in the village attended, as was the tradition. He wanted to ask his mother about this, but he was afraid he knew the answer. People were afraid of how his father died.

Stigma is a formidable presence in the lives of children affected by HIV but one that is difficult to measure. Stigma can be witnessed in the form of outright discrimination – not allowing children who are infected or those associated with people infected (like children of infected parents) to play or associate with uninfected children is one of the major ways that children experience stigma. The POFO study sought to measure stigma by asking people employed as caregivers in orphanages and people who took care of children who were not biologically their own if they would hypothetically allow their children to play with a child who was known to be infected by HIV. The research team also asked the participants if they would care for a relative who was sickened by the virus. The results showed that individuals associated with institutions were more accepting of those infected with HIV (willing to care for relatives and/or letting their children play with an infected child) and more knowledgeable about the virus (Messer et al., 2010). Unpublished qualitative data from the same study asked about stigma experienced by both children orphaned by HIV and those who were orphaned by other causes. The participants reported that children orphaned by HIV were sometimes stigmatized and shunned by other children and even their caretakers treated them poorly. A few children reported that they felt that being an orphan 'marked' them either through the simple fact of being parentless or by the poverty that often befell them as a result of losing an adult breadwinner in their family. There have been numerous interventions and attempts at reducing stigma targeted in the areas hardest hit by the epidemic. However, as a global society we have yet to evolve enough to where being HIV+ is not a mark of shame for individuals and/or their families.

Joshua's younger brothers continued to go to school and he continued to work the fields with his mother while his elder sister worked at home and took the vegetables they could afford to sell into town. He missed his father and he had less to time play with his friends. When he did have a little spare time, he had less in common with them because he felt older and more mature than them. He was not sure, but he thought that some of his friend's parents didn't look at him directly anymore, like his friend Michael. His mother used to invite him inside every time he would play football with Michael, but since his father died, she had not invited him in the house. Michael and he used to talk about the other kids in their class a lot. Michael kept him updated on the school gossip, but it just made Joshua sad because he realized while it felt important to be taking care of the family and to be the 'man' of the household, he missed his old life; he missed his friends and he even missed school. He started making up excuses to not play football when Michael came around to spend time with him. It wasn't difficult to come up with reasons to not go, because truthfully there were always more chores, more things to be done for the household – animals to tend to, water to be fetched, children to be bathed. And his mother seemed more tired than usual lately.

Another stress that is not measured or noted much in the literature but is a very real and concerning issue is how children in families affected by AIDS find themselves cut off from their former social networks and from their friends. Most importantly, they are often cut off from their natural emotional outlets for sharing and working through problems with their friends. Whether this is done through sitting down and talking under the acacia tree or on the football field with nine other boys, the outlet is crucial and when these begin to crumble through stigma and through new responsibilities to the family, these children suffer.

Things were different at Joshua's house now. Paul, the seven year old, was getting in trouble in school not infrequently; he was bringing home letters from the teacher detailing his poor behavior during lessons and sometimes discussing fights he instigated with others. When questioned, he claimed he is

called names at school and must fight for his honor. At nighttime, both his younger brothers would have nightmares. Sometimes they would call for their father and sometimes for their mother. Beatrice would go to them and hold them and sometimes if they could not be settled she would bring them to mother and show them mother was still with them but she tried not to do this too often because she knew inside mother would not be with them much longer.

Children deal with stress and fear differently and one common way is to 'act out' in school, which a child's attempt to bring attention to themselves in the often unconscious hope an adult will pick up on the underlying problem that they need help with (a sick parent, bullying at school, etc). This acting out is frequently seen as a negative behaviour; being disruptive, not completing assignments, talking back to the teacher, etc.

At first he attributed it to her grieving, to her missing her husband, but he soon noticed that his mother was less able to work the fields and began to take longer and more frequent breaks throughout the day. One day, she left the house very early in the morning, saying she had to take a trip to town – to the clinic - she would be home by nightfall. When she returned her face was very worn and troubled. Not very long after this trip into town, his mother stopped coming to work in the fields. While they did not discuss this change, he knew that the disease that had taken his father was to take away his mother, too. In the coming months, a quiet sadness descended on the household.

It is not uncommon that families do not discuss illness and/or impending death, in spite of its overarching presence. There are a myriad of cultural taboos, in the United States and Europe included, that make discussing difficult subjects like life-threatening illness and death planning difficult or impossible to broach. The inability to discuss and prepare children for such a cataclysmic event has far-reaching repercussions, and NGOs all over the globe have made an effort to break the silence around serious illness and death, particularly for the benefit of the children who are left behind. There are now dozens of 'Memory Book' type projects that seek to help parents and other loved ones create books and other types of media to leave behind for their children. As the child grows without the parent, these books/projects can provide a crucial touchstone, a link to that parent: a positive keepsake containing memories, traditions, and histories that might not have been known had they not been created, and really play an important role in that child's healthy grieving, part of which is having positive memories of the deceased. It is well documented that creating positive memories of the deceased loved one is an important step in the grieving process, particularly for children. In many cases, the children themselves create these books with their sick parent or loved one and the experience in and of itself can be a catalyst for important conversations that may not have been had while the parent was still living (Kilimanjaro Women Against AIDS [KIWAKKUKI], 2005).

Only a few aunts and neighbors came to visit, while others who had previously brought them extra ugali now did not bring them anything. Joshua worked harder and longer in the fields and helped his brothers at night with their homework and tended to his mother as best he could. He desperately tried to maintain a level of normalcy in the home all the while knowing that his mother was slipping away from them, from him. She died in the night, just as his father had. He was 10 and now the man of the household. His sister was 12.

Beatrice, Joshua's sister, tended to her mother as best she could as she suffered her illness. She knew that it was the same sickness that took their father. She knew it was the virus they called AIDS and that was why people shunned them now. She acted as mother to her little brothers, though Joshua now acted as a 'man' of the house, working only in the fields and telling her what to do. Recently, shortly before her mother's death, she had experienced her first blood, so she knew that she was marriageable, though she had not shared this news with brother – partly out of custom, but also out of

fear. Tradition demanded she tell her mother of her news, and she did, and she was fairly certain her mother passed this news to her aunt. What this meant for her future was unclear because surely news of the virus in her family was everywhere. Who would want her now? Would she have any choices for marriage? When her mother was still living they would giggle and speculate about the different possibilities for her in the distant future, after she had finished school and maybe even attended university! Beatrice was at the top of her class. School work came easy to her and she knew she possessed an above average intelligence. She often wondered how she could apply this in the future; she loved to argue, she could change minds by virtue of her gift of wordplay and logic. She dreamed of becoming a lawyer, as women did that now in her country. She knew of a few girls who had gone on to university in the city. While her family had been poor and she had no idea how this might happen for her, she knew it was not an impossible dream. Well, it had not been; perhaps there was no place for dreams now perhaps her choices would be made for her.

While the life of the eldest boy child can be directly changed in ways such as dropping out of school to work in the fields or work directly for money/salary, the experience of a girl child with a sick and dying parent is equally life changing but can look quite different. For an older girl, she might also leave school so she can care for younger children, be the caretaker for the sick parent and/or be the primary domestic worker – fetching water or firewood, cooking, buying food at the market, etc. When that parent dies, however, if she does not become the head of household for the remaining children, which is always a dire but very real possibility, she may either marry or go to work.

Early marriage is something that young women and girls face in many parts of the world and the challenges of orphanhood only serve to exacerbate this problem. Already vulnerable and dependent, these young women/girls are, by virtue of being a minor, in an unbalanced power dynamic, and have less power to negotiate their own safety. For example, a young bride whose husband wants sex without a condom – does a 15 year old have the skills to negotiate her own personal value and safety, particularly if there is a cultural belief that supports the idea of her 'obeying' her husband? Sadly, young married women have a higher rate of HIV infection than women of the same age demographic but who are unmarried. Furthermore, young women who are unmarried but in sexual relationships are more likely to become sexually involved with younger men and data show that younger men are more likely to be willing to use condoms (Clark, 2004; Haberland et al., 2005; UNICEF, 2003).

More disturbingly, there are stories out of Africa that males have been seeking out young girls, even infants, who are virgins because they are believed to be safe and free from disease, and that they can in fact 'cure' men of HIV/AIDS by having sex with them.

2.1 Mother dies: Children become double orphans

Joshua continued – The problems began immediately upon his mother's death. First, he had to pay for a proper funeral. Soon after his mother's funeral his mother's sister came to the home and told him to pack his things, as he and his youngest brother were moving to a nearby village where this aunt lived with her husband and children. This came as a complete shock to him because while he knew they were a poor family in terms of wealth, they did have their small plot of land and their home. He expected to inherit this and live here with his siblings. At the very least, the money from the sale of the home and adjoining land was to go to him and his siblings, or so he understood.

One of the biggest legal problems facing families who experience parental/spousal death and orphaning is related to land-grabbing and inheritance loss. Because of poorly enforced or even non-existent laws concerning land and home deeds and property ownership, one repeatedly hears the story of wives and children who expected to continue to live where

they did when their loved one(s) was alive only to have relatives claim/take/steal this property for themselves. A lack of will-planning, paper deeds and other 'estate' documentation, and birth certificates as well as a lack of law enforcement related to the above all contribute to orphans/widows losing any property that is left to them by the deceased. For a widowed woman with dependent children, this makes her very vulnerable and often requires her to move in with other relatives or move away from neighbors and friends who might have served as social support during a trying time. For orphans, this can be life-shattering since, as children, their rights are rarely recognized. As a result, they are at the mercy of adult relatives' choices and, in all too many cases, simple greed (Kalanidhi & Coury, 2004; McPherson, n.d.).

Joshua was saddened by the thought of moving from his home and worried that his aunt did not mention his sister and other brother in her announced plans. Joshua yearned for them to never be apart, particularly now – he didn't want to lose anyone else - though he knew he had no say in this matter as he was only a child. Within days he was living in his auntie's house, going to school again, as was his brother, but at a different school. At this new school, the other children did not speak to them and appeared to whisper to one another when the two brothers passed by. They tried to join in games during recess but they were shunned. The teacher looked at them with pity but did nothing. His aunt was kind to him but it was clear her husband resented their presence in his house as extra mouths to feed. He felt funny in the house anyway because he had been a man when his parents were alive and now he was again treated as a child, like he had been demoted, and this felt demeaning – disrespectful, even. Joshua was the one who had run the household following his father's death and his mother's sickness. He was no child! Joshua swore to himself that as soon as he was able, he would run away to the city so he could find a good job. Then he would come back for his brothers and sister if he could find her and they would be together again.

For single orphans whose fathers have died, living with the mother is very common. In the reverse situation, with the mother dead and father living, it is less common that the child live with the remaining parent (UNICEF, 2006). While the data tell us that there are more single orphans with fathers lost than there are double orphans (with both parents lost), when one parent dies of HIV it is likely that the other parent has also been infected and will also die prematurely leaving any children in the family labeled a 'double orphan' (Ainsworth, 2002; UNICEF, 2006). While all children who have been orphaned face hardship and challenges, those who have been double orphaned or abandoned by both parents have a particularly difficult road ahead. There are between 13 and 16 million double orphans in the world today (UNICEF, 2006).

The age of a child at the time of orphaning is significant for what responses both the local/origin community will have in terms of planning for the orphan's future. In the case of those children who have a family member to care for them, the younger they are, the more likely it is that they will be absorbed into another family. Depending on the region of the world, culture and familial circumstance, it is the grandparents, aunts and uncles who are most likely to take on the task of caretaking for the orphaned and/or abandoned children. It is also not unusual for siblings to be split up due to financial hardship of the families who are acting as caregivers – they are limited to how many more children for whom they can care, school fees and costs of uniforms are high, etc.. This can serve as an additional trauma for the orphaned children. After losing their parents, they then lose additional member(s) of the family (United States Agency for International development [USAID] et al., 2002). Research on sibling separation suggests that sibling-orphans who were separated after parental death experienced higher rates of anxiety and depression than those who were not separated from their siblings (Gong et al., 2009).

For children who do not have family to whom to go, there are several possibilities that have been observed. Some children find their way into an institution or orphanage. (While the current 'opinion' in the NGO-aid world is that institutionalization is a last resort and should always remain so, there is evidence to suggest that this is not such a black-and-white situation. Indeed, there is evidence that some institutions, by no means all, do have the ability to provide a child-centered, healthy environment from which a child can grow). The quality and type of institution varies wildly across the worldwide landscape, though it is popularly considered a bad situation for a child to live in an institution of any kind.

Another possibility is for children to enter the work force. There are an estimated 215 million children engaged in what is defined as child labor by the International Labor Organization (ILO) but very little data exists on orphans and child labor. Baseline results from the POFO study show that of the 1258 caregivers who responded for the community based children, of the 1258 caregivers who responded for the children, nearly 22% were engaged in what is defined as child labor – a child under the age of 15 working 28 hours a week. Orphans (and vulnerable children) not attending school were four times more likely to have reported engaging in child labor than those attending school. Moreover, children working more than 28 hours a week were twice as likely to not be attending school than those working less than 28 hours (R.Whetten et al., 2011).

The weeks that followed for Beatrice confirmed her worst fears. Her aunt approached her while she was cooking the family dinner and told her about the man who was to be her husband; the ceremony would take place in four weeks' time. Noting the fear on Beatrice's face, her aunt chided that she should be happy anyone was still willing to take her given the family circumstances (HIV in the family). She would no longer attend school, and university was "clearly out of the question, so don't ever mention it again, as it was difficult enough to get him to agree to have you" is what her aunt told her.

Other consequences of the combination of orphaning and trauma have yet to be seen on a large scale, however there are predictions of nothing short of an alarming societal breakdown in the face of children who, having not been properly cared for, will grow to adulthood and run businesses, ministries, government offices and every other part of the private and civil sector and this is a serious risk to the future of society and the world at large (Barnett & Whiteside, 2002; Bellamy, 2005; Kalanidhi, 2004; Lewis, 2002; Natrass, 2002; UNICEF, 2003). Whether this is a truism or a gross exaggeration remains to be seen. However, at the very least, for children who have experienced the trauma of losing their parent(s) and may have experienced additional traumas, we do know they are at risk for further traumas as they grow up. Trauma begets trauma, and this is a cycle that desperately needs to be broken.

2.2 Exposure to trauma is common in adults, particularly in those living with HIV/AIDS

Many HIV positive adults report having been physically or sexually abused during childhood. A history of childhood trauma is also associated with recurrent exposure to traumatic events in adulthood (Parks et al., 2011). Women who were sexually or physically abused during childhood are 2.5 to 3 times more likely than the general population to experience physical or sexual abuse in adulthood (Parks et al., 2011). Many people living with HIV/AIDS report having experienced some kind of traumatic event in their life, including physical and sexual assault. Poverty , a condition many HIV positive people live

with, is another risk factor for numerous kinds of traumatic exposures, from childhood abuse or neglect to sexual and interpersonal violence. (Matzopoulos, 2008). The HIV epidemic has taken hold in the poorest parts of the world, and poverty arguably has been a significant contributor to the spread of the disease. Exposure to violence profoundly impacts emotional and mental health; the connection between trauma, HIV, and poverty becomes inextricably linked, perpetuating HIV transmission and worsening poverty, and mental illness including post-traumatic stress disorder (PTSD), depression, and substance abuse. These factors are transmitted across generations by way of problems including orphanhood, child labor, and childhood trauma.

The cyclical or recurrent nature of exposure to trauma is most striking with respect to sexual assault. In one study of 162 primarily low-income, ethnic minority HIV positive adults, on average 45% (68% of women and 35% of men) reported experiencing a sexual assault at some point in their lifetime (Kalichman et al., 2002). These estimates are dramatically higher than the general population, in which the rates of lifetime forced sex are 6.5% in all adults (10.6% of women and 2.1% of men) (Basile, 2007). History of trauma leads to exposure to even more trauma during the lifespan. For example, people who have been sexually assaulted at least once are likely to experience multiple sexual assaults. 80% of those with a history of sexual assault had been assaulted two or more times, and the mean number of lifetime unwanted sexual events was 9.7. Exposure to even one such traumatic event leaves painful and lasting marks on peoples' lives, so one can imagine the devastating cumulative impact of nine such traumas on every aspect of life, including mental health, behavior, relationships, and work.

Post-traumatic stress disorder is perhaps the most clearly defined and well-known sequela of trauma. A diagnosis of PTSD (American Psychiatric Association, 1995) can be made when an individual has exposure to an event or situation in which s/he experienced a threat of death or grave bodily harm, and that experience was met with feelings of intense fear, helplessness, or horror. In addition to history of exposure to a traumatic event, PTSD is characterized by symptoms in three clusters: intrusive recollection, numbing or avoidance, and hyper-arousal. Symptoms of intrusive recollection include nightmares about the traumatic event and vivid memories of the trauma that may be associated with strong emotional and physical response. A few examples of the numbing or avoidance cluster of symptoms include diminished feelings, activity, or memory of the traumatic event. Hyper-arousal involves having an exaggerated startle response, difficulty sleeping, irritability, impaired concentration, or outbursts of anger. While there are a number of different symptoms associated with PTSD, the impacts of trauma on individuals, families, and communities are far more diverse than what can be conceptualized under the umbrella of this diagnosis. Effects of trauma can manifest in many ways in addition to or instead of PTSD, including depression, substance abuse, exposure to violence as a perpetrator and/or victim, increased health risk behaviors, and physical illness.

Cultural differences in how distress is experienced and expressed may lead to different manifestations of distress in response to trauma exposure (Kira, 2010). There has been much debate over the legitimacy of the PTSD diagnosis across cultures. While it is indeed important to consider cultural context in evaluating the relevance and applicability of Western diagnostic and treatment models, that is not to say that trauma does not profoundly impact people of all different cultural backgrounds. Distress may be expressed with different words or actions, but is still distress. Experiences such as rape or torture cannot be accepted as a normal part of any culture, and we cannot minimize or negate the

profound impact of trauma or the importance of working to alleviate such suffering and break the cruel cycle of trauma, poverty, and HIV.

Given the high rate of exposure to traumatic events among people living with HIV/AIDS, it is not surprising that many have a diagnosis of PTSD. Studies have found alarmingly high rates of PTSD among people living with HIV/AIDS ranging from 7% to 54%. In the general population in the US, lifetime prevalence of PTSD is 6.8% (Kessler et al., 2005). In a study of 611 adults living with HIV/AIDS in the southeastern U.S., 7% of respondents were found to have a probable diagnosis of PTSD. A parallel survey conducted in Tanzania of 72 adults revealed that 22% of those surveyed had likely PTSD. Though a number of different traumatic events were reported, particularly notable were high rates of sexual assault in both locations: 36% of participants in the southeastern U.S. and one fourth of Tanzanians in the survey reported history of sexual assault (K. Whetten et al., 2006).

3. A case study: Isaac. Childhood sexual trauma, poverty, and how these circumstances affect HIV risk behaviors

Isaac was raised in a Tanzanian village where his family had a small farm. He was the eldest of four children, and when he turned eight he started to work selling maize in the village. Shortly after he started, he went to an older man's house to see if the man wanted to buy maize, and found that this man was very drunk. The man asked him to come inside, then exposed himself to Isaac. He offered to give Isaac some of his drink, but Isaac said no. Isaac was scared and confused, and asked the man again if he would buy some maize. The man didn't buy any, but told Isaac he would buy maize if he came back the next week. Isaac returned the following week, and the man was again drunk. He exposed himself, and told Isaac that he would only buy maize if Isaac touched his penis. Isaac was scared and did not know what to do. As he slowly approached the man, Isaac told himself that he would touch the man this one time so he could sell the maize, but that he would find a way not to have to go back there. The man did buy maize from Isaac and told him to come back again next week. Isaac didn't want to go back, but he really wanted to sell maize to help his family. He didn't want to tell his parents and worried that they would be upset if he sold less maize than he had the week before. He returned to the man's house every week for the next few years. The man was usually drunk, and would often make Isaac touch his penis. Isaac started taking a few sips of the man's drink and found that it calmed his nerves a bit. Once, the man made Isaac touch his penis with his mouth. Isaac was very ashamed that he did this and thought that if anyone knew what he had been doing with the older man they would be disgusted by him. He had heard stories about men who liked other men, and how they were sinners and were dirty. Isaac thought since the man never touched him back that maybe he wasn't like these men. He started to worry about this a lot and have bad dreams about the man touching him. He had a hard time concentrating when he went to school and when he went to sell maize, he would get very nervous and shaky before going to this man's house.

When he was twelve, Isaac was getting bigger and was able to help his father with farming work. His younger sister started selling maize, and he no longer had to do this. He didn't see the old man again, but still worried a lot about what had happened to him and feared that it may happen to his sister as well. He could not bring himself to say anything to his parents or sister. Isaac's friends were starting to talk about girls, and he wondered if girls would like him after what he had done, even though he had never told anyone. He felt like he was somehow different or dirty, and needed to try hard to cover this up so people wouldn't find out the truth. Isaac started to date girls, and felt like being with them proved that he was in fact a 'real' man. He prided himself on having the prettiest girlfriends in the

village, and a few times he even had three or four girlfriends. When he was sixteen, Isaac married a girl named Helen. She moved in with his family, and they both worked on the family plot. During the next year, the family's maize crops started doing poorly, and Isaac started worrying because he had just learned that his wife was pregnant with their first baby. He didn't think they would make enough money on growing and selling maize to get by. Isaac started looking for work on neighboring farms and in the village, but others were having the same difficulties with their crops. There was no work to be found. Some of the other young men in his village were going away to work in a Tanzanite mine a few hours away. He heard that these mining jobs had good pay, and that he could go work for a few months in the mine then come back and support his wife and family for the rest of the year.
Isaac went away to the mine and moved into a boarding house with several other mine workers. They were all young men, most were married, and all were away from their families for the first time in their lives. Mining was difficult work, but Isaac was optimistic that he could make enough money during a few months that he would be able to take good care of his wife and the baby they were expecting. Sometimes, women from the village would come to Isaac's boarding house in the evenings. Most of his roommates would pay to have sex with these women. It was so hard to be away from their families, they said, and nobody at home would ever know. A few of the men did not get together with these women, and the others started talking badly about them, saying that those men preferred the young boys who worked with them in the mines. Isaac started thinking back to what had happened when he was a boy with the older man in his village. He was afraid his roommates would think that of him since he had touched another man. The next time these women came over to the boarding house, Isaac had sex with one of them. He felt guilty, but it took his mind off the loneliness and hardship that filled his life as a miner. When he had a few drinks before the women came over, he was more relaxed and didn't feel so guilty. After all, he was working so hard so that he could be a good husband when he returned, and his wife would never know about what happened here in the mines or in his boarding house. He stayed at the mine for six months, returning home when he learned that his wife had given birth to their first son.

3.1 Trauma and risk of acquiring HIV

Like many people who were sexually abused as children, Isaac became sexually active at a young age and engaged in high-risk sexual behaviors including sexual activity with concurrent partners and hired prostitutes. Traumatic events and PTSD are not only more common in those with HIV, they are also risk factors for contracting HIV. People with history of exposure to trauma are more likely to engage in behaviors that place them at higher risk for developing HIV including unsafe sexual activity and intravenous drug use. In a U.S. study of homeless young adults, physical abuse, neglect, and sexual abuse were correlated with HIV risk behaviors (Melander & Tyler, 2010). The more types of abuse and neglect these young adults had experienced, the more likely they were to engage in HIV risk behaviors. Women prisoners in a U.S. study were surveyed regarding HIV status, traumatic events, PTSD, and sexual risk behaviors, and those with PTSD were 71% more likely to have engaged in prostitution and other high risk sexual behaviors (Hutton et al., 2001). In a longitudinal study of South African women, those who reported a history of intimate partner violence acquired HIV at a significantly higher rate. Forty-five of 123 women who reported more than episode of intimate partner violence acquired HIV, as compared with 83 of 846 who reported one or no incidents of intimate partner violence (Jewkes et al., 2010).
Back at home, Isaac was glad to see Helen and was proud to be a father. The crops were still doing very poorly, and he feared that the money he had made at the mine would not last for the rest of the

year as he had hoped. He decided to go back to work at the mine, planning to remain only until his crops started doing better. He would go back to visit his wife, son, and family one weekend every four or five months. It was a difficult and lonely life, but he did feel proud that he was providing for his family, especially when he saw his friends who had stayed in the village and how much they were struggling to get by. He even saw one of his school friends begging on the street. At his boarding house, Isaac continued to have sex occasionally with one of the prostitutes, and over time this became part of his normal routine in his mining life. Several years passed with Isaac working in the mines, he and his wife had two more babies, and his family's maize crop didn't improve very much at all. There was a terrible malaria outbreak one year during which both of his parents and one of his cousins died. With his father gone, Isaac returned home to care for the family's land and look after his family since he was the eldest son.

Isaac was glad to be back with his family and out of the mines, but it was very hard to keep everyone in his family fed. He started growing a few other crops beside maize with a little better luck, but it was still difficult. One day, Isaac learned that his sister-in-law had fallen ill. She had grown very thin and developed a cough. He had seen people at the mine get sick like this, and all of them had to stop working. He heard that many of them died and the disease they had was spreading, but he never knew what it was. Her husband, who was Helen's older brother, had gotten sick like this a few years beforehand; everyone said it was malaria but he thought it was probably the same thing he had seen at the mine and now in his sister-in-law. He worried about what would happen to her children, who had already lost their father. It was so much to think about; his sister-in-law had four children, and Isaac felt like he could barely take care of his own children. He prayed to God to make her better, then tried to put it out of his mind. A few months later, Isaac's sister-in-law died. Two of her children went to stay with other family members, and Isaac and Helen took in her eldest and youngest sons. Isaac sent both boys to school with his own children despite the protests of the eldest son, Joshua, who said he was a man and should stay on the farm and work like the other grown men.

Isaac insisted that Joshua attend school; while he could use Joshua's help on the farm, he felt like it would be dishonoring the family if he didn't keep their orphaned children in school. The boys would already have enough trouble since everyone knew that their parents were dead, and had probably died from the disease that brought so much shame and loss to their villages. Isaac tried to be kind to the boys and treat them as his own, but he found it difficult. The eldest, Joshua, was sullen and did not respect his authority. The younger boy, Paul, often asked about his other two siblings. Isaac didn't like that the brothers and sisters were separated, but he was having a hard enough time feeding them and paying school fees; he knew there was no way he could support the other two siblings. Shortly after she went to stay with her auntie, it was announced that Joshua's younger sister Beatrice was to be married. Even though she was so young, Isaac was happy that there was someone willing to marry her after what had happened to her parents. People whispered to one another about this disease and how it came to those who deserved it. Isaac never talked about it, and nobody in the house ever did either; it was as if their silence would bury the existence of this disease and the pain it had brought to the family.

3.2 Stigma, trauma, and HIV

It has been found that believing the stigma attached to an HIV diagnosis may cause PTSD or increase the severity of PTSD symptoms among individuals living with HIV/AIDS. People with HIV are stigmatized around the world, but where the HIV epidemic has hit the hardest, in sub-Saharan Africa, stigma associated with the disease has been particularly distressing and destructive. In a Nigerian study of 190 HIV-positive patients, 61.6% reported having experienced or witnessed a stigmatizing event, and 27.4% met diagnostic criteria for

PTSD. Of note, 28 of the 52 patients diagnosed with PTSD reported a past history of at least one other traumatic event, which further supports the notion that the effects of trauma exposure during the lifespan are cumulative. Some of the most common stigmatizing events experienced as traumatic in this study included verbal assault, neglect, denial of employment, housing or education due to HIV status, and physical assault because of HIV status (Adewuya, 2009).

In the U.S., HIV-related stigma was heavily focused on gay men during the early years of the epidemic, and the gay community has continued to experience high levels of stigma even as HIV rates have been declining among men and increasing in women, particularly in African-American women. Though to a great extent the face of the HIV epidemic in the U.S. has changed, HIV-related stigma remains pervasive. People living in rural areas experience greater stigma than do those living in urban settings (Heckman et al., 1998; Reif et al., 2006). Those who experience greater stigma have poorer adherence to medications, leading to poorer mental health and medical outcomes in those who have recurrent distressing and traumatic stigmatizing experiences related to their diagnosis of HIV (Logie & Gadalla, 2009). HIV-related stigma is painful for individuals and families. The silence associated with stigma is also a powerful force in perpetuating beliefs about disease and treatment that hinder prevention, testing, and treatment efforts. As stigma also stands in the way of education, employment, and housing opportunities, it contributes to poverty. Stigmatizing events can be *the* traumatic event or part of a perpetual cycle of trauma that permeates the lives of people living with HIV/AIDS.

3.3 Post-traumatic stress disorder and HIV

Arguably, receiving the diagnosis of HIV is traumatic in itself, and can lead to development of depression, PTSD, substance abuse, or to exacerbation of any or all of these conditions. Post-traumatic stress disorder was originally conceptualized as a disorder affecting war veterans after a discrete combat-related traumatic event. The time course associated with PTSD related to HIV diagnosis can be very different, as there are a number of potentially traumatic points throughout the lifespan of a person living with HIV. The initial trauma of disclosure of HIV status is followed by stigma-related traumatic events that are quite commonplace in those living with HIV. Recurrent fear accompanies declines in clinical status such as beginning treatment, discontinuing treatment, developing opportunistic infections, or encountering significant medication-related side effects (Kelly et al., 1998). The future-oriented nature of these fears, i.e. fear of looming death as compared with a response to a past threat of death classically associated with PTSD does pose a challenge diagnostically. While the current diagnostic criteria do not clearly include such fear of death or threat to bodily integrity in the future, mental heath clinicians increasingly agree that living with HIV can be traumatic to an extent that it does cause clinically significant impairment and symptoms consistent with a diagnosis of PTSD (Martin & Kagee, 2011).

Because the time course of HIV is a chronic one punctuated by acute stressors, the development of PTSD related to HIV diagnosis can occur years after the diagnosis was first made (Delahanty, 2004). In a 2008 cross-sectional study of HIV-positive patients attending a public health clinic in South Africa, 54.1% of participants met diagnostic criteria for PTSD during their lifetime, and 40% met criteria for HIV-related PTSD, as described by PTSD symptoms attributed by the patient to receiving the HIV diagnosis and/or living with HIV (Martin & Kagee, 2011). In a South African longitudinal cohort study, 14.8% of patients with

recently-diagnosed HIV met diagnostic criteria for PTSD at study baseline, and 26.2% met criteria at 6 month follow-up. One-third of the patients with PTSD identified the diagnosis of HIV as the index trauma causing PTSD (Olley et al., 2005, 2006).

Overall, people with PTSD, whether related to HIV diagnosis, HIV-related stigma, other traumatic experiences, or a combination of these factors, are less likely to adhere to anti-retroviral medications (ARVs). This leads to poorer medical outcomes and higher viral loads, which in turn make them more likely to transmit the virus to others. This taken with the increased HIV risk behaviors in individuals with PTSD, yields a group of people at great risk of infecting other people since they are engaging in high-risk behaviors and, if already HIV-positive, are likely to have higher viral loads. Incomplete adherence is directly related to lifetime traumatic events, and individuals who have experienced more lifetime traumatic events are more likely to be incompletely adherent to ARVs. Similar to the additive effects of multiple traumas on HIV risk behaviors, there is also an additive effect of multiple traumas on ARV adherence. In the CHASE study, overall incomplete adherence was reported in 9.5% of all subjects, 22.4% of subjects who had experienced three categories of trauma, and 34% of those who had experienced five or more categories of trauma (Mugavero et al, 2006).

HIV-positive individuals with PTSD report higher levels of physical pain (Smith et al., 2002) and fatigue (Barroso et al., 2010) than do those without PTSD. Post-traumatic stress disorder impacts physical symptoms, but also appears to directly impact immune function and disease progression in people living with HIV. Kimerling et al. demonstrated a more rapid decline in CD4+/CD8+ cell ratios among women with a history of trauma exposure (Kimerling et al., 1999). Subsequent studies have suggested a more complex relationship between PTSD and HIV disease progression with medication adherence playing the dominant role in CD4 counts and other indicators of immune function and disease progression (Delahanty, 2004).

Isaac started to become very thin. He occasionally wondered if he might be getting the same disease as his brother and sister-in-law, but he dismissed this, telling himself it was because he was working so hard to take care of his family. Isaac and his wife had been skipping meals so that the children would get enough to eat, and even though he heard Helen's stomach growling a lot Issac didn't seem to mind much at all. He started to feel tired and was having a harder time getting his work done on the farm. Joshua noticed that Isaac was slowing down and offered to stay home from school to help him out. The first time that Joshua talked about this to Isaac, he smacked Joshua and told him never to say such foolish things. Isaac was adamant that he could take care of himself, his land, and his family. He also, in the back of his mind, didn't want Joshua, Paul, or his own children to go through what he had experienced as a boy when he was working to sell maize. Over the coming months, Isaac grew even thinner, and fatigue descended over him like a heavy blanket. He sometimes felt like he could barely walk to the door without becoming exhausted. Joshua eventually stopped attending school so he could work on the farm. Isaac said this was temporary, and that as soon as he got better Joshua would go back to school. Joshua knew, and deep down Isaac knew as well, that there would be no return to school. Joshua had been through this with both of his parents and knew what was to come. Isaac started coughing. He started to think more often that he probably had the terrible disease that had taken his brother and sister-in-law as well as some of his friends back at the mine. Even as he grew more certain that he was dying of this disease, Isaac could not bring himself to say it out loud; he wanted to think that he could make it go away if he ignored it.

One day, Paul was accompanied home from school by a man from the village. This man, who was not familiar to Isaac, had heard from Paul's teacher that Isaac was very sick. He wanted to tell Isaac that

there was a clinic that could help him and other people with this disease. Isaac did not believe him that there was any help, because everyone he had seen with the disease had died. Isaac was also very ashamed that people in the village knew he was sick, and he didn't want even more people to find out by going to the clinic. He kept getting sicker, though, and when he started coughing blood, at Helen's urging Isaac finally agreed to go to the clinic. Joshua and Helen helped him get to the clinic, a long and tiring walk from the farm. When they arrived, Isaac saw other people waiting who were very thin like him, and also saw some other people who looked well. He recognized one of the ladies working in the clinic from his primary school class. She greeted him, and told him that she also had this disease called HIV. She had been very thin and weak like him but was getting treatment, and with the treatment had gotten much stronger. She told Isaac there was hope for him – and for his family – as there had been for her. He was scared, but did start to feel a little bit of hope.

Isaac had some tests, saw the doctor, and it was confirmed that he had HIV. One of the nurses asked him questions about his history, and one of the things she asked him was if he had ever gone to work in the mines. It seemed that a lot of the young men who had worked in the mines came back with HIV because of how commonplace prostitution had become in mining towns, and this was in fact how the virus had reached a lot of the nearby villages.

Isaac took the prescribed anti-retroviral drugs, and he did start to feel better – less tired, and his cough was easing up. Since his first visit to the clinic, though, Isaac had been very troubled about having HIV, about what had happened when he worked in the mines, and also what had happened to him as a boy. As his body grew stronger, his mind grew more distracted by these bad memories. He started to drink a little, remembering how drinking had eased his nerves and sadness when he was in the mines. He did find that this made the bad memories and nightmares quieter, but he also started to have more arguments with Helen. He gradually spent less and less time with his family, and more time drinking by himself. He stopped taking all of his medications.

Substance use disorders are very common in people with PTSD who are HIV-negative. Data on the prevalence of these disorders in HIV-positive people are limited, but substance abuse, like PTSD, is considerably more common in HIV positive individuals than in the general population. Alcohol and drug use are strongly associated with interpersonal violence including sexual assault and intimate partner violence (Boles & Miotto, 2003; Najavits et al., 1998). The relationship between substance abuse, HIV, and trauma is a complex one; substance use increases the risk of exposure to traumatic events that may lead to PTSD or worsen existing symptoms.

Helen urged him to take his medicine, but as he drank more he felt even more depressed and hopeless. One night he drank so much that he passed out in the field next to his house. Joshua found him there in the morning and helped him back into the house. Isaac stayed in bed, and over the next day developed a high fever and bad cough. Helen called the doctor, and even though he gave Isaac medicine, he told Helen that Isaac might not survive. His body was weak from drinking so much, and since he had stopped taking ARVs the HIV had again taken hold on his immune system. Isaac died the following night.

The relationship between HIV and depression is better characterized than that of HIV and trauma. Depression is very common among HIV-positive individuals, with prevalence rates in the U.S. of 35-36% (Pence et al., 2007; Zierler et al., 2000). Among Rwandan women exposed to trauma during the 1994 genocide, 81% of the respondents who were HIV-positive endorsed clinically significant depressive symptoms (M.H. Cohen et al., 2009). Individuals with HIV who have a diagnosis of PTSD also have worsening of CD4 count that appears to be independent of adherence, suggesting a detrimental effect of PTSD on immune function and disease progression. People with co-morbid depression in addition to PTSD have lower CD4 counts than those with less severe or no depressive symptoms (Sledjeski, 2005).

3.4 Treatment for PTSD and other sequelae of trauma in people living with HIV/AIDS

Isaac and Joshua's family was entangled in a web of poverty, trauma, and HIV, and unfortunately suffered a tremendous amount of loss as a result. Isaac did start ARVs and had a chance at surviving for many years. He was haunted by the traumas in his past, however, and as is unfortunately all too common, this stood in the way of him adhering to treatment. Though remarkably effective, anti-retroviral drugs can only go so far in tackling the HIV epidemic. As HIV medication regimens are improving and becoming accessible to more people with HIV, people are living with HIV for many years. It is therefore crucially important to address trauma in people living with HIV. Targeting interventions for people living with HIV/AIDS who have experienced significant trauma and suffer from psychiatric sequelae including PTSD, co-morbid depression, and substance abuse can alleviate great suffering, decrease HIV transmission, reduce risk of future trauma exposure and HIV risk behaviors, improve ARV adherence, and improve overall health outcomes.

The picture of trauma in people with HIV can appear bleak, and it certainly is complex, but effective and feasible treatments are available for adults and children alike. Cognitive-behavioral interventions (CBI), for example, have effectively been used for people living with HIV/AIDS and have been shown to improve symptoms of depression, anxiety, anger, and stress (Crepaz et al., 2008). CBIs are simple interventions that are readily implemented in primary care or specialized HIV care settings. Further, these interventions can have a beneficial effect on improving immune function as evidenced by CD4 count (Crepaz et al., 2008). Similar treatment interventions have been modified to target ARV adherence, and have been found to be effective in improving adherence in addition to improving depressive symptoms (Safren et al., 2009). Most CBIs have been implemented in the U.S. and other wealthy nations; however, a few studies of CBI in less wealthy nations have yielded promising results. For example, in Thailand, a study of a culturally adapted CBI demonstrated improvement in general health and mental health (Li et al., 2010). Integrating behavioral interventions with HIV care for HIV- positive individuals with co-morbid mental health and substance use disorders significantly reduces psychiatric symptoms and improves medication adherence (K. Whetten et al., 2006). More difficult to quantify are the effects of such interventions on families and communities. Given the profound effects of trauma on mental health, HIV risk behaviors, and medication adherence and the cyclical effect of trauma that begets more trauma, mental illness, and HIV transmission, it is crucial to focus efforts on trauma prevention and care around the world. Effective treatments and interventions for trauma are available, and more widespread understanding of and attention to the grave effects of trauma can go far in improving the lives of people living with HIV, their families, and their communities.

4. Conclusion

While this narrative and illustrative case studies are meant to drive home the reality of many children and adults in the world today, it would be wrong for these authors to suggest that the suffering highlighted here begins and ends with orphanhood, traumatic experience or even AIDS. Poverty has always been the root cause of child labor, child marriage, children dropping out of school to care for ill parents and/or to work to pay for life-saving medications, prostitution, and of families on the edge of hunger and starvation. HIV/AIDS has served as a fierce and highly effective catalyst for pushing people on the precarious fence of poverty right over the edge. HIV/AIDS serves a lens from which we can

see the essence of inequalities all over the world. Children who are raised in poverty often become impoverished adults themselves, and HIV/AIDS is a powerful servant on the side of poverty in this cruel cycle. Compounding the forces of trauma and the fallout from traumatic experiences adds that much more vulnerability and challenge to an already desperate situation that is entrenched in poverty. As we have detailed, individuals who have experienced trauma are at a higher risk for experiencing depression later in life, and are also more likely to experience more trauma, contributing to an already heavy emotional and spiritual burden as they enter adulthood. It behooves us as a global society to recognize the reality of traumatic illness and unresolved grief and to make room so those affected can find some help and maybe some peace. This is not only for the benefit for the individual, but for the benefit of society at large. A world of people with unresolved trauma is not a healthy environment for building a global economy, for political diplomacy, for solving public health problems. We owe it to those who have been hurt, but also to ourselves and our own children to have the opportunity to create a healthy and well-functioning global society, one where people aren't constantly looking over their shoulders out of fear, or terrified that everyday will be their last. We owe this to ourselves and to each other. The Lancet Global Mental Health working group recently published a series of articles addressing the issues and challenges of global mental health care provision. In their words: " Change in public health only comes about if three core elements are present: a knowledge base, strategies to implement what we know, and the political will to act.,…Now we need political will and solidarity, from the global-health community…... The time to act is now" (Lancet Global Mental Health Working Group et al., 2007) .

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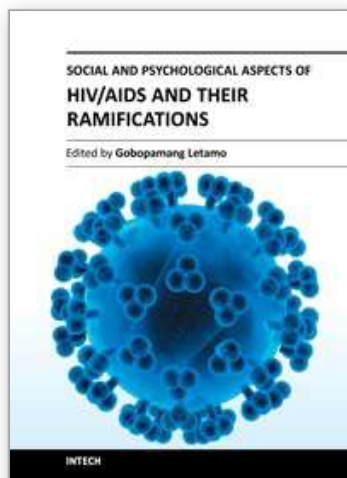
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Edited by Prof. Gobopamang Letamo

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