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After my parents died: The effect of HIV on the mental health of children: a clinical review

By Theo Smart

Contributors and reviewers

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The prevention and management of mental health problems in children affected by HIV/AIDS

Although there is currently an ongoing debate about the extent of the disadvantage faced by AIDS-orphans and HIV-affected children relative to other children in resource-limited settings, there is a substantial body of evidence demonstrating that AIDS-affected children often lack adequate food and shelter, have more trouble staying in school and accessing medical care, and are at high risk of economic exploitation and sexual abuse. Bereavement because of HIV/AIDS and related traumatic experiences during childhood may have long-lasting psychological consequences in some children—and may increase a child's risk for becoming HIV-infected and having other serious trouble in life. However, while funding to provide basic social support for orphans and vulnerable children has increased in recent years, few settings are specifically addressing such children's mental health needs.

By definition, a palliative care approach aims to alleviate the HIV-affected family, physical, emotional, spiritual and psychological suffering. In this palliative care clinic report, we try to make the case for the need for these services, and show how palliative care not only helps prepare children for bereavement and deal with grief, but also helps the family and community cope with the child's other needs, addressing factors that increase the risk of mental health complications. In addition, we look at a number of interventions that are being piloted in some countries to manage post-traumatic stress, depression, anxiety and other psychological disorders that may emerge in orphans and vulnerable children.

This review specifically highlights the problems that are common to being an orphan or vulnerable child in general, and does not address the problems that are unique to children infected with HIV. We hope to address these issues (including 'disclosure') in an upcoming HATIP.

The plight of orphans and other AIDS-affected children

With 12-15 million children globally having lost a mother, father or both parent to HIV/AIDS, and millions more in danger of losing their parents due to HIV infection, it is all too easy to find sad and disturbing stories regarding orphans and vulnerable children.

The problems often start while their parents are ill:

"The weather is so cold, but my family does not have money to buy coal... I am so scared that my mother will catch a cold, as the doctor said that she would not be able to survive if she catches one. Because I am not a real AIDS orphan [by government's definition], the county government does not assist us financially. But our life is even harder than that of [some of the double] orphans" (Quote from a 13-year-old whose father has died of AIDS and whose mother has advanced AIDS.¹)

The strain of living with a parent whose health is failing—possibly over quite a long period of time, can leave a lasting imprint on a person's psyche. For most children whose parents have HIV, this ultimately leads to bereavement—which may be made all the more challenging by the cause of death, or rather the community's prejudice about it.

"After my parents died, the kids in the village did not play with me any more. Nobody in school wants to speak with me. I have not spoken to anyone for a long time because no one will listen to me... I wanted to speak with my good friend before, but she is not willing to talk to me at all and always covers her mouth with her hands. Today, I finally found someone I can talk to: [a] big yellow dog..." (Quote from a 9-year-old girl orphaned by AIDS.²)

This child lives in China, but stigma isolates children closely affected HIV almost everywhere.³ For instance, a world away in Zambia, extensive fieldwork by Dr Virginia Bond of the London School of Hygiene & Tropical Medicine, found precisely the same thing—that children orphaned by HIV in Zambia expressed feelings of rejection, exclusion, loneliness, pain, feeling "different" because they aren't treated the same as other children or because they don't go to school.⁴ (Although it varies by setting—particularly depending on whether there are fees for schooling—the children of poor people with HIV often must quit school (at least temporarily) to find work or become caretakers to their siblings and ill parents, especially the daughters.^{5, 6, 7, 8, 9, 10})

"Orphans are looked on "as the remains of the dead person who only bring problems and whose needs are always a second priority." said one youth officer interviewed in Bond's study. Note, this may be true of orphans in general (see below)—but it is important to stress that HIV/AIDS is responsible for more than one-third of the orphans in Africa, and more than half of the orphans in eastern and southern African epidemics.

"When you don't have parents, no one to buy you clothes, maybe you live with another family and you get none," said one child quoted during a presentation by Dr Lucie Cluver of the University of Oxford at last year's International AIDS Conference in Mexico.

Clearly this depends on who is caring for the child. Where the child is placed depends upon the setting, culture and other circumstances and there have been a lot of popular misconceptions about orphans and vulnerable children (OVC). For instance, at one time, there were concerns that many OVC would have to fend for themselves. But while there are some cases where a child in a family (often the eldest girl) becomes the head of the house, this

does not seem to be as widespread a problem as once feared. In fact, according to a study presented at this year's South African AIDS Conference, current models suggest that while there are 4 million children in South Africa who have lost one or both parents, less than 0.7 percent of these children are living in child-headed households (comprising less than 0.5 percent of South Africa's households) and these figures seem to be relatively unchanged over the last several years.¹¹ Rather, the vast majority of OVC live in intergenerational households, with their grandmother, or other extended family members.

Sometimes, the gulf in age and even culture between the child and their caretakers (such as when children must go from an urban setting back to the ancestral village) can lead to poor communication, and cultural misunderstandings. For instance, in Botswana, it is common not to tell a young child that their parents have died, and so orphans wind up confused, or feeling hurt and rejected.¹² Another case comes from Karilyn Collin's work in Tanzania:

During a lesson on personal hygiene and regular bathing, a girl of 11 from Muheza whose mother had recently died of AIDS, burst into tears. She was upset because she said her grandmother was 'very cruel' and would not let herself or her brother wash. When questioned, the grandmother said this was the tradition in their tribe, that one had to wait at least 2 weeks before changing clothes and washing in case a little of the deceased spirit was still on you – but no one had explained this custom to the child, so she had felt she was being punished.

Fortunately, this misunderstanding was resolved because the palliative care team noticed it and intervened. But some homes have more difficult problems to address. Most importantly, many caretakers' ability to cope with another mouth to feed is limited by poverty. The familiar narrative of orphans being treated as an unwanted burden is thus common across many cultures. For instance, a study in Mozambique reported that non-biological children placed in a non-poor household are treated more or less the same as the biological children, but in the poor households, there appeared to be "discrimination in the intra-household allocation of resources against children that are not direct biological descendants of the household head."¹³ In impoverished rural settings in Zambia, the children in Bond's study described orphans who were forced to work while other family members were eating. One child spoke of an orphan being "sent to the market to buy things and on the way home the money gets lost. After reporting back to her aunt – the aunt just poured hot water on the orphan, but she wouldn't pour hot water on her own children."

Orphans (regardless of cause) appear to be more often forced into child labour – one study in Ethiopia reported that more than three-quarters of the domestic workers were orphans.¹⁴ In Tanzania, 38% of the children working full time to quarry tanzanite are orphans,¹⁵ while in Zambia, 47% of the children involved in sex work were double orphans (in other words, they had lost both parents), while 23%, were single orphans.¹⁶

In South Africa, evidence suggests that AIDS-orphans are significantly more likely to start having sex at an earlier age.¹⁷ A study at the South African AIDS Conference this year suggested that early sexual debut may be more common when the parent lost is the same gender as the child.¹⁸ Unfortunately, the sexual debut may be due to sexual abuse or survival sex. According to one study in Zambia, orphans and vulnerable children surveyed said that their greatest problem was 'defilement' (sexual abuse).¹⁹

AIDS-affected children are also increasingly subjected to 'spiritual' abuse – or abuse in the name of God, with revivalist church pastors and others accusing AIDS-orphans of witchcraft. A

Save the Children report quotes one church 'prophetess' who gave the following explanation of orphanhood in one family in the DR Congo:²⁰

'Three children had been bewitched by their maternal grandfather. Their father had fallen ill and died of tuberculosis. The mother had died of AIDS caused by the children through witchcraft. Two of the children sought refuge with their maternal grandmother and one of the boys decided to look after himself. Basically, the family lived well but the mother had refused to give money to her parents, and so the grandfather decided to take revenge. The father's sister was angry with the children because she thought they should have warned her so that she could get them exorcised and thus break the circle of death.'

The prophetess ended her story in this way: 'They are orphans through their own doing'.

According to a recent United Nations High Commissioner for Refugees (UNCHR) report, child witchcraft reports are occurring in various countries in Africa, as well as Papua New Guinea. "Since the early 1990s, particularly in large towns, accusations have shifted to children, the number of such allegations skyrocketed, and the subsequent treatment has become increasingly violent."²¹ An article in the evangelical magazine *Christianity Today* describes the effort of one African minister to address the crisis – and how he found starving and sometimes tortured children incarcerated in desolate church compounds. Many of the children believed the charges levied against them.²²

Given such difficulties, it isn't surprising that some children choose a life on the streets – where life is pretty much guaranteed to be traumatic, according to a study of street children in Durban, presented at this year's South African AIDS Conference.²³

"My mother passed away. I had 4 brothers, one passed away and 3 are left. We are 4 girls, my sister died of AIDS and she left her child," said one young girl participating in a focus group. *"In the morning we always think about food, we don't have the money to buy soap so we don't wash. The police will chase us and say we are not supposed to be there, we are supposed to be in school."*

At night, they depend upon the boys for protection, but are raped frequently and not just by one person – gang rape is common. Four of the twelve girls had given birth to babies, and they discussed among themselves where they could get back-alley abortions for 75 Rand (\$10).

We list these cases not to evoke pity but to emphasise that some OVC must deal with very real challenges that are almost certain to leave emotional and psychological scars. Unfortunately, research into mental health issues in children in resource-limited settings has been neglected (just as it has in adults). The available research does indicate that psychological distress (with depression, post-traumatic stress, anxiety disorders, alcohol and drug abuse) is common in HIV-affected children – but the quality of the data is uneven, and quantitative data rare. Nevertheless, there can be little doubt that there are children in need of mental health services.

Who is an AIDS orphan and a vulnerable child, and are their problems so much worse than other children?

Several years ago, UNICEF's Global Monitoring and Evaluation Group proposed the following definitions for orphans and vulnerable children:

An orphan is a child below the age of 18 who has lost one or both parents (ignoring any distinction between single orphans (who have lost one parent) and double orphans (who have lost both parents)).

A child made vulnerable by HIV/AIDS is below the age of 18 and;

- a) has lost one or both parents, or
- b) has a chronically ill parent (regardless of whether the parent lives in the same household as the child) or
- c) lives in a household where in the past 12 months at least one adult died and was sick for three of the 12 months before he/she died, or
- d) lives in a household where at least one adult was seriously ill for at least 3 months in the past 12 months, or lives outside of family care (i.e. lives in an institution or on the streets)

However, there are millions more orphans due to other causes (143 million total worldwide) and countless children dealing with especially difficult circumstances, challenged by poverty, disabilities or social instability in resource-limited settings. Are AIDS-affected children really that much worse off, and should they be singled out for special treatment?

"A growing body of evidence does not clearly demonstrate that orphans (especially single orphans) suffer greater deprivation," said Dr Penelope Campbell during a presentation at the International AIDS Conference last year in Mexico City.²⁴ She based this conclusion on a multivariate analysis of Demographic and Health Survey (DHS) data (from 2000-2005) from eleven southern and eastern African countries. Looking at individual indicators, she did tend to find that double orphans have poorer outcomes, for instance, orphan girls— especially those in urban areas— were more likely to quit school, and orphans were more likely to have an early sexual debut.

However, in the multivariate analysis "the overall conclusion from this DHS analysis is that while orphan hood is clearly one important dimension of child vulnerability, other factors are not only important but in some cases have a much stronger quantitative association with the child's developmental outcomes," she said. Namely: factors such as poverty, whether the child was from an urban or rural setting and gender are often more significant variables when considering whether a child is "vulnerable."

But the omission of South Africa, which has the largest population of children orphaned by AIDS, from this analysis is problematic because there are specific problems children have in this setting because of their difficulty in getting birth registration (and thus access to social services). Furthermore, there are very different HIV epidemics occurring in different African countries which are at different stages of maturity, and cultures and approaches to coping orphans and vulnerable children differ in these countries. A multivariate analysis pooling all data may obscure or even negate differences that are very real and important at the local/national level — and local programme responses should respond to local needs.

That being said, Dr Campbell's point that a number of factors "should be included in targeting criteria" to make certain that vulnerable children (regardless of cause) are not excluded from psychosocial support services is well made. While recognising the heightened need and stigma associated with HIV, programmes should be inclusive when it comes to considering which children are vulnerable and cast the net as wide as possible. Children orphaned by tuberculosis or other diseases may face similar hardships, as do children who have lost homes or families due to military conflict.

Richter and Rama argued a similar point in *Save the Children's Building Resilience: A rights-based approach to children and HIV/AIDS in Africa*.²⁵

"The terms used to speak about children affected by AIDS have evolved from AIDS Orphans to Orphans and Vulnerable Children (OVC) to Children Affected by AIDS (CABA) and most recently to Children Living in Communities Affected by HIV/AIDS. The categories OVC and CABA are both used as if there was wide agreement about

the children included — when, in fact, there are often very different views about which children are vulnerable and even which children are orphans. The definition of Children Living in Communities Affected by HIV/AIDS is general and embraces the many different categories of children affected by HIV/AIDS."

When it comes to mental health services, it really doesn't matter what causes the child's vulnerability — any child suffering from bereavement, depression, trauma or post-traumatic stress, whatever the cause, deserves care and treatment, and actually, any child suffering from these problems in a high burden setting may also be at risk of HIV. However, most of the following research pertains to children orphaned or in danger of orphanhood due to HIV/AIDS — and suggests that there are significant differences in outcomes.

Does AIDS-orphanhood or being a child in danger of orphanhood due to HIV/AIDS affect mental health?

Bereavement is a natural part of life, and if managed well (see *Addressing grief and bereavement* below), should not result in any clinically significant mental disorder. But the impact of other traumas and factors already mentioned on mental health is under-studied.

"The world of a child living in a family affected by HIV/AIDS goes through many changes," wrote Orne-Gliemann and colleagues in *AIDS* last year.²⁶ "These children have to witness the physical deterioration and pain of their HIV-infected parents, especially when they are unaware of the nature of the illness affecting their parent(s) or refuse to acknowledge HIV infection. Children are anxious about their source of livelihood and their ability to retain the family home after the parent's death; separation from siblings is a frequent and important source of trauma. The serial loss of adult figures and carers such as parents, teachers or mentors is also likely to create a sense of insecurity or abandonment."

However, Dr Cluver, who has conducted some of the most rigorous research and also co-authored what is perhaps the definitive review on the subject believes there is clear evidence of psychological distress in AIDS orphans, but not so much regarding AIDS-affected children: "I think that we now know quite a lot about children who have lost a parent - the impacts on mental health, physical health and education are important. But we know far less about children whose parents are unwell with HIV/AIDS (or other illnesses like TB) — and it's essential that we understand what their needs are and how best we can help them," Dr Cluver told HATIP.

Cluver & Gardner's review — which again dealt primarily with orphans — found a paucity of quality research. Including both controlled and uncontrolled studies, in 2007, they could only identify 24 empirical studies (some of which were unpublished and a few ongoing) worldwide (including 5 from the US).²⁷ Most of the studies were rather small as well. While most of these papers identified significant mental health problems in these children, there were wide variations in sampling characteristics, outcome measurements and control groups.

For instance, there were inconsistencies between control groups (such as the lack of any, or the failure to include non-AIDS orphans) that make it difficult to determine the effects of AIDS-orphanhood. Some studies only look at the caregivers' reports on the child's mental health (which would tend to under-estimate internalising problems) while others interviewed the child. The tools used to assess mental health problems differed from study to study and they haven't been adapted for African populations — or for use by

non-clinically trained interviewers who tend to be conducting the surveys.

Finally, they wrote, “we must be cautious in assuming generalisability between studies conducted in diverse parts of Africa, due to variations in social, cultural and economic circumstances.”

That being said, most of the studies found a high degree of internalising disorders such as depression, suicidal ideation, anxiety and especially post-traumatic stress rather than externalising disorders (behavioural problems, anti-social behaviour) in children orphaned by AIDS. Different disorders have been found to be more common in different studies. For instance, depression was the most significant finding in orphaned children in Zimbabwe,²⁸ while a study in Cape Town, found that orphans more often had constant nightmares ($p = 0.01$), with 73% scored above the cut-off for post-traumatic stress disorder (PTSD).²⁹

Many studies found that other stressors, such as food insecurity, increased the likelihood of psychological distress. For instance, an Ethiopian study compared 479 children who had lost their mother to AIDS with a control group of 574 children orphaned for other reasons. The AIDS orphans had significantly more emotional and social adjustment problems – with the girls faring the worst.³⁰ Notably however, there were other important factors in the poor outcomes, including whether the father was present, whether the child could attend school, household income, clothing conditions, food security and emotional support within the fostering family. While many papers highlight the importance of having one parent still living, as the first case study indicated, sometimes orphans in single-parent families have a harder time economically than children placed with other relatives. Though that case study was from China, the same observation of greater financial hardship among single orphans was also made in one Zimbabwean study – and found to be associated with poorer psychological outcomes.³¹

In contrast to Dr Campbell’s multivariate analysis of selected African countries, some studies found orphanhood to be the only significant predictor of poor mental health outcomes. One example was a study by Atwine et al in rural Uganda, which interviewed 123 orphaned children and 110 matched non-orphaned controls aged 11–15, using the Beck Youth Inventory.³² Orphans were more likely to suffer from anxiety (OR = 6.4), depression (OR = 6.6) and to display anger (OR = 5.1, and were also significantly more likely to think about suicide. In a multivariate analysis that considered other living circumstances, only orphan status remained significant. Likewise, a national survey in Zimbabwe including 5,321 orphans and non-orphaned children aged 12–17 found that psychosocial disorders, especially depression were significantly more common among orphans, even when controlling for poverty, gender, age of household head, school enrolment and adult support.

In the largest South African study to date, which involved 1,061 children (455 orphaned by AIDS, matched controls of 278 non-orphaned children and 328 orphaned due to other or unknown causes), children orphaned by AIDS reported significantly more depression, peer problems, PTSD, conduct problems and delinquency than the non-orphans or orphans due to other causes.³³ Even when controlling for socio-demographic factors were controlled for, such as age, gender, poverty, migration and household composition, these differences remained.

Even so, some factors had strong ‘strong mediational effects’ and should be noted because they may offer potential targets for interventions that may alleviate or even protect against some of the mental health consequences of orphanhood. The following table is adapted from one of Dr Cluver’s presentations (see <http://www.hsrc.ac.za/Document-2033.phtml>).

What factors predicted the likelihood of AIDS-orphaned children being more likely to have a clinical-range disorder?

Factors	Measures of factors	
Food security	● Enough to eat for at least 5 days/week	P<0.000
Quality of care in the home	● Good caregiving monitoring ● Carer-child activities ● Frequent praise for child ● Sense of belonging in family ● Equal sharing of resources between children in household	P<0.000
AIDS-related stigma	● Teased due to family illness ● Treated badly due to family illness ● Gossiped about behind their backs ● How much this stigma upset child	P<0.000
Being bullied	● 8-item standardised scale on victimisation by bullying	P<0.000
Having had more than 3 + changes of caregivers	● Usually through deaths of successive caregivers	P<0.01

When do these problems start?

Many mental disorders may have their inception while the parent is still alive but their health is failing. Of note, studies by van Rie and colleagues have found that simply being born to a mother with HIV may affect a child’s neurocognitive development, even when the child is uninfected.³⁴ These effects could be the product of HIV’s impact on the mother and the unborn child’s physical health during pregnancy or its impact on the family’s living conditions, and the decreased opportunity for maternal-infant interaction. A review by Dr René Brandt notes that the parental-child relationship is likely to be disrupted as the mother progresses to AIDS, and she also concluded that “children of HIV-positive mothers are at greater risk for emotional and psychological problems than children of uninfected mothers, especially internalising problems such as depression,” though she notes that impoverished children suffer similar problems.³⁵ One factor to consider is the HIV-infected mother’s own mental health status, which is often poor. Possibly counte-balancing this, she notes that caring for children in African societies is often distributed across multiple carers.

Cluver and Gardner write that “More longitudinal studies or studies with a control group of children living with caregivers who are ill with AIDS are also necessary. These can improve understanding of the chronology of distress for children within the process of parental illness and death.” Dr Cluver is currently running a national study in South Africa of children whose parents are sick with HIV/AIDS. It’s called the Young Carers study, which she says is the first of its kind, “a government-academic-kids-NGO collaboration”. (See - <http://www.youngcarers.net.au.net>).

Addressing grief and bereavement

Grief due to the loss of a parent is natural. "Much like the process of physical healing, the grieving process is a series of tasks that one must work through before fully adjusting to the loss," wrote Li and colleagues, "but characteristics unique to AIDS [such as stigma and discrimination] may create additional cognitive and social barriers for grief resolution among AIDS orphans,"³⁶ placing these children at heightened risk of prolonged mental and behavioural problems.

A useful overview to helping children cope with death and grief can be found in the recently published *guide Children's Palliative Care in Africa*, (which can be downloaded for free, see resources) from which the following words of advice are excerpted or summarised.

"Children who are not allowed to grieve normally are at higher risk of developing problems and complications at the time and later in life," Amery and colleagues write.³⁷ They note that in Africa, children often have to confront the deaths of "many other family members who have died as a result of the HIV epidemic, malaria or other causes" during their early years.

Bereavement assistance should start as soon as someone is diagnosed with a terminal illness because "children need to understand and make sense of their experiences in order to help learn that dying and death are part of life... and may later resent their exclusion — their involvement will assist in grieving."

"Never lie to children or prevent them from talking. It is immoral, unethical and negligent. Children have as much right to ask questions and be given honest, accurate information as adults do," Amery and colleagues write.

At the same time, caregivers need to be aware that it may be taboo to mention death in some cultures.

Caregivers should know that children may experience extreme fluctuations in grief between sudden sadness and then suddenly appearing happy. "Young children may experience bed wetting, loss of appetite, tummy upsets, restlessness, disturbed sleep, nightmares, crying, attention-seeking behaviour, difficulty in concentrating, increased anxiety and clinginess. These only become a cause for concern when they occur over a prolonged period of time. Older children often display changes in personality and alterations in their normal behaviour including signs of depression, anger and rage, sleep and appetite disturbances etc... Health workers should advise families to be on the lookout for changes in behaviour."

The time of death is critical, and it is best to have "a rehearsed plan for all the worst case scenarios in advance and to practice exactly what you will do for each."

After death, it is important not to just treat the child but the whole family.

The chapter also provides some advice about making **memory boxes** (to collect items that remind them of the person who has died and times they shared); **a family record** to help a child or young person gain a sense of where they and the person who has died fits into the family. This is particularly important when a child is to be removed from their old home, or separated from siblings or cousins, and hence when there is a danger of losing a sense of his or her 'roots'; **telling the story** by helping the child write or tell (with an adult writing) their story so that they remember clearly what happened — which can provide carers an ideal opportunity to pick up misconceptions and misunderstandings; **handprints**: a print of their hand and their parents and other loved one's touching; **writing a "children's will"**: children are sure to have some items that they treasure and they might have a clear idea of what they wish to

happen to these; **permanency planning** so that children have a clear idea about what will happen to them (if they are bereaved); **a "bereavement tree"** (a practical tool that sensitises people to the feelings and behaviours of individuals and expectations of society, to create awareness about bereavement in order to encourage community support to all bereaved people — there is an appendix with this tool in the book).

The book also addresses the importance of spiritual development (as well as play), and describes a number of beliefs and practices surrounding death in Africa.

Some other useful resources can be found in the April 2009 issue of *Together Now*, the newsletter of the International HIV/AIDS Alliance in India including using art therapy for children and child-centred counselling.

Screening for mental health problems in AIDS-affected children

As Cluver and Gardner's review noted, there is great need for standardised psychological tools that have been adapted for African populations. Some key questionnaires used in some of the studies include the Child Depression Inventory,³⁸ the Revised Children's Manifest Anxiety Scale,³⁹ the Child Behaviour Checklist⁴⁰ and the Children's PTSD Checklist⁴¹ but these tools need to be translated and adapted to most local settings.

Other tools, such as the Catholic Relief Services 'OVC Well-Being Tool', have recently been developed and validated in five African countries to serve as a comprehensive screen of AIDS-affected children's wellbeing, looking at the domains of: nutrition and food security, shelter and environment, protection, family, health, spirituality, mental health, education, economic and community cohesion.⁴² The tool is administered to children themselves, however, it has only been validated in children above the age of 13.⁴³

Although also not a mental health screening tool *per se*, another interesting well-being tool, described by Dr Paul Hutchinson of Tulane University at the HIV Implementers' Meeting this year assesses the cost-effectiveness of interventions for AIDS-affected children, and includes measures of the child's psychological health (see www.hivimplementers.org for his presentation).

Some mental health interventions for AIDS-affected children

Basic services

There are a large number of basic psychosocial support interventions and programmes targeting the needs of children in communities affected by AIDS, though coverage is nowhere near adequate — and there is a clear need for national governments in resource-limited settings to take responsibility for the security and health of their children, rather than depending upon the charity of others. As Nelson Mandela said, "There can be no keener revelation of a society's soul than the way in which it treats its children." One notable barrier to accessing government services, in many African countries at least, is birth registration, which is very low across the region.

Describing the wide range of basic support services being implemented in HIV-affected communities goes well beyond the scope of this document. However, we should note that a recent review of more than 50 studies and programmes by the Joint Learning Initiative on Children and AIDS, concluded that interventions are needed targeting all poor children in communities heavily affected by HIV and AIDS; and that children's overall

wellbeing can be improved by policies and programmes that strengthen families, offer social protection for children and income support.⁴⁴ By addressing the co-stressors for poor mental health — such as food insecurity for vulnerable children, programmes could reduce the risk neglect and trauma. But psychosocial interventions do not go far enough for the child with established emotional or mental health problems.

Case study: don't forget the grandmothers

The mental health of the child is often affected by the mental health of the caregiver, so it is important to consider adoptive family, and especially elderly caregivers who may be as isolated and stigmatised as the AIDS-affected child.

Elisa Mudaka is 68 years old. She used to be a mother of eight but now she's left with only four children. Two of her sons died violently, and two of her daughters died of HIV/AIDS (as well as one of her granddaughters).

"When the funeral took place, it was very painful. I had to welcome the body of my grandchild, alone with my family because my home was an "AIDS" Funeral House. So the people were afraid to go there, thinking they will be infected," she told the audience at this year's South African AIDS conference.

All her life she has been a caregiver. Two of her sons are mentally challenged. In addition, another one of her daughters, the main breadwinner in the family, also has HIV and is presently in the hospital, though with ART, there is a chance she may recover.

"It is very hard to be a granny of a heavy burden. Because sometimes you feel tired, you feel angry, you feel depressed. Even now, I can say depression is my name. It knows me."

However, Elisa said she is now participating in a group called 'Grandmothers Against Poverty and AIDS' (supported by Secure the Future) with "some other grannies of the same situation as I. They provide comfort, support and counseling for each other. We have workshops where we learn about growing vegetables to feed these children of ours; and in our psychosocial groups we learn about how to sew, crocheting, and knitting to sell so that at the end of the day, we can have a piece of bread on the table, and money for electricity."

"We are no longer grieving. We are no longer filled with sorrow, because our grandchildren are paid for to go to the creche/day care center. And the creche is next door to the centre. So when you are finished with work, you only have to go and fetch your child and then go home."

A model for introducing more targeted interventions

"Basic psychosocial support has its own advantages and uses. It can be delivered by trained volunteers, is inclusive and can be offered to large numbers of affected children. Little training is needed and it provides a basic level of support for children who might otherwise have nothing, but it also has its limits," said Carl Henn, Palliative Care Advisor for USAID Zambia at this year's HIV Implementers' Meeting. "In many cases it's the only mental health option available. Children generally receive a 'one size fits all' package, regardless of need, and volunteers generally have limited training and skills and little or no training or tools to assess mental health needs. And often they have nowhere to refer children who need help."

So a number of implementing partners, including Catholic Relief Services, in Zambia came together to develop a model for providing mental health services for children with basic psychosocial support services as the foundation.⁴⁵ More specialised services (paediatric support services (PSS)) are targeted to children who themselves are infected, but community caregivers can also be trained to use a simple evidence-based locally validating assessment to look for the presence of more serious psychosocial needs in AIDS-affected children and either offered trauma-focused cognitive behavioural therapy (for severe needs) (TF-CBT) or interpersonal psychotherapy (IPT-G).

Dr Nancy Scott of Boston University explained the evolution of this model as the result of a four-phase methodological process that has been used in several countries now.⁴⁶ This began with an ethnographic or qualitative survey to determine the local needs. The results were used to develop quantitative assessment tools, which were locally adapted and validated. Then the feasibility of introducing the evidence-based treatment (necessary for that particular programme's needs) was piloted. Then the process either concludes with a randomized controlled study of the effectiveness of the intervention or — as in the case of Zambia, simply moving to scale up.

The ethnographic study in Zambia consisting of interviews of caregivers and children (already mentioned above) found that sexual abuse and related post-traumatic stress was far more common than expected, while disorders like depression were somewhat less common.⁴⁷ "We really did go into it thinking that we were going to find depression, and would choose IPT-G for the evidence-based treatment that we would implement. But the qualitative work obviously guided us differently," she said.

Next they chose assessment tools that were translated and adapted to be usable by Zambians of all education levels, and which could also be used as a tool to measure impact. (Previously, there had been no validated MH assessment tools for the Zambian context.) Working with the University Teaching Hospital, Child Sexual Abuse One-Stop Center in Lusaka; the tool was then validated in about 700 youth and caregivers.

The tool can be used by trained volunteers and was found to reliably differentiate between youth needing different services (HIV Treatment, Medical Services, Drug/Alcohol Services and/or one of the two psychosocial treatments. The validation experiment also detected a great need for the psychosocial services. Those with limited needs received group counselling (IPT-G) (generally depression).

About 20% of the youth assessed had symptoms of depression, according to Henn. Group therapy was chosen as the key intervention for these children on the basis of two controlled studies. One found it to be very effective in reducing depression and dysfunction in the Masaka and Rakai districts of rural Uganda.⁴⁸

The second found that it was effective for depression in the adolescent survivors of war and displacement in northern Uganda.⁴⁹ According to Henn, use of IPT-G in Zambia was piloted in Mazabuka and Chinda (small peri-urban areas), and almost any trained individual can lead the groups, though children have to be 12 years of age or older to participate.

Although he cautioned that the results were still preliminary, Henn said “95% of those diagnosed and participating in IPT-G, improved significantly. It has had a positive effect on families, caregivers and in communities. Are there barriers? Yes, IPT-G involves a certain amount of cost and complexity. But the costs are manageable and the barriers are not insurmountable.”

The Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) is offered for those “who need therapy or treatment to move past this traumatic experience in their life,” Dr Scott said.

TF-CBT was selected on the basis of USAID’s prior global experience with Victims of Torture Fund in the Democratic Republic of Congo, Indonesia and Haiti and over 10 randomised controlled trials.⁵⁰

“It can be used with 3 to 18 year olds over a discrete 3-month time period; and it’s been adapted and shown to be effective across different cultures,” said Dr Scott. “It’s not just for sexually abused children, it’s effective for all types of trauma histories. But it reduces the effects of child abuse, neglect or violence in the short term and symptoms like depression, self-efficacy, behavior problems, nightmares. Over the long term has been proven to reduce drug/alcohol use and/or abuse; violence in relationships: clinical depression and also long-term HIV risk behaviors. So it really is a prevention tool.”

They then performed a feasibility study, training 23 Zambians over six months (working very intensively for five days with a clinical psychologist and, and then completing training as a distance training course. These were people with very different training backgrounds: clinicians, counsellors, students in psychology, and nurse mid-wives.

“It’s been very effective so far,” said Scott, noting that results are being tabulated and will first be presented to the partners in Zambia. “It requires intensive supervision and practice but can be done locally.” She also noted that though they were concerned about finding space to offer therapy confidentially, “during the feasibility study, we found that nobody wanted that. They wanted to meet in churches; they wanted to meet under a tree; they wanted to meet somewhere else. So it wasn’t even necessary to build that space.”

Scott said that they have decided to scale up the intervention rather than perform a larger randomised trial.

Simple interventions to improve the mental health of AIDS-affected children can be introduced in low-income settings

These interventions don’t work for every child. In the Zambian programme, Henn said some still may require residential and day care options to deal with alcoholism and drug addiction or very severe psychiatric problems.

But the take-home message from the Zambian experience seem clear. There is a clear need for therapeutic interventions, and basic psychosocial support alone is not enough for all children, said Henn.

“You need a variety of methods and services at various levels, to meet a variety of needs. But simple, low-cost methods exist now that are viable in Zambia. And Zambia has shown that the host government can be a strong advocate for the mental health of its children.”

Some selected resources

- *Children’s Palliative Care in Africa*, Edited by Amery J. Oxford University Press, 2009. *Children’s Palliative Care in Africa* addresses key palliative care themes, which are crucial to expanding the provision of children’s palliative care, and is focused on experience in Africa (though it should have relevance in other resource-poor settings. **Download** a free electronic version from ICPCN [here](http://www.hospicepalliativecaresa.co.za/). **Purchase hard copies** via Hospice Palliative Care Association of South Africa: <http://www.hospicepalliativecaresa.co.za/> or from Oxford University Press: <http://ukcatalogue.oup.com>.
- UNICEF www.unicef.org
- UNICEF’s Demographic and Health Surveys: www.childinfo.org
- UNICEF’s *Africa’s Orphaned and Vulnerable Generations: Children affected by AIDS*, New York, 2006: www.unicef.org/publications/index_35645.html
- The Joint Learning Initiative on children and HIV/AIDS: www.jlica.org
- The Young Carers’ study, a national study in SA of children whose parents have HIV/AIDS: www.youngcarers.net.au
- ICPCN (International Children’s Palliative Care Network): <http://www.icpcn.org.uk/>
- Children of Parents with AIDS (COPWA): www.copwa.org/scopeofservices.html
- Building Resilience in Children Affected by HIV/AIDS, by Sister Silke-Andrea Mallmann and Catholic Aids Action, Namibia; downloadable at <http://www.caa.org.na/>.
- The Big Shoes Foundation: <http://www.bigshoes.org.za/>
- A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa: www.fhssa.org/i4a/pages/Index.cfm?pageID=3361
- Coalition of Children Affected by AIDS. A collective of private and public foundations and re-granting organizations in the North and South concerned with the welfare of children affected by AIDS: www.ccaba.org
- More than a bailout: Social protection for children affected by AIDS (a radio interview with Prof Linda Richter, an expert from Children’s Services in Kenya, about the need for child-sensitive, AIDS-inclusive social protection to be included in the agendas of world leaders.): www.hsrc.ac.za/News-1171.phtml

Some resources listed on PEPFAR.gov:

- Plan International <http://plan-international.org>
- Promoting child rights to end poverty: *Circle of Hope: Children’s rights in a world with AIDS*, published by Plan, July 2006
- *Assistance to Orphans and Other Vulnerable Children in Developing Countries Act*, signed by the President, November 8, 2005
- State Department Fact Sheet: *President Bush’s Emergency Plan for AIDS Relief: Aid to Orphans and Vulnerable Children*
- www.pepfar.gov/press/82280.htm
- www.pepfar.gov/press/docs/126827.htm

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Providing HIV care in mental health services

By Theo Smart

Providing HIV services to participants in mental health programmes

In HATIP 145 (September 17 2009) we reviewed the mental health care needs in people with HIV in resource-limited settings. This follow-up article looks at one particular mental health programme's approach to integrating HIV care into its service.

People with severe mental illness are at high risk of HIV infection but because of the many disadvantages they face in life, few have access to needed HIV services, especially those within mental health institutions.

"The lives and well-being of psychiatric patients are threatened by the AIDS epidemic, and there is much clinicians can do to minimise the devastating impact of HIV and AIDS on clients in hospitals, clinics, and other psychiatric treatment settings," according to McKinnon et al, who found a high burden of HIV, and a high frequency of HIV related risk-taking behaviours among people with psychiatric disorders in the US.¹

There have been a few similar reports in resource-limited settings.

"All patients can benefit from a sexual health assessment as a part of standard clinical care," wrote Carey et al after their survey found higher than expected rates of sexually transmitted infections, including HIV, among mental health patients in India.² "This recommendation may seem obvious. However, research has shown that mental health providers often do not receive training in human sexuality; some providers believe that patients should not be sexually active, or that the mentally ill are too disabled to be sexually active, or that discussion of sexual matters may exacerbate patients' psychopathology... All patients should be encouraged to participate in counselling and testing for HIV and other STIs."

This pattern of denying that people with mental illness could still be sexually active led Dr Pamela Collins of Columbia University and colleagues to perform an intervention to change this attitude among healthcare workers in South Africa.³ Many of the nurses had HIV themselves, but were extremely reluctant to talk about sex with their clients.

The irony is, according to Joska, Kaliski, and Benatar, that many of the severely disabled are institutionalised without their consent – and yet their consent may be required to provide them with HIV testing services, which could lead to treatment that would save their lives.⁴ "It is in the best interests of those with severe mental illnesses, who often lack the ability and means to engage in safe sexual practice, to test for HIV infection for prevention and treatment. These patients cannot be denied the opportunity to benefit from treatment," they wrote.

Gradually, new guidelines for testing and treatment are emerging, however thus far there are not many reports of HIV services being successfully integrated into mental health services.

Integration of HIV into mental health services in Rwanda

This year at the HIV Implementers' Meeting, when Dr Alfred Ndirababyeyi described the integration of HIV care and treatment services into Ndera Neuropsychiatric Hospital, in Rwanda.⁵

According to Dr Ndirababyeyi, hospital staff were observing HIV neurological disorders in their patients. Many were in denial of their HIV status or suffered from severe anxiety about HIV – but these patients did not have the same access to ART as other populations in Rwanda.

So last November, the hospital piloted an HIV programme in collaboration with ICAP, and MON through the Treatment Research HIV/AIDS Center (the TRACPlus).

Thirty-one staff members were trained in November on HIV counselling and testing and eight in HIV care and treatment. TRACPlus and ICAP provided on-site training and clinical mentorship to Ndera staff.

In January this year, a workshop was held to discuss key issues that the hospital needed to tackle including obtaining consent for HIV testing among people with mental illness; developing adherence tools, planning for follow-up care of patients leaving the hospital, patient flow, principles of disclosure and the interactions between psychiatric medication and ART. Algorithms and protocols drafted during the workshop have since been finalised.

Structure of HIV services at Ndera

Nurses, psychologists and social workers began providing assessments and individual counselling at the hospital. Pre- and post-test counselling were provided in an HIV clinic that was set up in the hospital, with ART initiation and follow up provided at the clinic. Nurses also provided group education on HIV to clients in the pre-discharge wards. The clinic routinely collects data on demographic variables, HIV serostatus, the uptake of testing, psychiatric diagnosis and medication, the ART regimen prescribed, enrolment onto ART, adherence and retention in care – and reports these data to ICAP and TRACPlus on a monthly basis.

Findings

Between January and the end of April 2009, 192 patients received HIV counselling and testing. Eighteen tested positive, and other HIV-positive clients with mental illnesses were referred from other settings. Overall, 31 were enrolled into HIV care (12 men and 19 women). 29% have schizophrenia, 10% mania, 19% bipolar disorder, 10% drug abuse, 22% depression and 10% are currently without a mental health diagnosis.

Eleven have begun ART. One patient with advanced AIDS at the start of the programme has since died. Five have missed follow-up appointments after leaving the facility but they followed them up with phone-calls and home visits.

The next steps

Training of the Ndera staff will continue on HIV/AIDS issues, then expand to all district hospital mental health teams and district hospital HIV care teams on mental health issues. This will be organised with the MoH.

Adherence assessment tools specific to psychiatric settings are being finalised (this includes psychiatric symptom assessments to systematically document mental health status).

Dr Ndirababyeyi say that they plan to develop mentorship and supervision procedures in collaboration with TRACPlus and National Mental Health program, and to renovate facilities to extend the programme.

"We are also planning programme implementation in the district hospitals and peripheral health facilities," he said. Research protocols are in development to study how HIV interacts with mental health, and for new and improved treatment strategies in people with HIV and mental health problems.

“The current programme suggests that integration of HIV and mental health services is feasible in a Rwandan tertiary care psychiatric facility,” said Dr Ngirababyeyi. “And with continued training and mentoring; careful monitoring of ethical considerations; development of referral strategies and adherence support; and documentation of challenges and lessons learned accompanied by collaborative problem-solving, Ndera Hospital will be able to successfully integrate HIV services into routine care and can be a model for integration into other settings.”

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