

# COMMENT

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These orphans in Zimbabwe have looked after themselves since their parents died of AIDS.

## Children of the AIDS pandemic

Practical support and psychosocial interventions are desperately needed to help those dealing with the fallout of AIDS, says **Lucie Cluver**.

I'm sitting on a piece of corrugated iron in a dusty South African township, with the smell of burning rubber in the air. A set of graphs comes to life for me. A 15-year-old girl traces patterns in the sand as she tells me how she found out she is HIV-positive. Lindiwe is one of 12 million children in sub-Saharan Africa orphaned as a result of AIDS. Her parents were said to have died of 'TB and bewitchment', but their symptoms confirmed that their deaths were among the 850 caused each day by AIDS in South Africa.

HIV/AIDS turns 30 this year, and so will a million or so of the children it has orphaned. It is not yet clear what the epidemic's long-term impact on this generation has been, or what it will be for all the other youths affected. Lindiwe is part of the developing world's first longitudinal study of the impact on children of parents made ill or killed by AIDS.

Beginning in 2005, a group of social scientists, psychologists and social workers followed 1,000 girls and boys in South Africa over four years — including those orphaned

by AIDS, those orphaned by other causes and those whose parents were still alive. As study director, I had never anticipated that our team's repeated visits would make us confidantes for these children, whose opportunities to talk about the disease are constrained by stigma. I had also underestimated the extent to which their lives would offer a window onto the complexities of the HIV epidemic.

### LONG SUFFERING

For 30 years, the scientific community has fought the war against HIV/AIDS on many fronts: prevention, treatment, the elusive cure. Much has been achieved: 37% of sub-Saharan Africans who need antiretrovirals are receiving them compared with 2% in 2003.

But research is now revealing a new and daunting battlefield — the multiple social consequences of AIDS on families, especially children<sup>1</sup>. With more than 22 million people in sub-Saharan Africa infected with HIV, many of whom are parents, some 70 million children are likely to be enduring the consequences of living with people sick from AIDS in this region alone.

Along with other studies, the data we have collected over the past seven years (for the four-year Orphan Resilience Study and subsequent projects) show that AIDS in a family has major and long-term impacts on children's development and psychological health.

In the Orphan Resilience Study, my team and I asked children whether they were experiencing symptoms such as flashbacks and nightmares. Their responses revealed that children orphaned by AIDS were 117% more likely to be suffering from post-traumatic stress disorder than children whose parents were alive, and also — to our surprise — 67% more likely than children orphaned by other causes, including homicide, suicide and cancer<sup>2</sup>. Researchers in Tanzania, Uganda, Ethiopia, Zimbabwe and China have similarly found heightened psychological distress among children orphaned by AIDS<sup>3</sup>.

Moreover, our larger, national study in South Africa suggests that 'orphanhood' starts long before a child's parents die. Since 2009, we have ▶

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► interviewed 6,000 children and 2,600 of their caregivers (not necessarily their parents), in six urban and rural sites, as part of the National Young Carers Study ([www.youngcarers.org.za](http://www.youngcarers.org.za)). Our preliminary findings indicate that children with caregivers sick from AIDS are just as likely — if not more likely — to suffer from a lasting psychological disorder (depression, anxiety or post-traumatic stress disorder), and just as severely, as children orphaned by the disease (see ‘Cause for distress’). Moreover, 50% more children with caregivers affected by AIDS are afflicted with these disorders than those whose caregivers have other chronic illnesses.

A combination of social factors seems to make having AIDS in a family worse for children than having a death or chronic illness due to other causes. People gossip about the family; the children may be bullied or excluded from the community; and infected caregivers are often severely impoverished and depressed<sup>4</sup>. “They say that my mother is a prostitute and I will die just like her,” one 10-year-old girl told us<sup>5</sup>.

## LOSING OUT

Such high levels of psychological distress have severe knock-on effects. One is on education. Several studies, including an analysis of demographic and health-survey data collected by governments in ten sub-Saharan African countries<sup>6</sup>, have shown that orphans do not attend school as much as children with living parents.

Our findings paint a similar picture. In a pilot study, we interviewed 850 children, asking questions such as: “How’s school?” Forty-three per cent of children living with someone ill with AIDS said they couldn’t concentrate due to worry about the sick person at home: one 14-year-old boy said, “I can’t stop thinking about my mother. She looks like she is going to die like my father.” Forty-one per cent missed days at school or had dropped out entirely to care for adults at home.

Children may also pick up infections through toileting the sick person, washing wounds or cleaning soiled bedclothes. As part of the National Young Carers Study, we surveyed more than 5,000 children and caregivers in the KwaZulu-Natal province. Among children living with healthy adults, 4% had symptoms of pulmonary tuberculosis. For those whose caregivers were infected with HIV, this rose to 17% (ref. 7).

Other knock-on effects are higher levels of physical and emotional abuse. Preliminary unpublished findings from the Orphan Resilience Study indicate that 5% of children in healthy families are physically abused

(slapped, punched or hit with a sharp object at least once a week) and 8% are emotionally abused (told at least once a week that they are lazy, stupid, or threatened to be sent out of the house or cursed by an evil spirit). For children living with a caregiver who is sick with AIDS, the numbers rise to 12% and 23%, respectively.

Girls in families affected by AIDS are particularly likely to engage in sex in exchange for money, school fees, transport or shelter. Newly analysed data from the Orphan Resilience Study indicate that girls between 15 and 24 years old in healthy families have a 2.8% chance of being exploited in transactional sex. This climbs to 19% for those with carers sick from AIDS. Among girls with AIDS-sick carers who also experience physical or emotional abuse, 46% say that they have had transactional sex.

The long-term effects of these deprivations have yet to be quantified. But various studies worldwide show that school attendance correlates with a child’s chances of getting a job later on. Abuse during childhood is associated with cognitive and social changes that persist long into adulthood — for instance, a smaller hippocampus and reduced capacity for learning and memory<sup>8</sup>. Certainly, the data from our Orphan Resilience Study indicate that psychological disorders worsen as children orphaned by AIDS become young adults, whereas for other orphans and children whose parents are alive, they remain stable.

What can be done to lessen the devastating effects of the AIDS epidemic on upcoming generations?

Happily, the South African government is enthusiastic about implementing research-guided policies for children. The South African government’s departments of social development, health, basic education and agriculture are incorporating the results from our studies and others into national planning policies, such as the 2009–2012 National Action Plan for Orphans and

Other Children made Vulnerable by HIV and AIDS.

The Department of Social Development is also piloting programmes involving life-skills training for affected children and the training of community care workers. For instance, care workers are being taught how to help families with ‘succession planning’ — ensuring that children will be cared for after their parents have died.

## INTERVENTION AND SUPPORT

Non-governmental organizations such as the Regional Psychosocial Support Initiative, headquartered in Randburg, South Africa, which serves 13 countries in east and southern Africa, are creating training and support programmes for children living in homes affected by AIDS, based on the results of studies in South Africa, Kenya and Tanzania. These programmes include workshops to teach children caring for sick adults how to lower their risk of infections.

Meanwhile, major development organizations such as the Swedish International Development Cooperation Agency and UNICEF are using and commissioning research to design and improve interventions, including schemes that provide families with money or food.

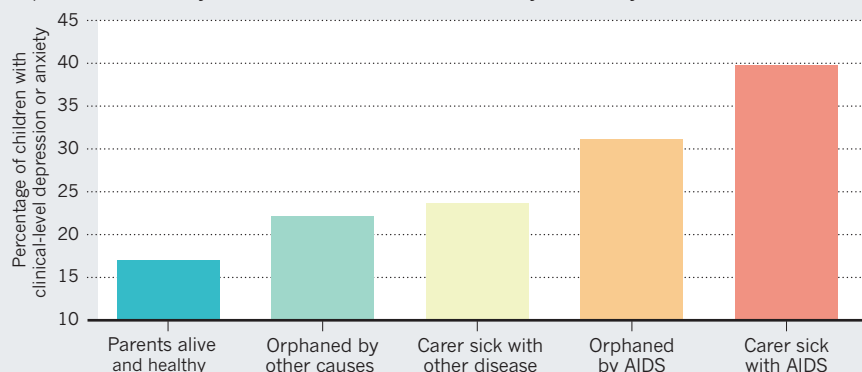
Yet there is far more to be done. Children’s access to tuberculosis testing must be improved. Also, more parents infected with HIV should be taking antiretroviral medication: a study in Kenya, published by US economists in 2009, showed that children were better fed and had better attendance at school when their parents, unwell with AIDS, started taking antiretrovirals<sup>9</sup> (see page 29).

Research is needed to understand how to reduce child abuse, and how to make it easier for children to attend and re-enter school — whether by helping them catch up on missed studies, dropping school fees or providing free school meals. Lastly, evidence-based psychosocial interventions, such as cognitive behavioural therapy and support groups,

**“Orphanhood starts long before a child’s parents die.”**

## CAUSE FOR DISTRESS

Children orphaned by AIDS, or whose carers are sick with AIDS, are more likely to have depression and anxiety than children whose lives are similarly affected by other diseases.



SOURCE: ORPHAN RESILIENCE STUDY

are urgently needed for children orphaned by AIDS or living with sick adults.

For such interventions to be effective and accepted, they must be developed through the collaboration of researchers, governments, communities and affected families. So scientists need to focus on the messy, multifaceted social context of the epidemic, not just on the disease itself.

Support programmes must also be properly resourced. Fortunately, organizations such as Save the Children, UNICEF and USAID are already partnering with the governments of South Africa, Swaziland, Malawi and Ethiopia to ensure that essential psychosocial interventions are provided. These include training community care workers in bereavement support.

The evidence as to which interventions are effective is still thin, but we are not starting from scratch. Last year, for instance, a collaborative study involving health practitioners from Uganda and Sweden showed that depression, anger and anxiety lessened in children who had lost one or both parents to AIDS if they had access to support groups and intensive medical care<sup>10</sup>.

Lindiwe has told only her brother and us about her diagnosis. She asks whether she could call us if she needs to talk to someone. What Lindiwe craves is affection, acceptance. Her boyfriend loves her but in her township, love is Russian roulette: HIV prevalence in her age group is 25%.

A few days after talking to Lindiwe, I spoke in a government meeting in Johannesburg. I put up a graph showing how non-stigmatized children with enough to eat have a 19% risk of developing a clinical-level psychological disorder; children who are stigmatized and hungry have an 83% risk<sup>4</sup>. I looked up at the audience of senior officials. A few of them had tears in their eyes. We must win this battle. ■

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A woman receiving her AIDS test result at Kibayi Health Centre in Rwanda.

# Stigma impedes AIDS prevention

Medical advances cannot help those who deny they are at risk of HIV and avoid HIV tests. **Salim S. Abdool Karim** describes how such attitudes may be overcome.

**T**hirty years since the first cases of AIDS were described, there is much to celebrate regarding progress in the treatment and prevention of the disease. Within the past year alone, several studies have revealed that anti-retroviral drugs can prevent the sexual transmission of HIV.

Yet worldwide, many people who are potentially exposed to the virus avoid finding out whether they carry it, or deny that they are at risk of contracting it. Unless people establish whether they are infected, they will not be able to adopt the most

appropriate preventive measures. As scientists and clinicians, our ability to overcome this denialism will determine whether we ultimately succeed in using combinations of all the preventive and therapeutic tools now available to slow, and eventually stop, the HIV/AIDS pandemic.

During its first decade, the disease brought death, pain and suffering, made worse by the stigma that accompanied infection. As a newly qualified doctor in South Africa, it was agonizing for me to watch hundreds of patients die from AIDS — unable to do much more than treat ▶

▶ their tuberculosis or pneumonia infections and make their last days comfortable. Amid this despair, charlatans and 'snake-oil' cures were plentiful. The real hope among the medical community was that science would produce a vaccine or a cure.

This hope was not entirely misplaced. The most significant advance in the second decade of the epidemic was the development of antiretroviral drugs to treat AIDS patients and to prevent pregnant women from passing on HIV to their children. In the late 1990s, 'triple' antiretroviral therapy transformed AIDS from a uniformly fatal condition to a treatable chronic disease — but only in those countries that could afford the roughly US\$20,000 a year that it cost to treat each patient.

For Africa, the turning point came in 2000, at the 13th International AIDS Conference in Durban, South Africa, when community groups, activists, patients, scientists and health-care workers jointly protested against drug companies and governments, and called for an end to global inequities in access to AIDS treatment. Within a few years, antiretroviral therapy became a reality throughout most of the continent, mainly thanks to funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the US President's Emergency Plan for AIDS Relief (PEPFAR).

### DENYING THE RISK

Events took a different course in South Africa, where today 5.4 million people are thought to be infected (see graphic) — more than in any other country. Until 2004, government hospitals were barred from giving antiretrovirals — whether to prevent rape victims from acquiring HIV or to treat patients dying from AIDS. Thabo Mbeki, South Africa's president at the time, denied that AIDS existed. He and his supporters saw the assertion that a new sexually transmitted disease was sweeping through Africa as a racially motivated attack against blacks and a way for pharmaceutical companies to exploit the poor.

Following persistent activism, advocacy, litigation and mass mobilization involving people living with HIV, the Mbeki government eventually initiated a national antiretroviral rollout in 2004. The delay caused an estimated 330,000 unnecessary deaths and some 35,000 avoidable HIV infections in babies<sup>1</sup>.

Back in 1999, I was asked to join Mbeki's advisory panel, established to assess whether HIV causes AIDS. Sitting on that panel, engaging in futile debate with AIDS denialists while the epidemic raged on, marked the

lowest point in my life. I never imagined that a decade later, long after Mbeki had stepped down, one of the biggest obstacles to curbing the epidemic, both in South Africa and throughout the world, would be another form of denial — this time at the individual and community level. The two kinds of denialism are very different. But both illustrate that scientific knowledge and innovation alone are not enough to save lives.

In the epidemic's third decade, compelling evidence accumulated from clinical trials that male circumcision reduces the likelihood of men contracting HIV from infected women by more than 50%. Last year, my colleagues and I showed that an antiretroviral drug called tenofovir, formulated as a vaginal gel, reduces the chance of heterosexual women contracting HIV by 39% (ref. 2). Also in 2010, epidemiologists showed that a combination of oral tenofovir and another oral antiretroviral, emtricitabine, reduces the likelihood of men who have sex with men acquiring HIV by 44% (ref. 3). Most promising of all, the results of a multinational clinical trial released last month suggest that antiretroviral treatment can reduce the transmission of HIV from infected men and women to their uninfected partners by 96%.

With these tools — circumcision plus antiretroviral drugs that can treat AIDS patients, prevent mother-to-child transmission of HIV and block the sexual transmission of the virus — stopping the epidemic is within our grasp. But only if more people acknowledge their risk of contracting HIV and find out whether they carry the virus.

Acknowledging infection risk is a first step to getting tested for HIV or taking precautions. Risk awareness must be sustained, as taking preventive antiretroviral pills or applying the microbicide gel inconsistently can lessen their effectiveness. Also, it is crucial that people who do take preventive measures know whether they already carry HIV, because exposing infected individuals to a single antiretroviral drug designed to prevent uninfected people from contracting the virus could facilitate the emergence of drug resistance.

Moreover, when people know they have HIV, they may be less likely to pass on the virus to uninfected partners. For instance, American men and women who are unaware that they carry HIV are 3.5 times more likely to transmit the virus to others than those who know they are infected<sup>4</sup>.

### GETTING TESTED

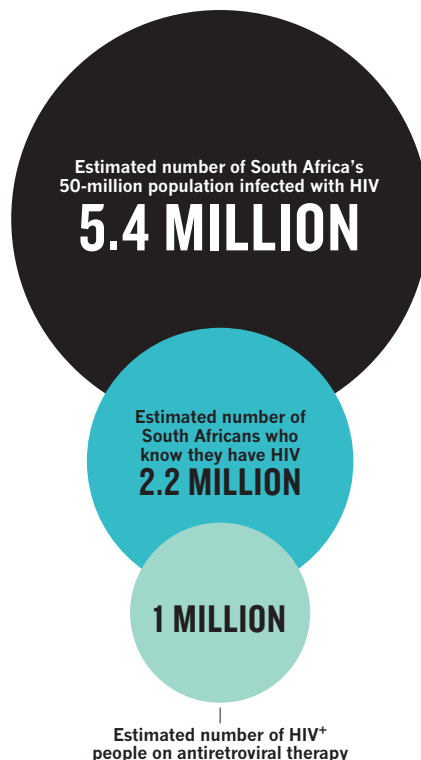
Ensuring that people are sufficiently aware of their level of risk and that they seek regular testing for HIV has proved difficult the world over.

In South Africa, the most recent national HIV survey revealed that 74% of those most at risk of acquiring the virus (including women aged 20–34) were unaware of their HIV status<sup>5</sup>, even though their answers to survey questions indicated that they were well informed about the disease. In 2008, the United States Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, surveyed more than 8,000 men who have sex with men, and found that more than 40% of those infected did not know it<sup>6</sup>. Relatively few of those at risk who are uninfected are taking antiretroviral drugs as a preventive measure<sup>7</sup>, which the CDC recommends.

The numbers volunteering for HIV tests paint a similar picture. Although testing has increased significantly in sub-Saharan Africa in recent years, only about 20% of men and 28% of women in South Africa received an HIV test and result within the past year. Similarly, in Kenya, the 2007 national AIDS survey of 18,000 individuals from nearly 10,000 households found that only 17% of those testing HIV positive reported knowing that they were infected<sup>8</sup>. China fares a little better: about 44% of people living with HIV know that they are infected<sup>9</sup>.

Denial is not the only factor hampering HIV testing and the use of antiretroviral drugs. For instance, in South Africa the public health-care system is already overwhelmed by tens of thousands of AIDS patients. Long queues and overstretched staff discourage many from trying to obtain medical help. But in countries ranging from France to India the practical problems hampering testing and uptake of antiretrovirals are compounded by people seeking care only after they have developed the symptoms of full-blown AIDS.

**“We must not allow the fourth decade of the AIDS epidemic to be the decade of missed opportunity.”**





Women attending an HIV clinic in Rwanda avoid the camera.

L. TOWELL/MAGNUM

We must not allow the fourth decade of the AIDS epidemic to be the decade of missed opportunity. Every prevention programme should involve a combination of interventions tailored to the risks and vulnerabilities of the people receiving them. In sub-Saharan Africa, for instance, teenage girls are up to eight times more likely to contract HIV than boys of the same age. For them, a microbicide gel that they can control is likely to be critical to reducing their risk of infection. Meanwhile, male circumcision is likely to have most impact for men in their twenties.

The challenge is how to implement these strategies effectively with the limited funds available, so that the successes emerging from clinical trials translate into real-world benefits. The recent call by the CDC and the US National Institutes of Health for proposals for 'implementation science' programmes to address the global epidemic is a step in the right direction. Together, these agencies are committing about \$50 million from PEPFAR to programmes involving interventions known to be effective in clinical trials, and which in combination are likely to improve HIV prevention, treatment and care in poor communities.

Most important, any programme of biomedical interventions should include strategies aimed at encouraging people to acknowledge their risk of contracting HIV.

#### WORKING TOGETHER

We cannot assume that demand for anti-retroviral drugs, or for any other prevention technology, exists just because the need does. A government attempt to introduce female condoms in South Africa in 1995 illustrated the pitfalls of rolling something out without

concomitantly creating a demand for it. The \$2.6-million effort to distribute 1.3 million condoms to women proved ineffectual because patients did not request them and health-service providers did not adequately promote them.

South Africa's era of denialism at the highest political level illustrated that simply giving people facts and information is not enough. Fear and avoidance must be understood in the context of both the individual and society. Health practitioners and researchers worldwide must engage local communities to find out what factors are preventing people from making the best choices in terms of prevention and treatment. Community members and patients are best placed to advise practitioners how to couch advice and information in ways that are likely to be effective.

This approach has already proved successful in some cases. For instance, my co-workers and I designed a dosing strategy for the tenofovir microbicide gel whereby women apply one dose of gel within 12 hours before sex and a second as soon as possible within 12 hours after sex. We selected this strategy partly on the basis of scientific information about the drug and its effectiveness in animal studies — but also as a result of detailed consultations with rural women in South Africa revealing that having some flexibility over when to apply the gel was essential<sup>10</sup>. With this dosing approach, nearly 900 women enrolled in a clinical trial were able to successfully apply the gel about 80% of the time<sup>2</sup>.

An underlying obstacle to finding effective ways to intervene is the separation between biomedical and behavioural research in HIV/AIDS. This emanates

not only from our failure, as researchers, funders and clinicians, to fully appreciate that every biomedical prevention strategy includes a behavioural change, but also from counterproductive hierarchies and territorialism within science. If behavioural and biomedical scientists work together to develop solutions, the coming decade may prove to be the one when the tide was turned against the global AIDS epidemic. ■

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