

Strangers in our midst: the struggle to make living with HIV a family affair

Sometimes Dimakatso doesn't understand her grandson. "There are times when he is very naughty. Is it how these sick people are? Then there would be times when he is very quiet and when I ask him if he is upset, he says that he is not angry, he is just thinking."

The old woman pauses and folds her hands in her lap. She throws a gentle but perplexed glance at the nine-year-old who silently fiddles with an ornament on the table.

"I don't understand him. Maybe because he's an HIV-positive child he behaves differently."

Raising the two boys after the death of their mother has added unexpected stress to the life of the 60-year-old. She has accepted the situation. "What can I do?" she says.

There was no time for grief. On days when she feels she can't cope, she withdraws to her bed or watches TV. When she can afford it, she buys the boys fast-food chicken as a treat "and they'll be happy with that".

Thabo, the older of the boys, is HIV-negative. Dimakatso admits that she doesn't treat the brothers the same.

"The difference is there," she says. "I shout at Thabo more than at Nhlanhla but not in a negative way. He's 15, so he's older than Nhlanhla and must take responsibility. I'm old now. I say to him: 'One day I'm going to die. Then what are you going to do? You need to take that responsibility now'."

The impact of HIV/Aids on the health of those living with the virus and on the survival of households struck by disease has been well documented. Less so the impact HIV has on family dynamics and the parenting of caregivers burdened by multiple fears and stresses: the fear of telling the child that it or the parent is HIV-positive; the fear of disclosing their status outside the immediate family; the fear of not surviving long enough to raise a child; the stress of keeping the secret; and the stress of losing loved ones, the stress of surviving.

"All research starts with adult males, then women and then children. Children are last in line to benefit and of whom there's least knowledge, says Johanna Kistner, a child psychologist who runs support groups for HIV-positive children and their caregivers in Johannesburg.

"We've got to become a much more child-centred society before HIV-positive children will benefit.

"I think what the country is not doing is looking at the psychological needs of individual children. We're looking at it large-scale, not at this child, for example around bereavement, or sibling rivalry complicated by Aids. Not enough individual theory has been developed in relation to this overwhelming picture."

The reason: children don't have clout, argues Lorraine Sherr, a professor of clinical and health psychology at the Royal Free and University College Medical School in London.

"Children have always been affected by HIV/Aids. Attention to children generally, and young children specifically, has lagged behind. This has occurred as a result of multiple factors: for example that children lack political voice and power."

International research has shown that HIV affects children's physical, neurological and language development, to what extent is not clear. Effects on their psychological maturation are less well researched, writes Sherr.

"HIV/Aids can affect their experience of love and being loved, their parenting experience, levels of attachment and separation occurrences, for example, due to frequent hospitalisation.

The social situation for a child where HIV/Aids causes illness, death or disruption may affect all levels of development, learning, role modelling, self-esteem, schooling, relationships and families."

In South Africa, HIV/Aids exacerbates family situations already made difficult by poverty. The virus adds further burden to the lives of mothers raising children without financial or emotional assistance from fathers whose departure is accelerated by the woman's positive HIV test. Grandmothers become mothers again at a time when they should be retiring from parenting children and teenagers. Some relatives isolate or abuse positive family members, while others step in to raise more children on tight budgets.

In South Africa, as elsewhere, research has shown that many mothers favour their HIV-positive child above those born negative, fuelled by the desire to create a loving memory before they die

- and by guilt for having passed on the virus. The bond between siblings is cemented by worry and protectiveness, and tinged by jealousy.

In a study published in *Aids Care*, Canadian researchers argued that not framing HIV as a "family infection" has "serious quality of life and planning consequences for parents and children living with HIV".

In South Africa, the government has recognised the importance of keeping mothers alive. But in the context of family networks already fragmented by poverty and burdened by stigma and illness, maintaining a care structure becomes both more difficult and more crucial for children's survival and quality of life.

According to Professor Linda Richter, executive director: child, youth and family development at the Human Sciences Research Council, what these children need is a caregiver devoted to their wellbeing who is given the support he or she needs to care for the child, and assistance for the caregiver and child "to be part of the social institutions that make up our communal endeavours", including families, schools, religious groups and civic associations.

"Without this, external agencies attempt to provide material and psychosocial care, often in unsustainable ways that do not address the child's primary needs to be in relationship with others," Richter argues.

"If we don't keep our eyes on these goals, much of what we do is not likely to be effective or sustainable."

Stigma is undisputedly the greatest obstacle to fulfilling the third item on Richter's list, including families with HIV in communities and their structures. Children with HIV struggle under the burden of the secret they carry, a secret placed upon them by adults fearful of social isolation, who wish to protect their children from this real and perceived threat. The children have internalised the fear and shame that surrounds families living with HIV.

"My mom told me not to tell other people because this disease is for me, not for them."

"I'm scared to tell them because then they might gossip about me on the streets."

"If they knew, they will hate me." "They won't want to play with me. They will say that I might infect them."

These are just some of the responses from 7- to 11-year-old children to the question: "What would happen if others knew you are HIV-positive?"

Most HIV-positive children - and their adult caregivers - share those fears. What sets these particular children apart is that they, together with their primary caregivers, were part of a support group where they could explore those concerns.

When the group was launched in 2001, "HIV was a death sentence. The group helped children cope with death and bereavement. But the adults refused to disclose to the children or allow us to disclose to them. So we couldn't tell the kids what the group was about," says Kistner, the group's founder.

"Only when anti-retroviral treatment was almost on the scene were we able to push disclosure as a life-saving device."

For the caregivers and children the group became a place for much-needed release. "The group exposes them to peers in the same situation," Kistner says. When eight-year-old Faith was asked to choose a picture representing how she felt after joining the group, she picked "happy".

When asked why, she answered: "Because it's not only me that's HIV-positive."

- Christina Stucky is a research fellow in the HIV/Aids and the Media Project, managed by the Perinatal HIV Research Unit and the Journalism Programme at the University of the Witwatersrand. This article was made possible by Johns Hopkins Health and Education in South Africa, the US Agency for International Development and the President's Emergency Plan for Aids Relief. Names have been changed and locations not revealed to protect the identities of the people interviewed

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