

“Are you going to die, Mom?” Research shows that talking to your young children about your HIV status helps them cope better

New scientific research from South Africa strengthens international evidence that children whose parents have a life-threatening disease such as HIV can benefit from their parents communicating with them about their illness and possible death.

South Africa has high rates of HIV and recent estimates from 23 Sub-Saharan African countries show that up to 30% of children live in a household with an HIV-infected parent, most often their mother. This increases the chances that from early on in their life children might be exposed to parental illness, hospitalisation and death.

The research, which was conducted at the Africa Health Research Institute (AHRI), was led by Dr Tamsen J. Rochat, a researcher from the Human Sciences Research Council. It forms part of a programme of work called the ‘Amagugu Intervention’ which was funded by the Canadian International Development Agency. Between 2010 and 2012 Amagugu assisted 281 HIV-positive mothers living in rural KwaZulu-Natal in disclosing their HIV positive status to their HIV-negative children, aged 6-10 years.

In [this paper](#), published on November 21 in the academic journal *Social Science & Medicine*, Rochat and her colleagues analysed data from Amagugu on children’s death-related questions following disclosure.

The research team found that:

- Two-thirds of the children asked questions of the mother following her disclosure. The content of the questions ranged from asking about how HIV caused illness, how the HIV medication worked and how long it would last, how HIV transmission took place and about the mother’s access to health care for HIV.
- A third of children (31%) asked a specific death-related question following disclosure. The content of the children’s questions about death suggests a high level of exposure to familial illness and death.
- There were no significant age or gender effects, with some children as young as six asking questions about death. For most children, questions centred on increasing their understanding and seeking reassurance.
- The study found that full disclosure (using the words HIV) as compared to partial disclosure (using the words virus) increased the odds of the mother and child discussing the possibility of death. The child bringing up the topic of death was associated with the mother describing the child’s first reaction to her disclosure as fear.
- The content of the children’s questions focussed on establishing the *threat* of death to themselves and the mother, the *implications* of HIV and the mother’s prognosis and how they would be cared for during periods of illness or death and *clarifications* about prior family deaths.
- Having discussed death did not impact negatively on children’s mental health, at least in the short term.

Prior research has shown that there is often a mismatch between what caregivers believe children can understand, and what children actually understand. In some cultures parents may believe it is bad luck to talk about death, or they may feel that children are too young to understand. However it is established that if there is no communication they are likely to become worried when they observe changes in their parents' behaviour, or their health. Parents may think the child is unaware, but research suggests they most likely are.

The study confirms international research that while children may not have a mature understanding of death until age 9 -11, they can develop a good understanding of the causal relationship between a biological disease process (such as HIV), the affect it can have on one's body, and the threat of death at younger ages. The study also supports evidence that children exposed to familial illness and deaths appear to more rapidly assimilate these concepts when compared to children not exposed to familial deaths. Children who were exposed to high levels of death prior to the study appeared more frightened by their mother's disclosure, and were more likely to ask questions about this in order to get reassurance about her illness and the possibility of her death. For this reason Rochat says the study findings are highly relevant in South Africa and to other places with high HIV prevalence.

"We need move away from this idea that we can protect children from things that are highly prevalent in their environment, especially since children are observant and a lack of communication can increase their worries and fears. A parent's desire to protect their child is commendable, and a critical component of good parenting, but in this instance it likely does not achieve the outcome they hope for. We show here that there is very little evidence to support parental fears that talking to your child about your life-threatening disease, in an age appropriate way, leads to negative emotional impacts on the child. Sometimes to protect your children, you need to prepare them," said Rochat.

Rochat goes on to say: "If you are HIV infected, in South Africa you are likely to live a long and healthy life if you have access to HIV treatment and adhere to your treatment. But, realistically, illness will be part of your life. There will be times where you need additional medical care, or may need to be hospitalised. Preparing your child for that, having a plan and dealing with it directly, reduces your stress with it, and during those difficult times when you as a parent are coping with an illness or hospitalisation, the child will likely cope better. Of course we are not for one moment saying this easy to do, or that it is easy for the child, but we are saying that we have shown in this research, like we have seen in research from the United States and Europe, that younger children need information, and that providing it does not negatively impact on them."

Rochat cautions that communicating with younger children is not the same as communicating with adolescents or adults, and that parents need support and counselling to meet their younger child's need for information. The Amagugu Intervention gave specific guidance on how to do this, and this likely improved the outcomes for children. Amagugu demonstrates that there is a lot of support we can give parents that will help them to talk about these very difficult things while minimising the harm to the child.

Rochat recommends that both the public and private health and social support sectors in South Africa consider offering practical support to parents living with HIV and other life-threatening

diseases to help them communicate with their children about their illness in a timely and age appropriate manner.