Uganda : The cost of keeping children from knowing their HIV status

- Orphelins du sida, orphelins et enfants vulnérables (OEV) - EVVIH et enfants affectés -

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Throughout his childhood, Gordon Turibamwe, 20, was sickly, suffering from frequent bouts of malaria and chest infections, but his father only told him he was HIV-positive when he was 16, something Gordon says caused him serious psychological trauma.

"I was so shocked and so angry with my dad for a long time," he told IRIN/PlusNews. "I immediately thought I was going to die, I had very little hope."

Gordon had been diagnosed at the age of about ten, and was put on Septrin, an antibiotic, but was never told why he had to take the medication. When he was older, his frequent sickness, as well as his step-mother's death and his father's ill health, made him suspicious about his status. His father eventually buckled under pressure from a doctor and told him.

"If I had known earlier I could have dealt with it better, but I no longer trusted him and I blamed him for giving me HIV," he said. Gordon's father passed away in March - by then Gordon the two were on better terms.

Gordon is the author of a short book, an autobiography titled "How I Discovered I was HIV-positive". He hopes the book will highlight the importance of parents letting their children know their HIV status early on.

His younger brother, Graham, now 12, is also HIV-positive, but was told early on. "You can see that he is handling it well and he's in a support group - he'll be ok," Gordon said.

Stigma and denial

According to Goretti Nakabugo, a Ugandan counsellor with experience in dealing with young people living with HIV, the main reason parents don't disclose their children's HIV status to them is the fear that the child will be stigmatised.

"Children take late disclosure very hard, it's so sudden and they are often very ill when they find out, making it that much harder," she said.

"They are filled with anger, guilt and feel they have been denied a big role in their own lives," she said. "Disclosure is a process ; it should be done in bits from the age of about eight or ten years of age, depending on the child's cognitive development."

Often, Nakabugo added, parents are in denial about their own status, and so admitting their children's status would force them to come to terms with their own condition.

This was the case for Gordon's girlfriend, Princess Nuru, 22, who found out her status when she was 18 years old after a near-fatal illness. Her doctors told her she was HIV-positive and when she told her mother, she accused Princess of having acquired the virus sexually.

"But I knew I had never had sex before so there could only be one explanation that made sense, especially since I had been so sickly throughout my childhood," Princess said. "It was a shock to find out, but my mom's reaction made

it even more terrible."

Princess's father died several years ago, and although his wife knew he had died from HIV-related causes, she only got tested recently - almost four years after Princess was diagnosed.

"She got TB last year and that's when she finally got tested and when she confirmed that she was HIV-positive," Princess added. "Now we are on good terms, she has apologised and she is on TB treatment but is still quite ill."

According to counsellor Nakabugo, the key to disclosure was to deal with stigma first. "If the parents have self-stigma then they'll pass it on to their children," she said. "Stigma leads to denial and late disclosure and late disclosure in turn leads to stigma because the child thinks he or she cannot talk about their status since it was such a big secret for so long - it's a vicious cycle."

According to the American Academy of Pediatrics, research indicates that children who know their HIV status have higher self-esteem than infected children who are unaware of their status.

"Parents who have disclosed the status to their children experience less depression than those who do not," the Academy said in its policy statement on disclosure to children and adolescents living with HIV.

"Disclosure should not only take into consideration the child's age, maturity, and the complexity of family dynamics, but the clinical context as well," the statement added. "In critically ill children, issues of dying rather than disclosure may be more appropriate to address."