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**Families grapple with dark secret**

By ARTHUR OKWEMBA

The private struggles of a small but anonymous group of Kenyan parents of adolescent children have come to light in yet another twist to the decades-old battle against HIV.

While the challenges of parenting adolescent children are well known, a number of parents and doctors who opened up in recent days spoke of the far more complex matter of informing the children that they have been HIV-positive since birth — casting a shadow on future love and relationships.

HIV-positive parents said they had delayed this information to protect their children’s innocence.

But with the reality of teen sex fast approaching, they were forced to face the hard questions:

* What if my teenage child became sexually active before I tell them that they contracted the virus at birth?
* How do I communicate that I am responsible for their status?
* How do I explain the long silence?
* How will my child react?

It is a struggle that Margaret, who works at a government hospital in Nairobi, knows well.

Last year when her daughter Pat turned 16-years-old, she celebrated her birthday with a lot of apprehension.

During the party, her daughter invited her boyfriend who was about 17-years-old.

What frightened Margaret was not her daughter dating, but that she had not told the girl she was born HIV-positive.

For 16 years, she had guarded the secret of how the virus was passed to Pat from her and the father.

Margaret says she had to pray for strength to break the news to the teenager.

“It was not easy because I was trying to tell her that she has to take extra care than other young women of her age when it came to having relationships. I also had to find ways of explaining to her how she got the virus.”

Even though Margaret counsels HIV positive persons to live positively, this was the most difficult thing for her.

After several visits to a professional counsellor, Margaret and the counsellor disclosed to Pat her status.

“We started telling her of my status first and explained how I got infected. On the third visit, we disclosed to her that the virus was passed from us (mother and father) to her at birth.”

Pat was distraught for two days before she fame to terms with her condition.

“Since then, she is very responsible especially with relationships. Most of the time we share a lot like sisters, and so far so good,” says Margaret, smiling.

She suggests that parents with HIV positive children should be taught how to disclose to them their status.

**Sexually active teenagers**

Margaret is not alone. When Simon’s wife died four years ago from an HIV-related opportunistic infection, he struggled to ensure one person, their 15-year-old son, did not know the cause of death.

Simon and his wife had kept the secret about the virus they passed to their son, Jared, at birth. The sickness and the death of his mother brought him close to establishing his HIV status.

So fearful was the couple about him knowing his status that when he fell sick, one of them took him to hospital to ensure they managed the information he got.

To stave off opportunistic infections, they kept him on immune boosters and a very good diet.  So far, he has not started taking ARVs.

“His CD4 count is good as well as the viral load level. My prayer is he does not slip from where he is now,” says Simon, who has been on antiretroviral therapy for six years.

Simon is now faced with another dilemma: his son has started developing a strong interest in girls.

“So far I have managed very well. But the biggest problem I am experiencing now is to tell him that he is HIV-positive, and needs to abstain or have safe sex,” says Simon.

What worries him most is his son could be sexually active, and maybe having an intimate partner.

This means if Simon does not break the news soon, then he is going to unknowingly infect his partners or get infected with possibly another strain of the virus.

**Delicate assignment**

The possibility of this happening is more real, if documented evidence is anything to go by.

*The 2008/2009 Kenya Demographic and Health Survey* found that 22 percent of young men are twice as likely to engage in sexual intercourse before the age 15 than young women.

And by age 18, 47 per cent women and 58 per cent men have had sexual intercourse. Simon’s son maybe one of those young men engaging in sex before or by the age 15.

More worrying, the study notes, many young Kenyans reported engaging in unprotected sex the first time they had sex.

Of those interviewed, only 24 per cent women and 26 per cent men had used a condom when they had their first sexual encounter.

*The Kenya Aids Indicator Survey 2007* found about 2.3 per cent of those infected with HIV were aged between 15 and 19 years, and 5.2 per cent were aged between 20 and 24 years.

It is this reality and context that is pushing Simon to find appropriate time and place to tell his son the truth.

“I do not want any other person to do it. Let the counsellor come into the picture after I have first talked to him,” says Simon.

His biggest fear is Jared will hate him for not telling him about his condition if it is disclosed to him by someone else.

“He needs to understand why we took this long to tell him.” HIV experts warn that if the revelation is not done well, it can be devastating to the young person.

“The first thing they see is their world has come to an end, and may even commit suicide. Such disclosure should therefore be handled very careful and in a gradual, calculated manner,” says Surendra Patel, an adjunct professor at the University of Nairobi College of Biological and Physical Sciences.

A doctor at a private hospital in Nairobi’s Eastlands said a Form Two boy went into shock and refused to speak to anyone for three months when he was told about his HIV status two years ago.

He disappeared from school and was found after five months. “He was an orphan and nobody had told him about what killed his parents.

“Only to learn about his status when tests were done to establish the cause of an opportunistic infection he was suffering from,” says the doctor.

These cases are just a tip of the iceberg of the difficult situation that other parents with children who were born with HIV are going through. Disclosing to the children is frightening.

“Majority of the parents postpone disclosing to the child when young because they are likely not to comprehend what they are being told. Hence parents wait for an appropriate age to disclose,” says Prof Omu Anzala, head of the Kenya Aids Vaccine Initiative.

Prof Anzala adds that when the child has reached an appropriate age of 12 to 16 years, the parents faces another dilemma of explaining how he or she got infected.

“Some of these children have grown knowing that HIV is spread through sex. And here you are telling them they are HIV positive when they have never had sex. It is just a difficult area for parents,” says Prof Anzala.

 “It is even a bigger dilemma when the parent has to tell the child to start medication and take care when in intimate relationships.”

At the MP Shah Hospital in Nairobi, a doctor has offered to help parents facing such a dilemma to disclose to their children their HIV status.

“We are waiting for the April holidays to disclose to the two teenagers and chart the way forward, including speaking about relationships,” says the doctor who cannot be named because of the sensitivity of the matter.

HIV experts say parents feel guilty telling their children that they were infected by them. But the biggest question is how some of these children are able to survive without drugs for such a long time.

Researchers say their bodies have learnt to coexist with the virus and they only fall sick when the immune system is weakened.

Prof Anzala, who is leading research on adults whose immune system is able to control HIV replication, says this may be explained by two factors that host or virus related.

Either the child has certain genetic related factors such as human leukocyte antigen (HLA) which contains a large number of genes related to immune system.

The HLA play a critical role in immune defence, and a child with a good function of these genes has a better protection against diseases.

The other explanation is the child might be having a virus that does not replicate very fast.

Like in adults some of the children, although at a lesser frequency, might also be elite controllers-persons with antibodies able to neutralise the virus.

That is why when on good nutrition and care, some children live with the virus into adolescence without a scare.

Matters become complicated when they start experiencing changes that make them attracted to the opposite sex.

They want to fall in love and some start having sex, at times without protection.

Dr Patel, who was among the first doctors to handle HIV patients in the early 1980s, says these are some of the most difficult cases he has dealt with.

“They want to live and enjoy life like fellow teenagers and you have to ensure they do it in a more responsible manner. This is the most difficult part,” he says.

**Fear of falling in love**

But even those who know their HIV status are not finding it easier either.

“My friends have female friends and they always wonder why I am not getting intimate. Little do they know that my HIV status is the cause,” says 17-year-old Frank.

Frank says he fears that no young woman would want to fall in love with him if he discloses he is HIV positive.

“I fear I will be deeply devastated if she rejects me. So I am avoiding falling in love.”

When he decides to fall in love, Frank has resolved it will be with a girl who is also HIV positive.

Like Frank, other HIV positive young people are facing serious challenges especially when it comes to having relationships and starting a family.

But with advancement in technology, they are assured of getting HIV negative children and raising a family.

Support groups of young people living with HIV have also been formed to help them deal with these problems.

In these groups, young people are educated about the dangers of risky sexual behaviours and drug use. They are also sensitsed on relationships.