

Nurse cases

HIV Clinicians Society Conference 2018



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Case

A 21 year old male diagnosed HIV+ 2 years ago and commenced on TDF, FTC, EFV. He now complains of weight loss and feeling unwell. His most recent viral load was 5 400, CD4 count 280.

He says that he is not getting on well with his stepmother. She often locks him out of the house and he sometimes does not have food to eat. His mother died when he was young. His dad is also HIV+ but they do not talk about HIV in the house.

He has a girlfriend, but he has not disclosed his HIV status to her.

You notice that he had missed a few clinic appointments. When you ask him about it, he says that he does not like coming to this clinic and he would prefer being transferred.

*Always put yourself in others'
shoes. If you feel that it hurts
you, it probably hurts the
other person, too.*

— Rachel Grady



Patient perspectives: Accepting & living with HIV

There is time when we accept it, and there are times when you feel like “eish it’s hard” and you think like how to accept it, and you feel like lost now, there is no one who could say “am I really like HIV+”, it’s like hard to accept.

You find that you are sick, you know sometimes in the morning you feel, today that I’m not ok. Maybe it’s my CD4 count or maybe HIV is doing this to me, because the only thing you think is that HIV is doing this thing to me today.

Patient perspectives: Taking medication

When I was told that now you going to start medication and take ARV's for life. That's when I really got scared. That night I cried myself to sleep. I thought now I am really sick and I just thought my life is over.

But the thing is, you feel perfectly normal during the day, and then seven o'clock strikes and you're like okay, I'm different. So you don't drink it because you want to go on living life like a normal person.

Patient perspectives: Disclosure

If I am telling my girlfriend, it's been one year in a relationship, like she would turn it back on me that I am HIV. It must be like six years or seven years, then I can tell her because she has been with me all the time.

I had challenges telling her the truth. There are times when I would want my stepchild to give the medication to the baby. And I would just instruct her and not tell her what it was. She is a grown-up girl. One day I told her that it was medicine for diarrhoea, please give the baby when she wakes up. I was the only one who could give the medication.

Patient perspectives: Stigma

So it's something you wear, something that's like a shadow all over where you go, always being there for you.

They didn't even like us to come close to the children. To come play with the children.

The father of my baby never wanted to hear anything about HIV. Every time I spoke about HIV he would leave home and threatened never to come back. He left and stayed with another woman. He gets so aggressive.

Patient perspectives: Support

My father will say “my child I’m going out now” and he will go and drink and then he will come back and ask me “why didn’t you take your pills” and hit me.

After that when I got that results, I told him that I am positive. So he treated me different, like he didn’t eat in the house, didn’t want to talk to me... then I told him that I’m coming to the clinic and he didn’t talk to me. When it’s end of the month he doesn’t give me money. So like I told myself that it’s because I went to get tested and I’m positive. That is why he treats me different.

Patient perspectives: Health facilities

I find it very insulting that the government are like making these special areas for us. It's like showing people that we are HIV+, so now you are sitting there, and the people are looking at us and they know now those are the HIV+ people. So they are basically telling people we are sick.

Because if when I enter your office, for example, and there's a sign at the door that says HIV, as we are waiting, there's a lot of us outside, and they see that I enter your door with that sign, they will say, "yho she is already finished" so I'll be scared to enter your room, I will wait for all these people to go, then I'll enter alone when it's empty.

Patient perspectives: Health care

The fact that they keep changing the nurses. You already confided in one person. The next time you come it's changed again. You have to. Somebody else knows your news again. That was the one thing that used to irritate me; I don't believe in that confidentiality. I honestly don't.

It was not easy to get permission from work, I used to get permission for myself and now I have to get permission for me and the baby.

Patient perspectives: Health worker attitudes

If they can stop speaking impolite sometimes, because you are also a human being and you do not forget what has been said to you, you think about it and feel like nobody cares about you, the way you talk to someone...To be able to communicate because you can get some counsellors who just speak like “why are you not taking your pills, why are you like this, why are you not behaving well,” because they didn’t listen to your problem first as to why are you behaving the way you do, so they just ask what they ask.

Now reflect back on the scenario...

- ❖ Would you have a different approach if you knew the thoughts and feelings of the patient?
- ❖ Given the complex realities of providing HIV care, is it possible to make our approach more person-centred?

Take home message

Remember we are caring for people, not diseases.

“I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.” - Maya Angelou