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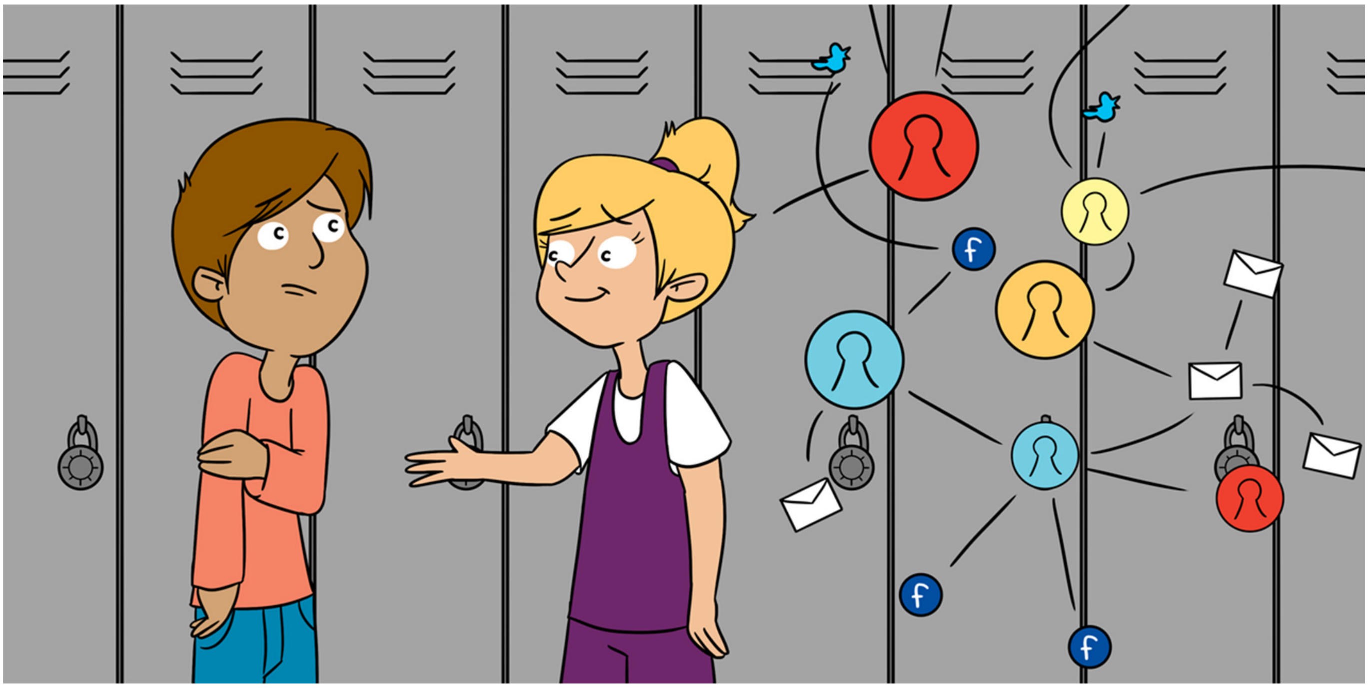

WHY IS IT DIFFICULT FOR YOUNG PEOPLE WITH HIV TO SHARE THEIR DIAGNOSIS?

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HIV is a virus that attacks the immune system and weakens a person's ability to fight infections. There are around 37 million people living with HIV, mostly in Africa. Nearly two million people with HIV are under 15 years of age. Most of these children and some older adolescents/young adults were born with HIV. Medication can help people with HIV to lead normal lives, but many young people find it difficult to tell others that they have HIV. Telling others about having HIV can help people get more support, reduce their chances of passing HIV to others, and help them take medication as prescribed. Telling people about having HIV can also feel risky, though, because there is a chance that those people may not react positively. This article presents research focusing on ways to help young people with HIV think about sharing that information, and how we can support children to make the decision to share.

The content of this article is most suitable for young people aged 12 or over.

YOUNG REVIEWERS:

BROCK
AGE: 13

DRACHMAN MONTESSORI K-8
AGES: 13–14

WHY IT IS DIFFICULT TO TELL SOMEONE A SECRET

Imagine that there was something about you that you wanted to share with a friend. It might be how you feel about your friend or someone else, or something that happened to you that you want your friend's help with. The problem is that you do not know how your friend will react. Will they think differently about you? Will they make fun of you, or tell someone else what you told them? Will they be offended that you had not told them before? You know that you do not have to tell your friend, so maybe it is best just to wait for another time. Or maybe it is best not to tell anyone at all. This is how young people with HIV often feel about telling other people about their HIV.

WHAT IS HIV?

HIV is a virus that attacks the immune system and weakens a person's ability to fight infections and disease. There are around 37 million people in the world living with HIV, mostly in Africa. HIV can be found in bodily fluids which are exchanged when people have sex, in blood, and in breastmilk.

Early signs of HIV infection sometimes include flu-like symptoms, but not everyone will experience symptoms immediately. It may take many years before other symptoms of HIV infection are seen, such as weight loss, recurrent diarrhea, night sweats, skin problems, and infections. HIV cannot be cured, but it is treatable. The treatment involves medicines known as antiretroviral therapy. These medicines control the virus and help people to remain in good health, without anyone being able to tell that they have HIV. If medications are taken as prescribed, people living with HIV can expect to have a normal/near normal life expectancy. That means that they can expect to live for the same length of time as anyone else.

HOW IS HIV TRANSMITTED?

HIV can be transmitted between people in several ways:

- Sex without condoms, with someone who has HIV
- During pregnancy, birth, and breastfeeding
- Sharing infected needles
- Blood transfusions

U=U stands for "Undetectable equals Untransmittable." In other words, when people who are HIV positive are taking their medications properly, the amount of virus in their blood will be so small that it will not be possible to detect it. If this happens, they will **not** be able to transmit the disease to sexual partners.

PERINATALLY ACQUIRED HIV

If HIV is transmitted from mother to child (during pregnancy, birth, or breastfeeding), this is called vertical transmission or perinatally acquired HIV. There are large numbers of young people who have perinatally acquired HIV, including most of the nearly two million HIV-infected children under the age of 15. This group faces many of the same challenges that anyone with HIV faces, including the need to take daily medication for life and go to clinics and hospitals regularly. As they get older, they will need to manage their own health and protect partners from the possibility of HIV transmission. However, people with perinatally acquired HIV have an additional challenge, in that their first sexual relationships will occur when they know that they have a sexually transmittable illness that is often stigmatized. Stigmatized means unfairly thought of by many people as being something to be ashamed of.

SHARING HIV

All people with HIV have to make decisions about sharing their HIV status with others. Telling others about having HIV can lead to more support, less chance of passing HIV to others, and help with taking HIV medications as prescribed. Telling people about HIV can also feel risky, though, because there is a chance that the friend, family member, or partner may not react positively. Negative reactions might happen because some people hold negative views about people with HIV.

As young people with perinatal HIV grow up, sharing their HIV status with partners and others becomes more important, because sharing this information may help them to feel intimacy (emotional closeness) and to gain support. However, in young people with perinatally acquired HIV, rates of sharing an HIV status are low [1]. Sharing is difficult, particularly in relationships, because of a fear of rejection, a lack of confidence about sharing, and concerns that the person being told will tell others [2]. One issue that is specific to young people with perinatal HIV is the attitude of the parents about sharing. Some parents might not want their son or daughter to share this information with others. Also, young people may be concerned that telling others about their own HIV status will reveal the status of their parents, as well.

We have conducted studies exploring the sharing of an HIV status in young people with perinatally acquired HIV. One study focused on intimate relationships in young adults [3]. We found that decisions about starting, continuing, and resuming relationships were shaped by issues around sharing an HIV status. Participants spoke about how fear of sharing affected their relationship decisions:

> *"…maybe that's why I don't think about having a proper relationship, cos it's always in the back of my mind sometimes, I think I'm going to tell a girl the situation, she won't be interested anymore."*

Another study involved interviewing young adults with perinatally acquired HIV who had become mothers [4]. They spoke about feeling socially isolated due to their difficulties sharing their status with others, including their partners:

> *"I would tell them (partners about status) and they would just all of a sudden disappear."*

> *"I just thought I would never have kids because of the whole status thing, I just thought that was too much to handle, I would have to tell the person I have this and I didn't think I would find someone that I could openly tell."*

A third study of young adults with perinatally acquired HIV [5] focused on sharing with friends. There was little sharing with friends, because people with HIV imagined that conversations about sharing their status would result in a stigmatizing response from others.

> *"Nowadays you've got Twitter and Facebook and so on. It's like you're connected to so many people…. if you told someone, someone knows someone, who knows someone who… and so, like it's worse to control."*

When people were able to share their status, though, they often found it helpful and it increased their confidence in terms of sharing their status with partners

> *"When [my partner] asked me [why I took medication], I was like ok [I'll tell you], because I'd told (two friends) before, so it wasn't like I was scared"*

One final study [6] focused on HIV communication between mothers living with HIV and their adolescent children with perinatally acquired HIV. It was clear that the adolescents felt that their parents advised them to keep their status secret:

> *"They're completely and utterly against it. Like, they don't want me to disclose because they don't think that like, my friends will stay…that if things go badly that at the end of the day, you just lost a friend and like, the implications that it can have on your life like, you don't know who that person is going to tell."*

HELPING YOUNG PEOPLE TO SHARE THEIR HIV STATUS

Young people with HIV, and professionals working with them, say that they would like more guidance about sharing an HIV-positive status. Researchers and healthcare professionals in the UK and Uganda are, therefore, trying to develop a four-session programme to help young people with perinatally acquired HIV to make decisions about sharing their status. This will be for adults between 18 and 25 years of age. The programme will include three group sessions for both males and females (run by a professional and a peer worker), to help young people explore their motivation to share their HIV status and build sharing skills. Then there will be one individual session to work on developing a sharing plan. We will develop the details of the programme by interviewing young people with HIV, their friends, family, and partners, and health care professionals. Then we will compare the programme with the usual care given in the UK and Uganda, to see whether it is reasonable and acceptable. Typical HIV care in both countries does not involve any routine or structured programmes to help young people to share their status. We hope that this programme will eventually become an approach that young people with HIV can use to help them with decisions about sharing their status no matter where they are in the world.

FURTHER READING

The Children's HIV Association have a great website where you can find out more about children and young people living with HIV—https://www.chiva.org.uk/.

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CONFLICT OF INTEREST: The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

YOUNG REVIEWERS

BROCK, AGE: 13
My interests include baseball, football, fishing, the outdoors, and reading. For the future, I am interested in becoming a conservationist or a scientist. I am particularly interested in trout and their habitats and the whirling disease that has impacted our Canadian lakes and rivers. I am an avid fisherman and am currently learning how to fly fish. I love science and I am very curious about the world around me.

DRACHMAN MONTESSORI K-8, AGES: 13–14
We are 15 eighth grade borderland kids at a public Montessori K-8 in Baja Arizona... and we have been working together so long, we are one big crazy family, like siblings, that lowkey like each other. We enjoy chillin', playing sports, and making each other laugh. Even our flatheads are actually smart. We are young but together we are strong.

AUTHOR

MICHAEL EVANGELI
Dr. Michael Evangeli is a Reader in Clinical Psychology with research and clinical HIV experience in the UK and Africa. In addition to his doctoral clinical training, he has a Public Health in Developing Countries M.Sc. He has led or is leading on studies evaluating psychosocial interventions for young people with HIV in the UK, Uganda, and Botswana. His main research interests relate to psychological

and behavioral aspects of HIV. There are five main inter-related themes to this work: HIV testing; HIV-related behavior change; Psychological elements to individuals' engagement with HIV care; Well-being and adjustment in HIV; HIV sharing/communication. *michael.evangeli@rhul.ac.uk.