

CHIVA Youth Committee - Symposium

Naming and Talking

By CHIVA Youth Committee and Katie Warburton, CHIVA Health Lead, Senior Lecturer in Children's Nursing, University of Central Lancashire

Arguing for a normalisation in their experience of HIV naming, the CYC presented a case for how to handle children with asthma and the importance of parents talking openly when managing their health. The CYC then debated with 'parents' voices and 'young people's' voices on why, when and how to talk about HIV.

This included recognising parental fears that their child would encounter stigma, would not manage the information and would not keep it a 'secret'. However, reasons for delaying the opportunity to tell the child about their diagnosis were seen as excuses - arguing that children, and young people, have a right to know about the condition (HIV) that lives within them, or they will become resentful. Yes, we might encounter stigma, but if we talk about HIV more there won't be the stigma, it will present opportunities to educate. You cannot accept something you don't understand.

They encouraged their parents to talk to them and to find support and come to terms with their own diagnosis, to face it - ideally before planning children. It will be easier for everyone.

CYC Top tips on talking about HIV

Keep on giving small bits of information. Start with the basics and then build upon that to include how HIV works in the body and what would happen if it is untreated.

The process can make you feel isolated so checking in with the YP.

Give space to talk.

Explain that there are people who don't understand, but don't say 'don't tell...' say 'who do you want to tell.'

Get them linked into CHIVA, camp and social media.

Use Information and resource packs.

Same age appointments in clinics.

Why? To increase confidence, stay healthy and provide motivation to take meds.

The attitudes to stigma of the 'old generation' and 'new generation' were compared. The older generation were encouraged to let go of stigma and let go of their fears and learn something new.

Katie Warburton presented the latest thinking and methods of talking and naming HIV.

CHIVA is trying to make a positive move away from the use of the word 'disclosure' as it associated with telling something negative.

CHIVA naming audit 2017 identified that 14% of 11-16 year olds don't know their diagnosis.

Parental resistance, cognitive impairment and lack of support were the main reasons why. Stigma is the challenge but we need to advocate for children and voice their rights.

She described the health led naming process; starting at 6 years old and full knowledge by 9 years old, in order to support adherence, self-esteem and engagement with health services. The process reduces self-stigma and helps with onward sharing.

Communicate by age and development - examples, steps and practice tools were provided that simplified the process. You can go through a series of explanations that keep the family on board, and then go back and build up info.

What makes you healthy? -> Who can you talk to about your health? -> White blood cells -> why blood tests -> virus (or infection) -> medicines -> transmission -> Human Immunodeficiency virus -> so that means you are HIV positive

In the end the tension between the young people's (new generation) and parent's (old generation) perspectives remained but the debate was opened up (and would usefully continue);

- parents are very anxious, it's really hard for them - how can we support them?
- parents need to accept their diagnosis so that their child can
- need to tell families how stigma works
- Health needs to lead the process and model confidence like with other health conditions, acknowledging naming needs to be supportive

With the last word going to our Swedish colleague Lars, 'We tell the children. Then we help the parent understand and bring them on. Otherwise there is endless discussion of when is best to tell.'

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