‘But it’s my story’: exploring the experience and effect of telling children how they have acquired HIV

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Disclosure of perinatal HIV

• Alongside adherence, disclosure to children focus of social science research in paediatric HIV
• Literature explores: reasons for disclosure, effect on adherence, (immediate) experience of disclosure
• Relatively absent: effect on relationship with parent/s, experience of onward disclosure and post-disclosure needs
• Focus of today’s presentation: post-disclosure experience.
Qualitative study design: BREATHER

• Longitudinal qualitative research embedded within clinical trial
• Repeat interview design with YLPHIV and carers

BREATHER (2011-ongoing): qualitative longitudinal study with 33 young people (aged 10-24 years) in Uganda and UK; Interviews with 15 carers (Uganda).
  – Investigating acceptability of short cycle therapy and broader context of adherence
  – Also exploring broader context of growing up with HIV on ART
  – Participants – perinatally infected
Disclosure *for* ART adherence

- Despite focus in national guidelines and recommendations across settings, disclosure remains mostly an *event* not a *process*
- Carers’ rationale for disclosure: improve adherence to ART
- Disclosure (and subsequent HIV talk) limited to virus, pills and consequences of non-adherence
- Full disclosure and post-disclosure talk an exception
Disclosure: a very incomplete picture

• Limited knowledge about:
  – how they acquired HIV
  – perinatal transmission (their past)
  – PMTCT (their future)

• Significant (silent) concern about how they came to live with HIV
• And what it means for them and their future
• Piecemeal knowledge generated deductively
• No questions asked; reflect dynamics not lack of curiosity
“My mum made me have a day off school and I can’t remember if I was 12 or 13 (...) and she gave me this leaflet and she said I’d got it. And that’s basically how she told me. What did the leaflet say? It said AIDS/HIV. And had you ever heard of it? Yeah. How had you heard of it before? Because the school tells you all about it in science, they tell you all about the sexual intercourse and stuff. So when you read the leaflet what did you think it meant for you? I don’t know because I didn’t know what it meant at the time (...) And did you chat about it with your mum? No. You just felt like OK there’s a leaflet here, this is what...And I read through the leaflet.”
Nelly, Uganda, 18 years old boy

“Sometimes when I get to hear the words itself, HIV I think of it and I start thinking ‘how is it?’ I still have the question, ‘how is it?’

Do you mean how you got it?
How I got it, what might have caused it, actually I ask myself that question: ‘what might have caused this disease to me?’ Because all my brothers are negative”.
Sean, UK, 17 years old boy

“So tell me about what you’re thinking about the future. If I’ll get married, if I have kids will they have it too? Will I ever find myself in a situation where I do pass it on, and that sort of thing.

And (...) how do you respond to [these thoughts]? I don’t know. I just find a distraction and then that puts it at bay, so yeah”.
Reaction towards parents

• Amongst those who knew - majority not angry
• Understanding towards parents
• Contrary to negative expectation of carers
• Carers’ concerns - postponed disclosure - broadly unjustified
• Exceptions:
  – One or two participants very angry about it
  – Many young people upset by lack of honesty (up to and after disclosure)
“To be honest, this actually brought me and my mum closer together because it’s something that only the two of us share. So I don’t really feel any anger or resentment towards her. When we sat down and talked about it once, I, we seemed to, well I seemed to think that it may have been from my real dad…. it wasn’t my mum that I blamed for it but I don’t really blame anyone to be honest. I don’t, I’m not angry about it. I’m not, I don’t, yeah, I don’t really hold as much anger about it”
“My parents still haven’t told me how they got it, I don’t know, I think they do but they’re not going to tell me anyway. Do you think they know? I'd say so. Does it occupy your mind? Yeah, like I'd like to know which one of them got it first (...) it’d just be interesting kind of. Do you feel like they should tell you? Yeah. How come? Because they passed it onto me like, so I deserve to know how I got it, because my, like effectively that’s how I got it, how they got it.”
Mario, 17 year old boy, UK

“They waited 12 years to tell me. My dad said he had a lot of personal demons about telling me because he still carried the guilt of giving it to my mum (...) My mum takes a lot of blame for giving it to me. So it’s kind of a chain reaction, if you think about it. I, no-one blames me. But it’s hard for me when my mum tries to apologise. It’s really hard because you’re just like, it’s done, like we can’t turn back time and stop it.”
A complex pattern

• Disclosure not always ‘vertical’
• Carers’ knowledge also partial
• Secrecy amongst carers’ within families
• And understanding of HIV transmission not always accurate
• All leading to partial disclosure, confusion and more silence
Amy’s stepmother’s story (Uganda)

- Through Amy’s HIV diagnosis she discovered:
  - her own HIV risk
  - her partner’s HIV status (Amy’s father)
  - the circumstances of Amy’s mother death
  - how Amy acquired HIV

- Yet neither Amy nor the stepmother know about PMTCT
- Amy thinks she will never have children or get married
Cycles of non-disclosure

• Encouraged when disclosed to not to tell anyone else (by clinic and household)
• Severe lack of post-disclosure talk (all settings)
• Ill-equipped to disclose to friends, family or partners
• Some want to – but they can’t
• Some say they don’t want to – but why?
“[My Mum] told me not to tell anyone, and stuff like that.

Why does she do that do you reckon?

Because she does it, I don’t think she just don’t trust anyone, because of what happened [to her] as well...

Do you think your mum would have the same attitude towards telling men that she’s (...)?

I don’t know if she tells, because she has boyfriends and all that, but I don’t know if she tells them, it’s really confusing.

But you never talk about that?

No.”
Implications

• Inadequate discussions of HIV beyond ‘naming’
• Carers require support with treatment literacy to inform disclosure
• Carers and clinicians need to better coordinate around and post-disclosure
• Silence about HIV within households → misunderstanding and misinterpretation
• Significant tensions about whose story it is to tell
• Growing up cohort- major challenges being created through inadequate post-disclosure support:
  – For public health
  – For young people’s concerns and wellbeing
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