



Positively Spoken: Amplifying the Voices of Young People Growing up with HIV Through Oral History

#51

INTRODUCTION

- Oral history has documented experiences of communities affected by HIV over 40 years
- Including young people who grew up with HIV is challenging due to privacy/data protection law
- HIV legacy now being discussed, crucial to capture the past through the eyes of the child
- Need to enable youth-led, participative research
- Must safeguard the high prevalence of post-traumatic stress disorder in people living with HIV (Tang et al, 2020)*

*mindful that not everyone with HIV has experienced trauma or likely to re-experience it through this project

AIMS

To establish sensitive method mapped on to the six principles of trauma-informed practice model (Gov.UK, 2022) **to create a safe space for truth.**

To create a model that mitigates risk of stressful interactions or re-traumatising young people, but allows telling of own stories.

METHODS

- **ORAL HISTORY** archived broadcast quality sound recordings of 35 young people's unique memories from whole life
- Participants mean age 24 years; 64% female, 28% male, 5% trans. 60% born outside the UK & Ireland. Interviews ranged 2-10 hours in length and explored diagnosis, stigma, family relationships, healthcare, identity and resilience
- **CASE STUDY** authorised life-story sound/transcribed extracts, interviewee feedback, peer-interviewer reflections
- **PARTICIPATION** five paid peer interviewers trained and mentored. Project communications and outputs lead by youth team
- **PARTNERSHIP** with British Library to look after (guardianship) and preserve (archive) recordings *in perpetuity*

Authors: Dr Wendy Rickard, University of Newcastle, UK. Amanda Ely, Chiva.

RESULTS

Illustrative Interview Extracts:

Double life

"I wish I had access to the ability to have told teachers at school that I was living with HIV. Because, you know, I was going to hospital every three months. And the things we were making up made me sound like I was skiving. And I was consistently written down as, you know, someone who just skipped school. And I wasn't, I was in hospital, but I couldn't tell them I was in hospital". Eli

Realisation

"It was like, that moment. Because it was like me, my Dad, my Mum, like in the living room, we were watching Comic Relief or whatever, a fundraiser. And I think it was just like the silence of like, they were talking about HIV on the TV and it was just like real like utter silence in the house. Where it was like, oh, this (HIV) is a really big deal". Hana

Censorship

"When I got my first digital phone, I remember I had started (Chiva) camp and all that, but my Mum was a lot of paranoid. So like, every week, she'll be like, at the end of the week, let's see your phone. What are you guys texting? And she'll be paranoid. I remember like, we had a group chat and she will like, see that we're talking about HIV, and she would delete the messages". April

Adolescent social development

"It felt very scary to even consider like, kissing a boy. Do I give it (HIV) to the boy if I kiss? ..And the nurse to be honest, did answer a lot of my questions that I had, that came up and you know, she said, like with saliva its just such a small amount in your saliva that you'd have to like produce, like gallons of saliva to pass it on. And I always kind of thought like, Yeah, but like, if you're gonna be kissing them ALL the time, you kind of [laughs] you know, I was like, there's a possibility... Like, I felt really dirty. I felt really contagious. Like yeah, it's just this thing that kind of just stained me. Aleisha

Illustrative Interviewee Feedback:

Cultural consideration

"The loneliness, the shame, the fear, the regret, the secrets, the duality, this double life, all of that kind of thing... the loneliness sometimes that you feel, the fear of being intimate or open with somebody. When you speak to your HIV peers about that, its almost as if to say, oh my days. I am seen. I am affirmed. I am acknowledged. I'm home" Bankai

Safe HIV Space

"A lot of us, we've grown up being told that we shouldn't talk about our lives, and that we can make up stories or make up that you got HIV in some other way, and I think it's nice to not have to lie. Not that I lie, now, I think I spent so much of my life lying about HIV, it's nice to just be like, there you go. That's all of it. And then you could just close it at the end and call it a day. And not have to worry about it, I think we worry a lot of us living with HIV, and it's nice to just sort of see it all. I don't know, it's been very freeing." Eli

Illustrative Interviewer Feedback:

Generational Challenges

"I found it really interesting interviewing people younger than me, especially sort of, you know, where they're like, not even in their twenties yet not quite made it to twenty and listening to how they have perceived their HIV growing up, because obviously, I know, there's not that much of an age gap. But it's quite shocking. The changes that there actually are. Yeah the generational gap. It's like the whole thing about like, people who like paved ways for people to have better experiences, but then also you get that bitter feeling of like, Where would I be if I had the support that I was advocating for?" Ruth

DISCUSSION

TRAUMA-INFORMED LEARNING

Safety - physical, psychological and emotional safety

- Complex institutional workarounds for privacy challenges centred on potential disclosure of maternal HIV diagnoses, challenging research protocols
- Creating shared HIV space
- 6-month seed programme to train and pilot

Trustworthiness - transparency in policies and procedures

- Mentoring with open acknowledgement of research process mistakes plus remedies
- Radical transparency, not overselling the benefits of participation

Choice - shared decision-making, choices adapted to individuals' situations

- Range of protective procedures devised by young people: authorising a limited selection of publicly accessible oral extracts, some re-recorded by actors for anonymity; archiving remaining data with scheduled release over 100 years.

Collaboration - mutual self-help, asking needs and collaboratively considering how needs met

- Individualised peer interviewing techniques in group settings

Empowerment - share power, strong voice in decisions, listening to what people need

- Paid job roles for young people, on-going training and mentorship
- Emergent integration of psycho-social support built flexibly into project delivery to enable self-determination, so no one deprived of opportunity to tell story
- Active empowerment for interviewees to set their own boundaries on questions to answer

Cultural consideration - move past cultural stereotypes and biases based on age

- Value and respect the input, presence and company of young people
- Respect and acknowledge generational differences

REFERENCES

GOV.UK, Guidance: Working definition of trauma-informed practice, 2 November 2022. <https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice#:~:>
Tang C et al. *Global estimate of the prevalence of post-traumatic stress disorder among adults living with HIV: a systematic review and meta-analysis*. BMJ Open 10:e032435, April 2020 (open access). doi: 10.1136/bmjopen-2019-032435

Sound Clips and Creative outputs (music production, live scribe art, podcast series, baby photo exhibition)

available: www.chiva.org.uk/positivelyspoken

Listen to audio clips



Life stories of growing up with HIV
Chiva.org.uk/positively-spoken

NATIONAL Life stories
In partnership with

BRITISH LIBRARY

