

‘I am scared of getting caught up in my lie’: **challenges to self-reported adherence for young people living with HIV**

Sarah Bernays, London School of Hygiene and Tropical Medicine
AIDS Impact, July 31st 2015

On behalf of the qualitative team: Janet Seeley, Sara Paparini, Tim Rhodes,
Stella Namukwaya Kihika, Rachel Kawuma-Kigawa, Hellen Nakyambadde and
Olive Kabajaasi and the ARROW and BREATHER trial teams



Background

- Young people HIV care dis/engagement as a global public health problem
- Poor adherence as core concern with severe ramifications
- HIV+ young people's behaviour as 'risky' and 'problematic':
 - treatment
 - poor care engagement
 - sex
 - drugs & alcohol
- Clinics or Health service providers seen as principal vehicles of change (key foci of interventions)

Overview of studies

- Qualitative research embedded within clinical trials- repeat interview design
- **ARROW** (2011-2013): qualitative longitudinal study with 104 children (aged 11-13 years), 40 carers and 20 healthcare workers in 4 trial sites in Uganda and Zimbabwe.
 - Exploring experiences of growing up with HIV
- **BREATHER** (2011-ongoing): qualitative longitudinal study with 43 young people (aged 10-24 years) in Uganda, UK and USA. In Uganda- interviews with 15 carers
 - Investigating acceptability of short cycle therapy and broader context of adherence
- 93% of overall sample- perinatally infected



Adherence challenges: social and intimate aspects

- Young people aware of HIV stigma and encouraged to keep their HIV status secret
 - and that of others in the family
- Pill-taking and deductive/unwanted disclosure of HIV status
- Coping with medication side-effects (degrees of severity)
- ‘Treatment fatigue’ after a life-time (and facing a life-time) of daily pills
- ART unwelcome reminder of their HIV
 - and of HIV in their family



Jacob, Uganda, 11 years old

“Children would come home so early in the morning, they would come so early and when the time for taking drugs comes, I would take it while they are there, and when they see me taking it they ask me, and when I tell them they start teasing me. So when they come I don’t find time to take it yet, even the tins [with the drugs] are in the sitting room”.

Clinic as social space

- Growing up with HIV in silence in most settings
- Clinics are rare places where:
 - their status is known
 - they receive care
 - they can access information about their condition
- Yet HIV-related discussions in the clinic limited to ART
- Insufficient acknowledgement of personal dilemmas and social challenges to ART



John, UK, 15 years old

“I'm just wondering what, to some extent, stops you talking about it with people here?”

Probably because they're, first of all, they're all real busy here, I know that, but I don't know. Normally it's just, nothing really to talk about it. So just kind of, for me, just kind of like take your meds, come in every three months and get on with it.”

Shaming non-adherence

- Navigating reputation as 'good' or 'bad' patients
- Pressure to maximise benefits of available ART
- Being reminded that many peers lack the same access
- Risks of 'failing' to adhere underscored with:
 - reference to death of biological parents
 - memory of childhood illness
 - examples of people living with HIV with poor health (e.g. on TV or in community)



Anita, Uganda, 12 years old

“There are some healthcare workers who can say that if you don’t want to take medicine and you waste it, others want to take it. You waste drugs, and they say that as they quarrel. And there, your mother will be angry with you.”



Nelly, Uganda, 18 years old

“And in case you missed, how would the clinic staff react?”

The clinic staff would get annoyed (laughs) (...) the hell out of you saying ‘you don’t take your drugs, what are you doing, what’s going on, what’s the problem?’... It’s only about understanding ‘what and why and how we can make this person take drugs without stopping, how can you solve that? Is it a problem at home, problem where the friends are, problem with the people he is living with, is it adherence or he does not like the drugs?’”

Silencing non-adherence

- Presume that disclosing non-adherence will have negative personal consequences
- Harsh measures are counterproductive
- Even in more supportive environments relational dynamics impact on capacity to voice difficulties with ART
 - Eg exemplary adherers
- Not disclosing adherence causes anxiety (know what they should be doing)



Rob, UK, 15 years old

*“...I’m still a bit scared and like maybe I shouldn’t have missed that dose. **Would you tell anyone?** No, I don’t think I’d tell anybody, no.(...) Yeah, it is a bit tough. I suppose specially to tell family and maybe the consultants themselves as well which you think they care about you so much and if you tell them that you’ve missed your dose they might think that you’re giving up on yourself and I don’t know anymore.”*

Truth economies

- Some young people cope by controlling what they will/will not disclose:
 - missed doses
 - periods of non-treatment taking
 - side-effects
 - changes to how/when they take their treatment
 - without seeking clinicians' advice
- Difficulty in admitting problems to access support
- And to pre-empt adverse clinical events
- Perverse effect of undetectable viral loads



Mike, USA, 20 year old boy

"I'm scared of disappointing people. I hate doing it because I worry about what people think a lot and so I'm really scared of disappointing them and making them upset so sometimes I will have times where, like you said before where I wouldn't tell or I wouldn't say anything especially if I know it's more than the usual I won't say anything or while I'm taking my medications I'll try 100% in my memory to take them and (...) I'm scared of getting caught up in my lie and saying, oh, well, I take, I haven't missed any this month and my VL and my CD4 comes back terrible, you know?"

Discussion

- Treatment literacy important but not the full answer- neglects the influence of social context (juggling social harms of adherence vs physical harms of non-adherence)
- Risks in characterising PLHIV as stable on treatment ('exemplary adherers) ignores fluidity of long term adherence behaviour.
- YP's relational anxieties and coping strategies must be acknowledged
- The expectation of perfect adherence can create a non-disclosure cycle
- YP should feel their issues with growing up with HIV (outside the clinic) are validated (within the clinic)



Acknowledgements

- All of our study participants
- ARROW and BREATHER clinical trial teams

Our funders:

- MRC/ CTU
- DfID
- ESRC
- The European Union Seventh Framework Program under EuroCoord
- The NHS R&D Health Technology Assessment Programme



Sharing children's voices

