

Young people, clinical trials and ‘the HIV experience’

*What can similarities across time and place tell us
about growing up with HIV?*

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Different yet similar?

- *Context-specificity* of:
 - the experiences of positive young people in the HIV pandemic
 - The narrative forms
- Yet striking *similarities* around:
 - Silence about HIV status
 - Being encouraged not to disclose
 - Isolation from peers
 - Treatment experience and adherence constraints



ARROW & BREATHER Studies

- Longitudinal qualitative research embedded within clinical trials
- Multiple phases interviews
- 93% of sample – perinatally infected

ARROW (2011-2013): qualitative longitudinal study with **104 children** (aged 11-13 years), 40 carers and 20 healthcare workers in Uganda and Zimbabwe.

- Exploring experiences of growing up with HIV

BREATHER (2011-ongoing): qualitative longitudinal study with **43 young** people (aged 10-22 years) in Uganda, UK and USA, interviews with 15 carers (Uganda)

- Investigating acceptability of short cycle therapy and broader context of adherence



Specificities: examples

- Geo-political and economic settings (low v high income)
- Pts in high income settings mostly from low-income and migrant households
- Healthcare systems and HIV care provision
- Socio-cultural relations between young people and adults
- Gender, ethnicity, sexuality and age differences
- Route of infection differences
- Different trials
- Access to support beyond clinic



1 - HIV silence in the family

- Common experience of loss for many whose parents died
- Many not living with biological parents
- Many alone (or presumably alone) with HIV in the house
- Lack of info about the circumstances of own infection and that of their parents
- Common experience of illness in childhood
- HIV kept secret in household
- Silence surrounding HIV that is not ART



2 – Disclosure of HIV status to friends and partners

- Being taught not to disclose (at school, home, clinic)
- Witnessing carers' lack of disclosure:
 - of their own HIV to others;
 - of their own HIV to their children;
 - of their children's HIV to others
- Wanting to disclose to friends...
- but not knowing who (and how) to 'trust'
- Disclosing to partners



3 – Isolation from peers

- Little or no knowledge of other young people with HIV
- Most would like to – or find it beneficial when they do
- Yet where peer support available, surprisingly little uptake of services
- And for vast majority (in studies but also globally) not available
- Complicated by carers' views and mediation
- Need more support in clinics



4 – HIV care and ART

- Common awareness of the need to ‘stick to ART’
- Social constraints on taking ART
- ART constraints on social life
- Struggling with
 - pill-burden
 - side-effects (substantial)
 - pills as reminders of HIV –
- Stigma of ‘failed’ adherence: from scolding to reputation management



Producing similarities?

- Methodological filters in the qualitative study
- Clinical trial participation effects
- Focus of both qualitative and trial research



Value of focus on similarities (theoretical)

- Frameworks development
 - Common experience of stigmatisation in youth
 - Relationship between HIV and adolescent health: on a spectrum
 - Analysis of effects of (bounded) agency in youth on management of HIV
 - Analysis of health perils of periods of transition
 - Lack of knowledge about the future



Value of focus on similarities (applied)

- Counteract overwhelming complexity of working with adolescence
- Share learning within HIV pandemic
 - and across chronic conditions
- Shift focus from changing individual behaviours to shared social context
- Foster peer communication



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Examples of work from ARROW

