Understanding the HIV status disclosure process, social support structures and antiretroviral therapy adherence among young people in Soweto, South Africa: A qualitative study

Stefanie Hornschuh
Dylan Rice
Janan Dietrich
HIV prevalence

- In 2017, the prevalence for South African young people aged 15-24 years was 7.7%.\(^1\)
- 62% of young people acquired HIV perinatally.\(^2\)

HIV disclosure

- As more HIV infected children survive into adolescence, increased attention has been given to inform them about their HIV diagnosis.\(^3\)
Antiretroviral treatment (ART) adherence

- HIV disclosure has benefits in achieving long-term disease management and to improve ART adherence.\(^4\)

Social support

- Disclosure may lead to improved adherence through increased access to social support.\(^5\)
Objectives

1. To explore the experiences and needs of HIV disclosure initiation among HIV infected young people aged 15-24 years from Soweto, South Africa.

2. To understand social support structures for ART adherence among HIV-infected young people.

3. To explore barriers and facilitators of ART adherence amongst HIV infected young people.
Methods (1)

Setting

Type of study

Paediatric and adult HIV care clinics at the Perinatal HIV Research Unit (PHRU)

Qualitative study

Data collection

In-depth Interviews (IDIs)
- 10 IDIs – perinatally infected young people
- 8 IDIs – primary caregivers

Focus Group Discussions (FGDs)
- 1 FGD - eight health care providers
Study setting
Methods (2)

- Interviews (IDIs/FGD) were conducted in a confidential environment at the PHRU
  - IDIs – 15-45 minutes
  - FGD – 60 minutes
- Facilitation by two trained, multilingual female interviewers
- Semi-structured interview guides
- FGD and IDIs were audio recorded
- Transcribed and translated into English
Results (1)

Main Themes

- HIV disclosure initiation and experience
- Suggestions for disclosure improvements
- Social support structures for ART
- Barriers and improvement suggestions for ART adherence
Results (2)

Disclosure age
- Age of 7-16 years
- Initiation age should differ by individual
  - “I was I think 7…when my mom told me like I didn’t understand like what HIV was.” (young person)
  - “You think she should have told you sooner or later?” (Interviewer)
  - “Later…when I understand…when you are a child, you have no idea.” (female, young person)

Disclosure circumstances
- Young people asking questions about the medication;
- Caregiver fear of disclosing children’s HIV status

“I was asking a lot of questions – why am I drinking the medication?” (female, young person)
Results (3)

HIV disclosure initiation and experience

Disclosing person
- Multiple people disclosing as a process
- i.e. biological mother, health care providers, other caregivers (e.g. grandmother, aunt)

Setting
- Treatment clinic, home environment, church
Results (4)

Information received

- **Ongoing process** rather than a once-off process;
- **Disclosure in phases**
  - HIV Status
  - HIV education
  - Route of transmission
  - ART management

- Use of age appropriate language is important.
  
  …From 6 to 8 [years] you explain to them in the way that they understand. So you call HIV a ‘germ’ and they are taking their medication to help the super-heroes, which are the CD4 cells.” (Health care provider)

Reactions

- shock of being HIV positive,
- emotional and behavioural responses
**Results (5)**

- To receive stronger support structures

- To develop a more open parent-child relationship

  “…We support each other… When it’s time to take our medication, he [the son] brings everything all at once.” *(Caregiver)*

- To manage and understand the importance of ART

- To avoid horizontal transmission

  “So that I don’t infect… other people with the status [HIV]… you think about your status and you [are] like no guys, this is not what you are supposed to be acting… .” *(female, young person)*
Caregivers

- Information sessions and tools:
  - Education sessions on HIV
  - Interactive practice sessions

- Counselling therapy sessions

  “...Start with them [caregivers] first so that we...can give them counselling first...You don't hide diabetes, you just come out and say it... HIV should be spoken out in the same way.” (Caregiver)

- Support groups to share experiences

  “...to deal with disclosure issues...share experiences...discuss what they are anxious about and they learn from each other.” (Health care provider)
Suggestions for disclosure improvements

**Young people**

- Education camps, peer support and post-disclosure counselling

“They can talk about anything. Like, probably they could ask them questions, you know... What is HIV?... How much do they know about HIV?... They can do like... dramas and everything; just... so that they can get to know what is HIV and the whole process. And... they can drift from HIV... they can do like, I don’t know swimming, netball you know, just to let them know how the experience is.”  (female, young person)
Results (8)

Social support structures for ART

"Even when I go over to my boyfriend's place, he asks if I have taken my medication. I say yes and leave with the medication I take in the morning. Please come with them [ARV's]." (Young person)
Results (9)

"...They [adolescents] have been coming to the clinic since they were young...now I am a young adult... they have been asking their mothers about the status but they didn’t want to tell them. So that’s why...they are still angry and they are not going to take treatment.” (Health care provider)

Barriers for optimal adherence

- Community stigma
- Pill fatigue
- Anger towards HIV and ART
- Mental health challenges
- Adolescence developmental phases
- Caregiver non-involvement
- Non-adherent HIV positive caregivers
“With some of the patients we stop their medication for a period of time...then we start...fresh. Most of the time we will...like over December holiday...[they] then can enjoy themselves and don’t worry...when they come back...they have to be 100% compliant and it works.”

(Health care provider)

**Improvement suggestions to optimize adherence**

- Peer support and education groups
- Continuous counselling
- Supervised medication breaks
- Mobile phone medication reminder applications
- School events, including medication hand-out
Conclusions

- **Timely disclosure** of HIV positive diagnosis and **social support structures** are critical for treatment adherence among young people.

- Disclosure should be an **ongoing, developmentally tailored process**.

- **Support groups and tools** are needed to equip caregivers for improved disclosure to their children.

- **Support peer groups** for young people are needed to discuss ART challenges and share experiences.
Acknowledgements

- Thank you to the young people, caregivers and health care providers who gave their time and provided great value to the project.
- Lethabo Ramskin and Sakumelo Mbele for assisting with data collection.
- The Perinatal HIV Research Unit (PHRU)
- PHRU Paediatric HIV Clinic staff
- PHRU Adult HIV Clinic staff
- Dr Avy Violari (paeds)
- Dr Lerato Mohapi (adult)
- Dr Janan Dietrich, PHRU Bio-Behavioural Research Division, PHRU

Funders:
- SoMCHAT Research funding to PHRU by the South African Medical Research Council (SAMRC)
- The Canada-Africa Prevention Trials Network (CAPTN)
References


Thank you for your attention!

Questions?

Contact
Stefanie Hornschuh
hornschuhs@phru.co.za