‘Taking them forever and taking them on time’

The treatment and care needs of adolescents living with HIV

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Introduction

• Led by Y+ supported by GNP+ and WHO
• August and September 2014
• Participatory workshops of group discussions
  • 4 African countries
  • 84 participants
• Anonymous Online survey
  • Five languages across
  • 386 respondents completed the survey
  • Total of 117 respondents from 30 countries were eligible for inclusion
• The inclusion criteria
  • 1) Living with HIV, 2) Aged between 15 – 29 years 3) Have experience taking ARV as adolescent.
• The findings were presented at the WHO guideline development meeting and influenced clinical and service delivery guidance.
Key Findings

The workshops and survey focused on the following 5 domains:
1. Understanding adolescents’ everyday lives on ARVs,
2. Challenges and benefits of ART,
3. Missing/stopping ART,
4. Information and support for adherence,
5. Services
1. Understanding adolescents’ everyday lives on ARVs

Challenges in taking ARVs:

• The inconvenience of taking ARVs
  • Frequency and timing of taking medication around their daily activities and the restriction this places on their lives
  • Sleep, travelling, going out to have fun and being at school were all mentioned as everyday activities that make taking ARVs difficult.
• Taking them on time and taking them whilst away from home
• Experiences of side effects
• Size, number and taste of pills

“I hate it that ARVs are to be swallowed every day. I wish it was an injection of once in a year”.

22-year-old female survey respondent from Uganda
Benefits:
• ARVs enhance their health and well-being
  "it reassures me to not get sick"
  20-year-old male from Burundi
• Being healthy enables them to partake in everyday life and makes them
• 81% of respondents acknowledged that ARVs keep them healthy, prevent new
  infections and give them strength to carry on with their work/study.

  “I feel that there is life ahead. Thanks to my medications. Now living with meds – it is my life”
  - 21-year-old, Male, Workshop Participant, Kenya

Mixed feelings:
‘I accept my serostatus but my dreams are shattered’
  17-year-old female from Zimbabwe
3. **Missing/stopping ART**

What are the common reasons that make you miss your ARVs? (n=185)

- Forgot the time: 50%
- Forgot to take the ARVs with me: 45%
- Ran out of ARVs: 35%
- Did not want to take in public: 30%
- Oversed: 25%
- Tried of taking ARVs: 20%
- I started a new school: 15%
- I started a new relationship/having a boyfriend/girlfriend: 10%
- I started to live by myself: 5%
- Other (please specify): 0%
• When asked about their feelings after missing ARVs; **guilt and fear dominated** the responses in both the workshops and survey.

• Amongst survey participants, 35% indicated that they had stopped taking ARVs intentionally at least once.

• Likewise, 1/3 of workshop participants confirmed that they had intentionally stopped taking ARVs.
  • Due to the burden of taking a life-long treatment, feeling depressed, HIV-related stigma, and/or attitudes of health providers.

• Interruptions varied in length from one month to two years and were undertaken without consultation with health providers.

“**Doctors are not willing to listen to you when you are struggling with adherence and want to have a break from treatment. Support is not offered.**”

- 26 years old, Female, Survey Respondent, Romania.
4. Information and support for adherence

Who do you discuss your experience of taking ARV's and having HIV? (n=107)
Where do you get information on ARV's and HIV? (n=144)
Strategies to improve information and support for adherence

• ‘Having support’ and ‘feeling supported’

• Face-to-face support through counselling, treatment buddies, sessions involving parents/guardians, and role models
  
  ‘Help us meet as groups and share our experiences [as opposed to] when someone stays at home thinking they are alone.’
  
  – 18-year-old, Male, Workshop Participant, Zimbabwe

• Reminders and triggers

• ARVs - smaller size, better tasting, differing colour for identification

• Less frequent doses - monthly and yearly doses

• Knowing their status

  ‘If parents can ‘man-up’ and tell their kids what they are living with, this will help adherence and ease the burden of the need for second line [ARVs].’

  - 24-year-old, Female, Workshop Participant, Kenya
5. Services

Good experiences

- Feeling cared for receiving services and receiving ARVs

‘Yes [I am happy] because I’m given the time to express everything that would be bothering me and just have a talk in general’.
- 24 years old Female, Workshop Participant, Zimbabwe

Negative service experiences

- Long waiting times and provider attitudes

“the service providers ill-treat us, they shout at us as if we applied for the virus... they think we got it through being promiscuous. We are painted with one brush.”
- 22 year old female participant from Zimbabwe

‘Health services are not friendly and not every young person is empowered like me to stand for himself/herself and get quality services.’
- 17-year-old, Female, Workshop Participant, Uganda
Barriers

• Missing school to attend clinic
• ‘just being given ARVs’ and not provided the opportunity to ask questions or discuss problems
• No orientated to adolescents
• Health system barriers
  • distance to services, drug stock-outs, out of pocket expenses and no access to viral load or CD4 testing
• Lack of SRH services

‘there is no privacy and we are mixed up with adults.’

- 18 year old female survey participant Burundi
7. Improving services

• Provision of services and information from an early age especially regarding SRH and disclosure

• **Flexible appointment systems** around school times

• Free, closer to home in the community to **improve access**

• Dedicated adolescent services - at **specific times or separate areas** - safe and stigma free environments

• **Peers interventions** (support groups and adolescents involved as providers) are highly valued

• Comprehensive services that **address their needs beyond HIV** – psychosocial support, SRH, nutrition etc.
7. Improving services

- **Ongoing effective support** is critical – support and environments that provide opportunities for open honest discussion and information
- Support and counselling that **ensures understanding of their status**, improves knowledge and is empowering and solutions focused
- **Skills development** and support on disclosure and safer sex
- Dedicated, consistent, friendly, trained and **competent providers** that understand their needs and can communicated effectively
Conclusion

- The transitional nature of adolescence and the **daily realities** need to be taken into consideration.
- Adolescents live with the knowledge that ARVs prolong their life, but they also live with **stigma, fear**, and the daily reality of taking treatment.
- The lack of adolescent-friendly services and psychosocial support compound their struggles.
- Adolescents need a **holistic response** from the health system to adhere to treatment and retain in care, including **adolescent-friendly services and strong networks of peer support**.
- Need for **further research**, including operational research, on innovative strategies for treatment adherence; integrated service delivery and psychosocial interventions.
Acknowledgement

• All the young people who shared their experiences as part of the consultation
• Y+ committee and steering group for this consultation - Janet Bhila, Lumumba Musah, Christine Anyango Beryl
• GNP+ and WHO
• Ed Ngoskin
• Kat Watson
• Alice Armstrong