

*‘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”

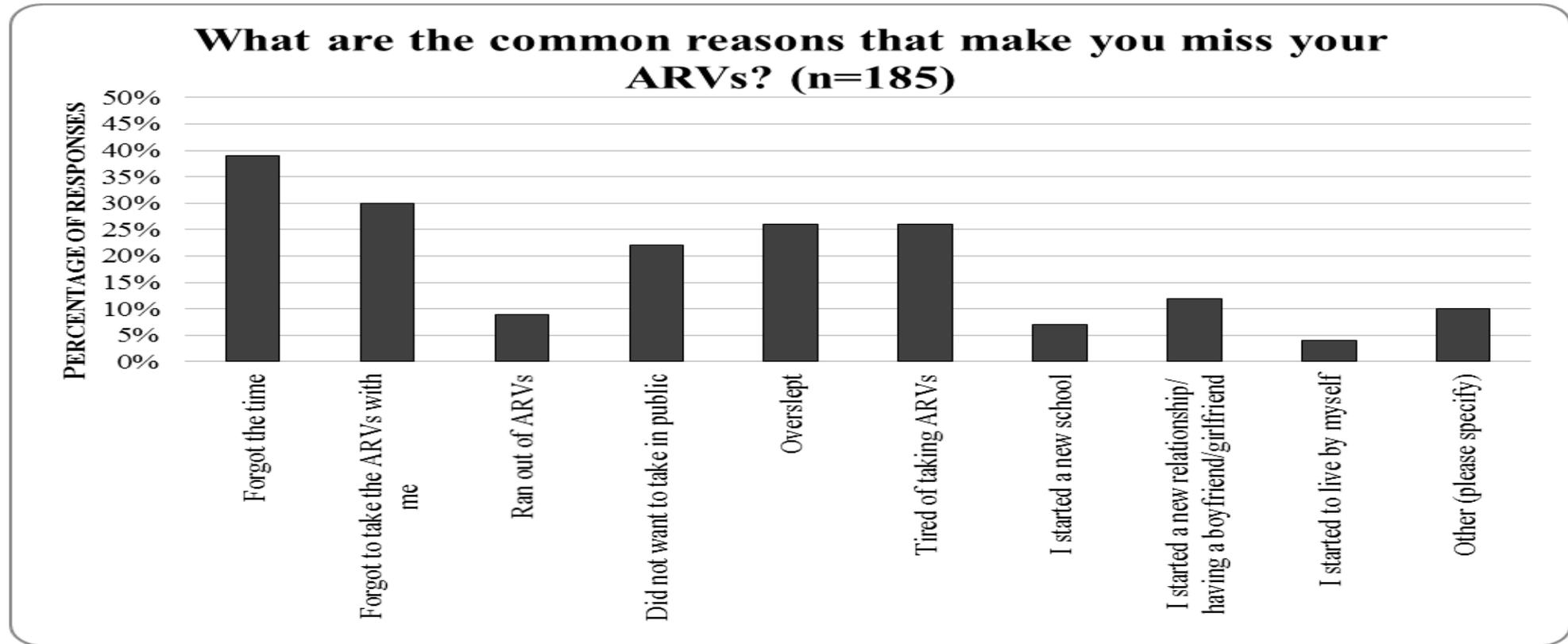
- 21-year-old, Male, Workshop Participant, Kenya

Mixed feelings:

‘I accept my serostatus but my dreams are shattered’

17-year-old female from Zimbabwe

3. Missing/stopping ART

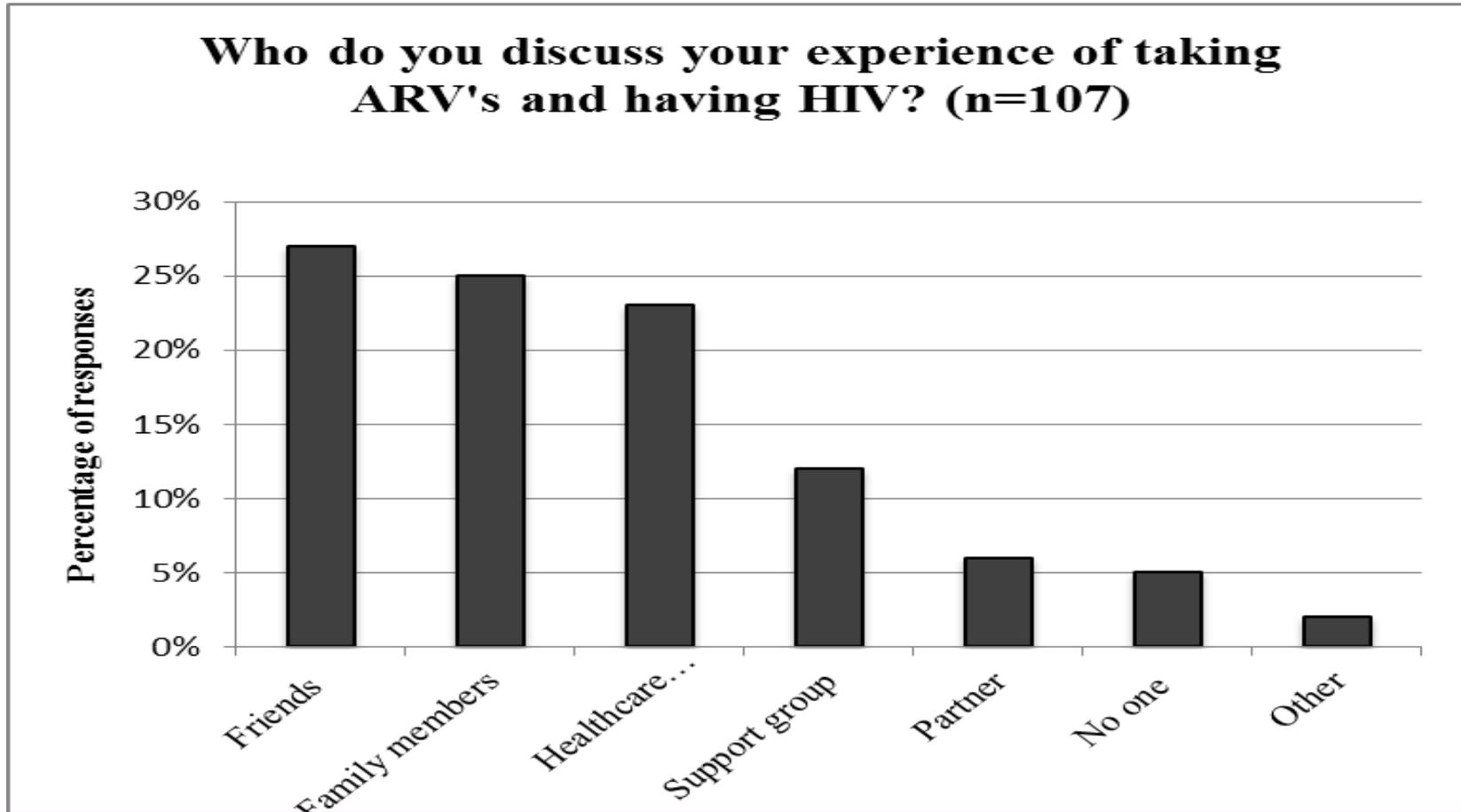


- When asked about their feelings after missing ARVs; **guilt and fear dominated** the responses in both the workshops and survey.
- Amongst survey participants, 35% indicated that they had stopped taking ARVs intentionally at least once
- Likewise, 1/3 of workshop participants confirmed that they had 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.

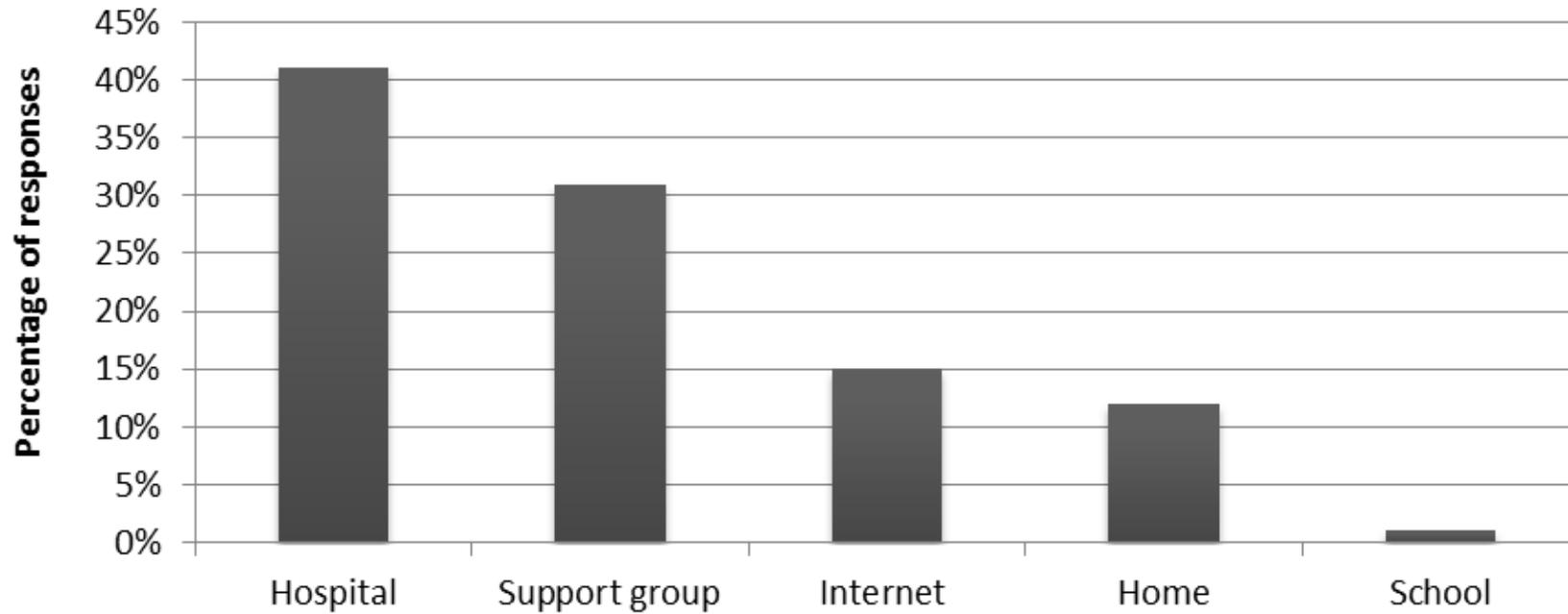
“Doctors are not willing to listen to you when you are struggling with adherence and want to have a break from treatment. Support is not offered.”

- 26 years old, Female, Survey Respondent, Romania.

4. Information and support for adherence



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 communicate 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.

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