HIV Learning Network
The CQUIN Project for Differentiated Service Delivery

icap Global Health

Addressing treatment literacy to enhance retention and viral suppression

Stella Kentutsi
Executive Director
National Forum Of People Living With HIV/AIDS Networks Uganda (NAFOPHANU)

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Outline

- Setting the pace
- Introduction and context
- Understanding treatment literacy
- Improving treatment literacy
- Recommendations

Setting the pace – I

- ***'I have been getting on and off my ARVs and nothing has happened. The moment I am tired of swallowing, I stop like for 2 weeks and thereafter resume. I am not sure it is dangerous since I have not had any problem.' Female PLHIV, 28 years***
- During a training of **expert clients** in April 2022, they were asked what ART they were individually taking. Selected responses, quoted verbatim, included:
  - **Some combination but I hear the word 3TC**
  - **"TDR"**
  - **"Efavirence"**
  - **TDF**
  - **It's blue in colour**
  - **TLD**
  - **TDF/3TC/DTG**
- As the Chinese proverb goes, ***'What is the use of running if we are not taking the right direction?'***

Setting the pace – 2

Ask yourself:

What does the term "treatment literacy" mean to you?

- How much information is given before initiation/re-engagement? How is it given?
- What does someone who is treatment literate (TL) know?
- What can they do?
- Why is TL important?
- How does someone become TL?
- How do we know if someone is TL?
- Is an individual who is TL today necessarily going to be TL next year?
- Whose responsibility is TL?
- What are the vulnerable points along the cascade that would be addressed by TL?
- How can programs build treatment literacy – are current efforts sufficient?
- How much do we need to roll out TL?

Introduction

- Established in May 2003, the National Forum of People Living with HIV/AIDS Networks Uganda (NAFOPHANU) is an umbrella organization that coordinates networks of PLHIV all over Uganda
- Our vision is: PLHIV able to live a quality and productive life in a sustainable manner
  - To live this vision requires us to use all approaches to increase retention in care and viral load suppression as part of positive living
- Despite growing access to ART, **treatment literacy** for PLHIV remains largely untouched
  - Chronic care calls for total adherence
  - HIV requires self-management and therefore informed, empowered recipients of care
- There are significant gaps regarding treatment preparedness, initiation and continuous treatment of PLHIV affecting adherence, retention in care and viral load suppression

Context

- Like most African countries, Uganda adopted the Test and Treat Policy in 2016 and Guidelines were revised in 2020 (currently under review)
- Early treatment initiation means that the 1.4 million PLHIV can remain healthy and productive, consequently reducing AIDS related deaths
- Despite the roll-out of Test and Treat, there are gaps in treatment preparedness, adherence, and retention/continuity of care
- **Inadequate treatment literacy contributes to these gaps**

Defining Treatment Literacy

"Treatment literacy means **people, both individually and in communities, understand what HIV drugs are, why they are needed and what they can and cannot do**. Treatment literacy translates medical information about Antiretroviral Treatment (ART) into languages and formats that are accessible for everyone." – WHO 2005

"Treatment literacy is defined as **understanding the major issues related to an illness or disease** – such as the science, treatment, side-effects, and guidelines – **so that the patient can be more responsible for their own care and will demand their rights when proper care is not available to them**." – Treatment Action Campaign

Treatment literacy issues: Individual level

- Limited awareness of the disease PLHIV are managing, not aware of drugs taken, why interruption in treatment is never allowed since HIV management is chronic
- Widespread myths and misconceptions including:
  - ARVs lower/increase men's libido
  - ARVs cause obesity, infertility, and death
  - Undetectable viral load means cured of HIV
- Ignorance of change of shape, colour or even label leads to no uptake, pill burden becomes an issue
- Internal stigma: ashamed, sinful, difficulty to tell others, hide status, inability to cope with HIV+ status, stress
- Poor storage: remove from original package to avoid being seen carrying ARV bottles, swallowing secretly, new relationship and/or discordance lead to hiding
- High illiteracy levels, especially among elderly care givers,
- Alcoholism, busy PLHIV forget to swallow, physical impairments, elderly with comorbidities
- Not belonging to networks that work as a buffer/safety mechanism

Key issues affecting TL – family, community and H/F levels

- Stigma associated with exclusion at family and social gatherings
- Poor administration of drugs e.g., by the caregivers
- Attacks; physical, verbal, discriminatory remarks
- **Religious;** spiritual healing and discarding of ARVs
- **Cultural;** traditional healing and herbal treatment
- **Health facility:** not giving ample time to explain the do's and don'ts of lifelong treatment, few counsellors, limited support to expert clients, overwhelming numbers, limited follow up and linkages, unexplained adverse side effects
- Few treatment supporters be it at facility or community;
- Tests and giving results; what does a sad or smiling face mean?
  - But also, regular tests not happening beyond viral load
- The peers remain inadequately supported to reach fellow peers, yet health facilities are understaffed, amidst low primary health care budget

Role of treatment literacy in testing, linkage, retention and re-engagement

- Test, Treat and Retain can work if people are aware of what they are managing
- With advent of T&T, role of TL very crucial; what windows can we explore to make ROCs understand what the processes are, why important to link, why treatment important and why must keep on treatment
- But that leaves many questions of; who, what, where, how, why and to what extent?
- Education will increase retention and retention will increase viral load suppression

Treatment Literacy in Uganda

Timeline	Milestones
1990's, 2000s and 2010s	Historically, PLHIV adhered due to strong treatment education, there was a lot of community support, individuals reaching peers, explaining why this generation has lived positively, with high retention levels.
2019	Point where we seemed not to be paying much attention to treatment education and the regional PEPFAR planning meeting brought on table issues of not having treatment literate ROCs,
COP 2021	Included funds to pilot treatment literacy
2022	Peer led literacy efforts pilot in 10 districts
2022 and beyond	Expecting an expansion (benchmarking on Community Led Monitoring - CLM!)

Piloting Treatment Literacy Project in Uganda - 1

- Period: February 2022-January 2023
- Goal: To demonstrate that treatment education influences retention and viral suppression
- Objectives: Support children, adolescents and young people, 'unstable' adults, and those aging with comorbidities to achieve:
  - increase in HIV retention
  - increase in VL suppression
- Targeting PLHIV; peer led, with, by and for PLHIV to increase retention in care and viral load suppression
- Targeting PLHIV holistically; individual, family, community, health facility and policy levels

The Peer led treatment literacy pilot

- In 10 districts of northern Uganda.
- These were selected based on low Viral load suppression and high interruptions in treatment
- The model targets Four health facilities per district, with 3 expert clients (man, woman and young person) attached
- A community program, for the community, led by the community

Piloting Treatment Literacy Project in Uganda - 2

- Trained and rolled out 120 district-based expert (effectively June 2022) and are finalizing rolling out of 20 KP trained expert clients. Expert clients conduct patient education at facility and community level, counselling, follow up, act as treatment buddies, home visits
- Provided materials to support implementation; bicycles, bags, T-shirts, tools, information pack
- Have had health facility engagement meetings to set targets but will also work as a feedback fora
- District entry meetings were held, and project owned by relevant stakeholders
- Developed with MOH and USAID/Social Behavioral Change Activity (SBCA) a Flipchart for peer-to-peer client literacy

Treatment literacy package - comprehensive

Basic HIV facts

ART and adherence

HIV, SRHR and other co-morbidities

HIV and other infections

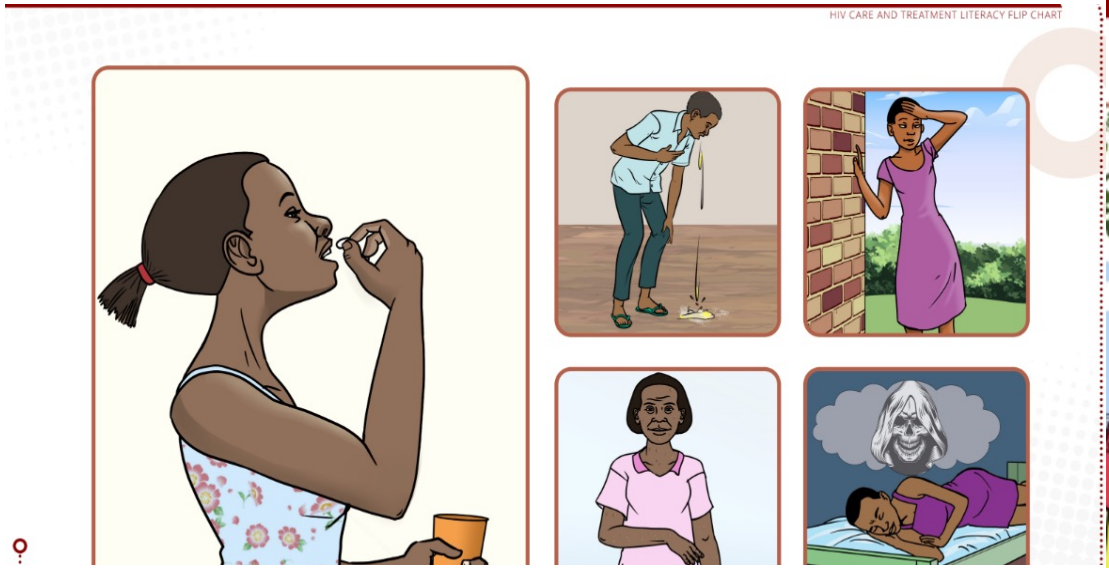
Drug resistance

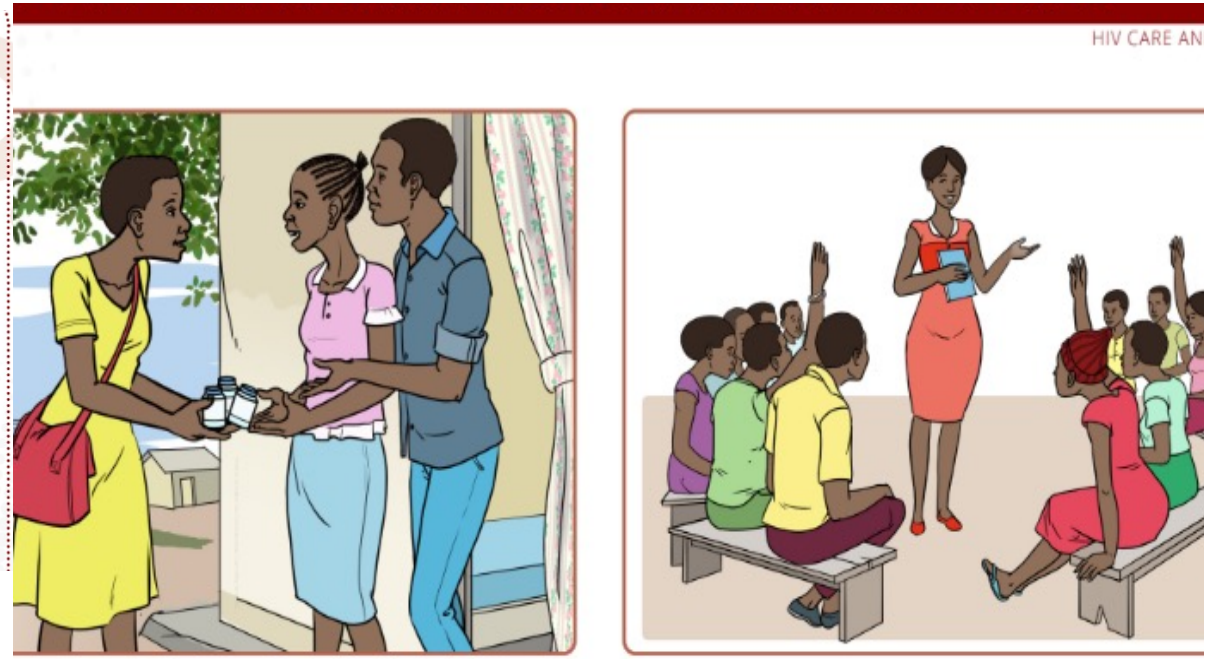
Disclosure

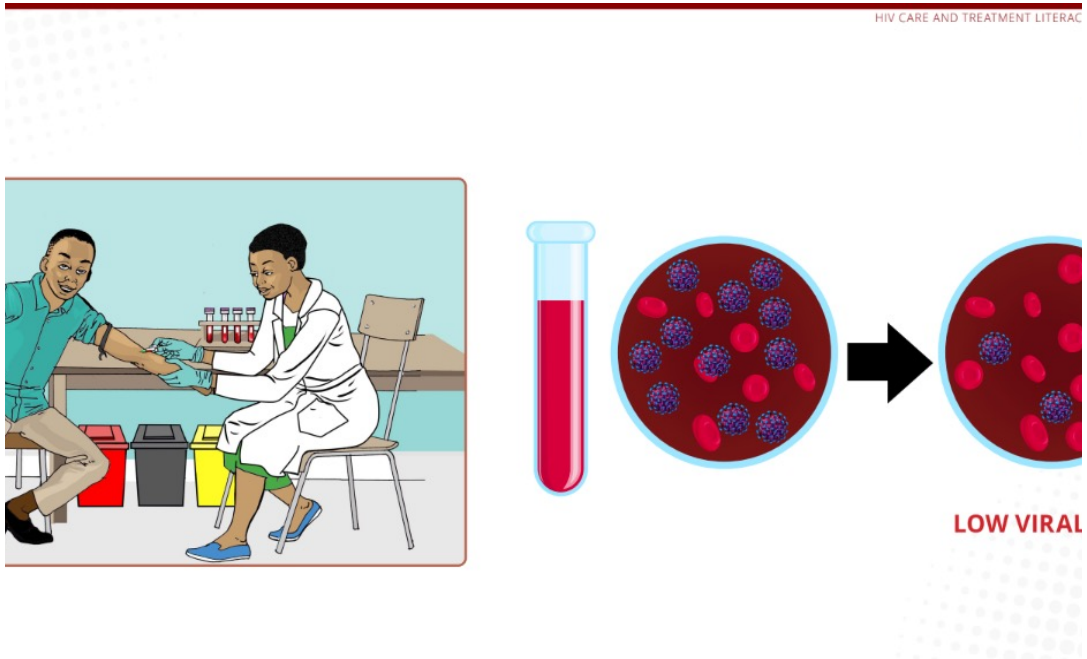
Stigma and discrimination

HIV and nutrition

Differentiated models of care


HIV CARE AND TREATMENT LITERACY FLIP CHART

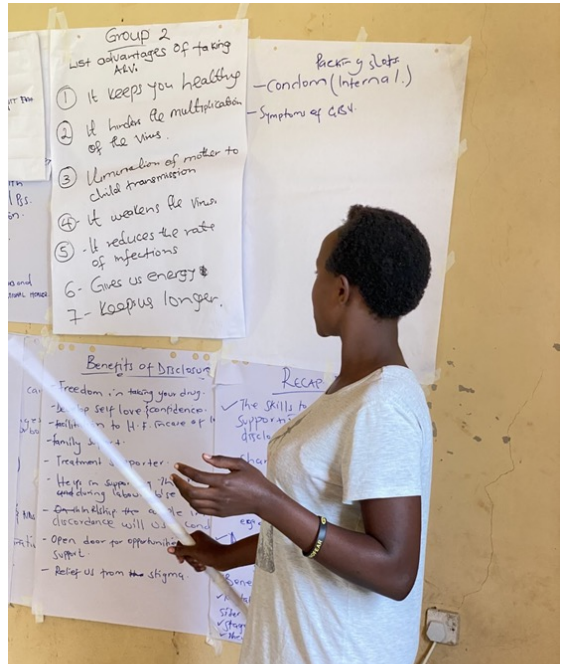

HIV CARE AN


HIV CARE AND TREATMENT LITERAC
LOW VIRAL


PHARMACY


ROMANS 14:8
For Whether we live, we live unto the Lord; & whether we die, we die unto the Lord.

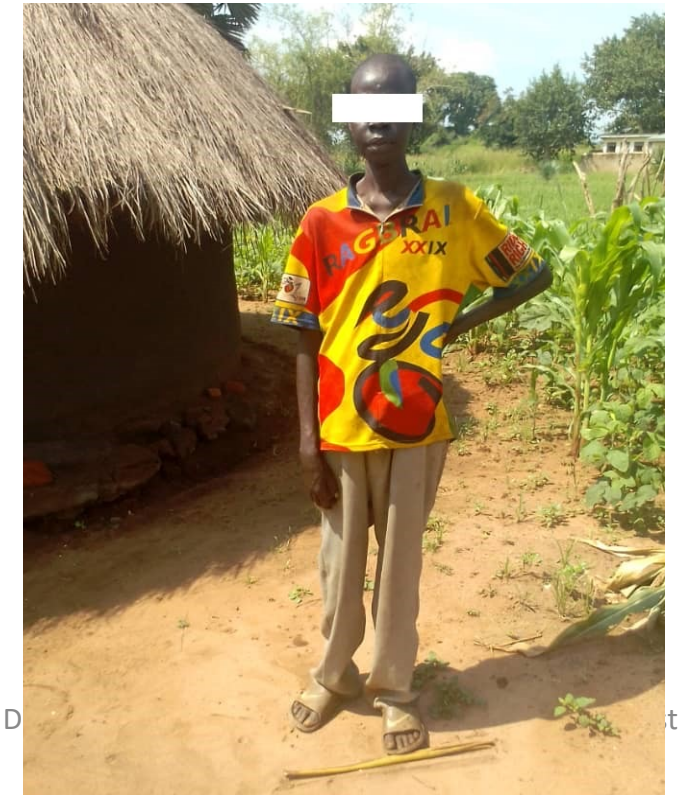

PROGRAMME DEPARTMENT


Group 2
List advantages of taking ARVs
1. It keeps you healthy
2. It hinders the multiplication of the virus
3. Circumcision of males to child transmission
4. It weakens the virus
5. It reduces the rate of infections
6- Gives us energy
7- Keeps us longer.
Benefits of Disclosure
Freedom
Recap

Lived experiences ;

A 35 year old lost client (pictured below) in Atiak okidi parish, Amuru district who was returned to care a week ago after abandoning drugs due to hunger, his weight is only 25kg. He is followed up everyday to ensure does not drop out again

That implies we need to consider other issues that affect retention such as food security, mobility, GBV, insecurity and displacement, health worker attitude among others



Key recommendations

- Use peers to reach peers but deliberate efforts must be seen to build their capacity and are facilitated to do this work, both at facility and community levels
- Facilitating PLHIV structures as part of fall back position
- Use of innovative approaches to reach people e.g. technology to disseminate information such as social media. For instance, they youth may not sit in a workshop but would easily pass on a WhatsApp message
- Use community settings to pass on information; community dialogues may come in handy
- AIDS competence trainings for health workers to address knowledge gaps and attitude
- Integration

Conclusions

Because treatment literacy is important in enhancing linkage, retention and re-engagement, it will only happen if well funded

There are many country based models of TL, but countries cannot do much without funding; small/catalytic grants cannot work to address this huge/amorphous 'elephant'

In all this, the ROCs must be at the centre using the buddy system and other models that have worked

Acknowledgements

1. Government of Uganda (MOH)

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4. District Local Governments

5. Implementing Partners – TASO, IDI

6. Civil Society organizations

7. PLHIV Networks/Communities

Thank you!