Community Perspectives

“Immediate Access to ART for All” Experiences from Swaziland and beyond

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This Presentation:

*Some observations and commentary from the point of view of the client on immediate treatment for all, from:*

- **MaxART:** Maximizing ART for Better Health and Zero New HIV Infections – Swaziland
  - SWANNEPHA
  - SafAIDS
  - CHAI
  - Stop AIDS Now!
  - GNP+ and other partners

- 2012/13 – Understanding the perspectives and experiences of women living with HIV regarding Option B+ in Uganda and Malawi
  - COWLA
  - ICW Eastern Africa
  - ICW Global
...its about the people: their needs, wants, expectations, actions, etc
Key Points* on Treatment as Prevention

- **Messaging:** Under specific conditions, effective treatment is likely to be as effective as condom use in limiting HIV transmission during sex.
- **Messaging:** While the individual-level benefits of treatment (as prevention) are clear, there is uncertainty about the population-level benefits. (Demonstration project in Swaziland may provide some more information)
- **Practice:** HIV-prevention workers may need to develop new skills and knowledge in order to help individuals and couples understand the implications of treatment as prevention.

* NAM Guide – HIV treatment as prevention
TasP: What it could mean for individuals

Early ART initiation – Opportunities

- Opportunity for increased access to HIV testing, treatment and prevention
- Builds on earlier interventions aimed at addressing barriers to HIV testing, treatment and care

Early ART initiation – Threats

- Possibility of potential human rights violations, including:
  - Overriding individual health outcomes for a prevention benefit,
  - Potential coercion in the provision of services
  - Stigmatizing messages
Treatment as Prevention

- Not entirely new:
  - Pregnant women taking treatments for the benefit of their unborn babies

However, common mind-set is for:

Treatment as treatment

- Primarily for the benefit of the individual –
  - they take the risks and side effects too!
- Possible benefits to others and the community, as a bonus.

How do we ensure that this (the TasP) vision is realised?

You can take the pills to the people, but can you get the people to take the pills?
A role for behavioural Science:
Understanding motivations and barriers,

- Swaziland:
  - Pre-study assessment by E.Vernooij and M.Mehlo 2013
  - Understanding the lived experiences of PLHIV; Social economic conditions that will influence uptake of services
  - Social Science — Adolescents and access to services (F.Shabalala)
  - Men and their access to services (A. Adams)

Result: interventions tailored to needs and behavioural patterns
Swaziland: Participants opinions on starting ART early

Motivators to early ART
- Accepting because of fear of being seen sick*
- Strength and better health
- Prolonged life
- Will accept if provider says so*

“If I start now when I am not sick, people will never know that I am living with HIV.” (Female 39yrs)

“If I go to the clinic and the nurse thinks, I should start then I will have to start because they know what is good for me” (men 21yrs)

Malawi: Older women, motivated by the “Lazarus effect”
Swaziland: Barriers to starting ART early

- Cannot start when feeling healthy*
- Fear of side effects*
- Fear to commit to lifelong treatment
- Stigma
- Disclosure

“In the past, providers told people that since their CD4 count was above 350 they could delay starting treatment and eat well. Why should I start treatment now when I feel healthy and my CD4 count is over 350?” *(Men 43yrs)*

I have seen that when you start these drugs you become disfigured, your face and body will become ugly and everyone will know that you are HIV positive. Some people even become sicker and die. I would rather not start early” *(Female 28yrs)*

Uganda: Fear of Drug stock-outs
MaxART Continuum of Care initiatives

Phase 1

Sensitization/Information:
What, Why, who, When – what is new?
- Community Radio
- Involve traditional leaders, Male/youth - focused health days, etc

Information on the options available: treatment not the only option
- Expert Clients providing information

Mobilize Communities

HIV Testing and Counseling

Enrollment in Care

ART Initiation

Retention in Care

- Ongoing care and support including clinical monitoring and information updates;
- Other support

Testing Preparedness /Information about testing / benefits etc
- Understanding and overcoming the barriers – stigma etc
- Creating the right environment

Information /Treatment preparedness;
- Timing
- Understanding barriers, concerns
Barriers to full information on TasP

Attitudes of some health care and community workers:

“Personally I think it is nice information to have for the health worker and not the client, because you know what people do, they will tell themselves I am not infectious and they will be spreading the HIV” (Senior nurse-In charge- Pre-study assessment by E. Vernooij and M. Mehlo April 2013)
TasP: What it could mean for individuals

- An HIV-negative partner could put pressure on a positive partner to go on treatment
- HIV-positive partner might use an undetectable viral load as a means of putting pressure on the negative partner to stop using condoms
- Some people may assume that a person taking HIV treatment has a low or no transmission risk
- Some people with HIV may feel that there is no need to disclose their HIV status if they have an undetectable viral load

**Therefore:**

There is need to clearly communicate complex information about risks and risk reduction and also need to address issues of disclosure, power imbalances in relationships etc

*NAM – HIV treatment as prevention*
Other considerations:

Feasibility affordability:
- Can countries afford it? -- Impact on future debt burden?
- Cost vs benefit
- Systems and infrastructure - are they prepared?

Messaging:
- Language: “Study” – connotations of experimental
- Conflicting messages - frequent changes in HIV messages informed by science
- Beware of information fatigue? what is really new?
- Impact of competing messages:

‘Volunteers in Mazabuka clinical trial contract HIV’