

## Module 2: Retention, Adherence, and Psychosocial Support in PMTCT Programs



## Module 2: Learning Objectives

- Define the terms “retention,” “adherence,” and “psychosocial support”
- Understand the importance of retention, adherence, and psychosocial support in PMTCT Programs
- Identify common barriers to retention, adherence, and psychosocial wellbeing among PMTCT clients, including those related to health services
- Identify challenges to providing quality retention, adherence, and psychosocial support services in the PMTCT setting
- Identify strategies to improve retention, adherence, and psychosocial support within the PMTCT program and throughout the PMTCT spectrum of care

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## Discussion Questions

- What do we mean by retention?
- What do we mean by adherence?

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## Definition of Retention

- Retention refers to keeping (or “retaining”) clients in the care program, in this case throughout the spectrum of PMTCT care and services.
  - For pregnant women, this means that they stay in care during pregnancy and throughout the duration of breastfeeding, and that they enroll in HIV care and treatment.
  - For HIV-exposed babies, this means staying in care until a final infection status is determined, and enrolling in HIV care and treatment if HIV-infected.

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## Definition of Adherence

- Adherence describes how faithfully a person sticks to and participates in her or his HIV prevention, care, and treatment plan.
- Adherence:
  - Is not the same as compliance
  - Includes active participation of the client in her care plan
  - Depends on a shared decision-making process
  - Includes adherence to both care and medicines
  - Impacts the success of PMTCT and HIV care and treatment programs

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## Adherence to PMTCT and HIV Care Includes:

- Entering into and continuing on a care and treatment plan
- Taking medicines to prevent and treat OIs
- Having a safe delivery in a health facility
- Practicing safer infant feeding practices
- Bringing the baby back often for checkups and for HIV testing at 6 weeks, and then again after weaning
- Participating in ongoing education and counseling
- Attending appointments and tests as scheduled
- Picking up medications before running out
- Adopting a healthy lifestyle (as is possible)
- Recognizing when there is a problem and coming to the clinic right away

## Adherence to Medications Includes:

- Taking ARVs correctly, as prescribed, even if the person feels healthy
- For women who are eligible for ART, taking ARVs as prescribed for their entire life
- Taking other medicines as prescribed
- Giving medications to HIV-exposed and HIV-infected babies and children as prescribed
- Not taking any breaks from treatment

**Remember: All pregnant women living with HIV need to take ARVs, the right way, every dose, every day!**

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## Non-adherence Includes:

- Missing one or many appointments
- Not following the care plan and not communicating difficulties in following the care plan to health workers
- Missing one or more doses of medicine, or not giving the baby doses on time
- Sharing medicines with other people
- Stopping medicines for a day or many days
- Taking or giving medicines at different times than recommended by health workers
- Taking or giving medicines without following instructions about food or diet
- Not minimizing risk-taking behavior (as much as is possible given the client's circumstances)

**Remember: No one is perfect!**

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## Why is Adherence Important?

- To reduce the chance of MTCT at all stages
- To ensure that ART and other medicines do their job
- To increase the CD4 cells and decrease the amount of HIV in the body
- To avoid resistance
- To monitor the client's health and link her to community support services
- To keep the person feeling well
- To keep families and communities healthy and productive.

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## What Happens When a Client Doesn't Adhere?

- The HIV keeps multiplying
- There is a greater chance of MTCT
- The CD4 count will drop; more OIs
- Children in particular will become ill very quickly
- There is a greater chance of passing HIV to others
- The client may become depressed or de-motivated due to illness
- Resistance can develop and the ARVs will stop working

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## Discussion Questions

- What do we mean by psychosocial support?
- Why is it important to provide psychosocial support services to pregnant and postpartum women, including those living with HIV?

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## Psychosocial Support

- Psychosocial support addresses the ongoing psychological and social concerns and needs of PLHIV, their partners, their family, and caregivers of children living with HIV.
- In the context of PMTCT services, psychosocial support addresses the psychological, social, and adherence needs of pregnant and postpartum women, their partners and families, and children throughout the spectrum of PMTCT care.

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## Remember:

- Since pregnancy is a relatively short period of time, it is important to assess and support pregnant women's psychosocial needs as soon as they are enrolled in ANC and PMTCT services.
- Retention, adherence, and psychosocial support are interrelated.
  - A client is more likely to be retained in care and adhere to her own and her baby's care and medicines if she receives ongoing information, education, and support at the clinic, in her community, and at home.

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## Discussion Questions

- What is the relationship among retention, adherence, and psychosocial support?
- Why is it important to offer ongoing retention, adherence, and psychosocial support services to PMTCT clients?
- What are the biggest challenges to offering these types of support to PMTCT clients?
- How is the referral system working now? What challenges exist with referrals for ongoing adherence and psychosocial support?

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## Remember:

- Retention, adherence, and psychosocial support are multi-dimensional
  - Every person is different
  - Every person's health, life, and family situation is different
  - People's needs change over time
- This is why retention, adherence, and psychosocial support services must be ongoing in PMTCT settings; not one time events
- The entire multidisciplinary team is responsible for providing these services

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## "Cardstorming" Activity

- Why don't clients stay in care and adhere to PMTCT care and medicines?



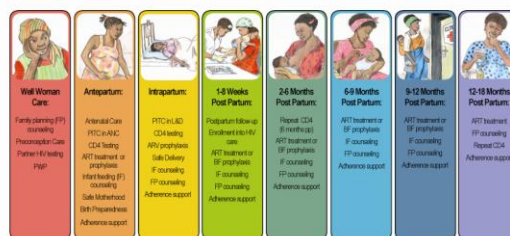
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## Factors Affecting Adherence

- Most clients want to adhere, but there are many challenges
- Some of the barriers have to do with the client herself, her family or her community situation
- Medicines themselves may also create barriers (e.g. side effects, pill burden)
- BUT...often the **health system** creates barriers to retention, adherence, and psychosocial wellbeing – as health workers, these are the barriers we can minimize
  - How can we address health system challenges and improve the quality of services for our clients?

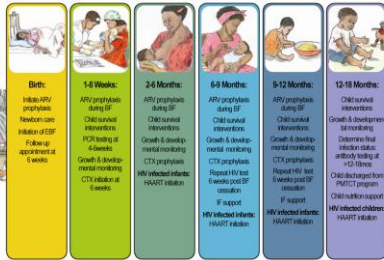
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## EFFECTIVE PMTCT IS A LONG TERM INTERVENTION FOR WOMEN



Effective PMTCT includes a series of biomedical and psychosocial interventions administered throughout the reproductive life of the woman living with HIV

## EFFECTIVE PMTCT IS A LONG TERM INTERVENTION FOR INFANTS & CHILDREN



## Discussion Questions in Small Groups

- What retention, adherence, and psychosocial support services do we **currently** offer to clients at this stage of PMTCT care? Who is responsible for offering these services?
- What are the **challenges** to offering quality retention, adherence, and psychosocial support services at this stage?
- What can we do better at this step in the **future** to improve retention, adherence, and psychosocial support services?
- What **tools** could help improve retention, adherence, and psychosocial support at this stage?

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## Case Studies in Small Groups



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## Remember:

Retention, adherence, and psychosocial support are ongoing processes, throughout the spectrum of PMTCT care for mothers, babies, and families. Providing them is everyone's job!

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## Module 2: Key Points

- Retention refers to keeping women (and babies) in the care program, throughout the spectrum of PMTCT care.
- Adherence means how faithfully a person sticks to, and participates in her or his HIV care and treatment plan.
- Adherence to PMTCT and HIV care and medications is important to make sure women and babies stay healthy and get the ongoing care they need, lower the chances of MTCT, know when and how to start ARVs or ART, and get psychosocial support.
- Psychosocial support addresses the ongoing psychological and social concerns and needs of people living with HIV, their family, and caregivers of children living with HIV.

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## Module 2: Key Points, con't.

- Retention, adherence, and psychosocial support are interrelated.
- There are many barriers and challenges to retention, adherence, and psychosocial wellbeing.
- Retention, adherence, and psychosocial support are important services in PMTCT programs and throughout the spectrum of care.
- The entire multidisciplinary team is responsible for providing these services and supports.

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**Any Questions?**



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