

KITSO AIDS Training Program

Lecture 10:

**Adherence in ARV Therapy:
the “Art” of HIV Clinical Care**

Objectives

- Know the definition adherence
- Understand the importance of adherence in ARV therapy
- Identify factors that influence adherence
- Identify potential barriers to adherence
- Discuss strategies to maximize adherence
- Understand the important and special issues involving pediatric and adolescent adherence

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Definition of Adherence

The extent to which a patient’s behavior coincides with the prescribed healthcare regimen, as agreed upon through a shared decision-making process between the patient and the healthcare provider.

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Compliance vs. Adherence
(The old way) (the new way)

Compliance is defined as acting in accordance to a command.

The doctor/nurse tells the patient what to do, and he/she must do it without question

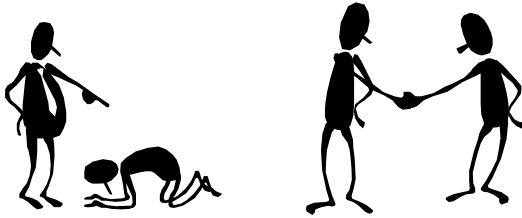
Adherence is defined as *mutual decision making*.

The patient understands and, together with the healthcare worker, agrees to make behavior changes to improve health outcomes.

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Compliance vs. Adherence (2)

COMPLIANCE	ADHERENCE
Willing submission to the commands of others	Shared decision making



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Overview of Adherence

- Adherence to most drug regimens is poor across all populations and all diseases.
- Most information we have about adherence comes from studies of diabetes, heart disease, and TB.

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Overview of Adherence (2)

- The percent of general medical patients who fail to take their medications as prescribed can range from 20% to 100%, with the average being 50%.
- Adherence is considered successful for most other chronic diseases when patients takes their medications > 80% of the time.

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Adherence to HIV Treatment is DIFFERENT

To be successful, ARV medications must be taken 100% of the time.

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Why is Adherence Different in HIV disease?

- The virus rapidly multiplies in the absence of ARVs, or when there are subtherapeutic levels of ARVs.
- With the increasing viral load in the presence of ARVs, more mutations will occur that cause resistance to the ARVs.
- Once resistance develops, the ARVs are no longer effective, and viral replication increases, CD4 count/% drops, and clinical illness develops.
- The very short life cycle of HIV (1-2 days) means that whenever there is any non-adherence, viral load increases very quickly—within 3-7 days, sometimes faster.

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**Relationship between Adherence
and Successful Outcome**

<u>Adherence</u>	<u>Viral Load <400</u>
>95%	81%
90-95%	64%
80-90%	25%
<70%	6%

(INCAS data, Paterson, et al, one year on HAART with unboosted protease inhibitors)

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**Maintaining adherence
is the
MOST IMPORTANT
factor for
successful ARV therapy.**

Ways of Monitoring ARV Adherence

- Health Care Workers are usually unable to predict who will adhere correctly and who will not.
- Health care workers usually overestimate patient adherence.
- Patient level of education and socio-economic status are *not* predictive of adherence levels: the adherence of the poorest, least educated patient may greatly exceed that of a highly educated, affluent patient.

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Ways of Monitoring ARV Adherence (2)

- Patient self-reports of good adherence may or may not be true.
- However, patient self-reports of sub-optimal or poor adherence are probably true, and should be taken seriously.
- Patient disclosure of HIV infection to anyone outside of the clinic is a significant positive predictor of adherence.
- Pharmacy refill data can be a helpful marker of adherence.

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Why is adherence with ARV therapy such a challenge?

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The Drugs

- Complicated dosing regimens, number of pills
- Interference with daily life routine
- Need for commitment to life-long therapy
- Side effects
- Interruption of medication supply
- Cost (for private sector patients without insurance)

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The Healthcare Worker

- Must have up-to-date knowledge of HIV medicine and ARV drugs, including side effects and drug-drug interactions.
- Must understand the relationship between poor adherence and treatment failure.
- Must project to the patient confidence in the therapy.

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The Healthcare Worker (2)

- Must have effective communication skills, to create trusting relationships with patients.
- Must have skills in patient education.
- Must be kind and forgiving, while still reinforcing the importance of adherence.
- Must understand and apply the Botswana National Program guidelines for proper use and combination of ARV medications.

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The Patient

- Requires basic knowledge of HIV pathogenesis and treatment options.
- Must have confidence in the treatment regimen.
- May need to overcome distrust of the medical system, and/or to understand the importance of routine clinic follow-up.

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The Patient (2)

- May have many psychosocial/ lifestyle issues that could complicate adherence.
- May suffer guilt and shame about his/her HIV infection, and thereby may be reluctant to risk disclosure of HIV status by taking ARVs at work, home, or school, with resultant risk of nonadherence.
- May have competing cultural beliefs and practices.
 - e.g., traditional medicine, religious prohibitions

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Adherence Research: Reasons for Missed Doses

- Just forgot
- Did not understand the regimen
- Slept through dose time
- Travel
- Change in daily routine, weekend activities
- Felt sick
- Depression

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Successful Adherence

- With so many challenges, is good adherence even possible?
- Is it realistic?
- What are the best approaches to maximize success ?

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Botswana Research

In a study of 94 adults on ARV therapy, responses showed that good adherence was associated with:

- Belief that the medications help
- Understanding of risks of not taking medications correctly
- Advice and support from doctors
- Family support
- Personal determination
- Improvement of symptoms on therapy

(Weiser, Marlink, 2001)

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Strategies for Successful Adherence

Strategies **MUST** be individualized.

A combination of interventions is most effective.

Adherence must be addressed at **EVERY** patient visit and by all healthcare workers who have contact with the patient at each visit.

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Adherence Strategies Must Be:

- Ongoing -- every visit
- Repetitive -- with consistent information
- Revised -- to meet the changing needs of each patient
- Multidisciplinary -- involving doctors, nurses, pharmacists, counselors, social workers, etc.

Healthcare Workers, including doctors, **MUST** address adherence at every visit, and not just refer the patient to other providers for counseling, or assume that other providers will address adherence.

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Timing of HAART Initiation

The question should never be WHETHER to start treatment but WHEN and HOW.

Before ANY medications are started, every patient must be assessed for treatment readiness, with all potential barriers to adherence identified and addressed.

HAART initiation is never an emergency: always take any necessary time to ensure good adherence before starting HAART.

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Adherence Assessment:

Determine level of patient understanding of:

- HIV pathogenesis and its implications
- Purpose and effect of ARV therapy
- Treatment options and limitations
- Cultural beliefs and practices regarding disease and treatment
- Previous experiences with illness and treatment

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Adherence Assessment (2):

- Stability of environment
 - Income, food, shelter, access to clean water and refrigeration
- Lifestyle
 - Single, married, children, work and work schedule
 - Whether there are other HIV-infected and/or sick family members
 - Family, friends, and community as potential supports and/or barriers. Studies have shown that an important determinant for adherence is *whether or not the patient has disclosed his/her HIV infection to anyone outside of the clinic*: a reason for encouraging patients to divulge their infection to a friend or family member.

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Adherence Assessment (3):

- Transportation
Ability to return to clinic for follow up
- Routines
Work/job – time off to attend clinic
Migration/travel – cattle post, lands
- Use of alcohol, other recreational drugs, traditional medicines, over-the-counter medicine
- Literacy level
Ability to read Setswana or English

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Adherence Assessment (4):

- Current state of physical health
 - Can the patient manage treatment on his/her own, or will he/she need other caregivers.
- Mental health
 - Depression related to HIV diagnosis (often overlooked)
 - Stigma, discrimination, guilt, self-hate
 - HIV-related neurological effects including HIV encephalopathy
 - Pre-existing mental illness

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Adherence Assessment and Alcohol

- Alcohol abuse can very seriously impact adherence, and can cause hepatitis, which complicates ARV therapy.
- Those ARVs requiring a neutral absorption environment, e.g., ddI, must never be taken with alcohol.
- As a rule, patients initiating HAART should be counseled to avoid alcohol, in order to enhance adherence and to lessen the chances of hepatotoxicity due to the ARVs.
- For patients who have been stable on HAART, and who ask about resuming moderate alcohol intake, determine from history whether there may be aspects of alcohol abuse. If there are none, counsel the patient to limit alcohol intake to no more than one drink a day, and to never go out on binges.

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Starting Treatment

- Reaffirm the patient's decision to begin HAART by again noting that treatment is a lifetime commitment, and is not a cure.
- Review the relationship between adherence and resistance, with the goal being 100% adherence indefinitely.

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Starting Treatment (2)

- Discuss the medications and how to take them, including timing and any special instructions or restrictions.
- Discuss use of other medications:
 - Drug-drug interactions
 - Traditional medicines, over-the-counter medicines
 - Advise patient to always inform other providers about ART use, and to always inform clinic staff about other medications he/she is taking, e.g., ATT.

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Starting Treatment (3)

- Discuss potential ARV Side Effects
 - Do not frighten the patient: reassure him/her that *most patients tolerate the medications very well.*
 - Prepare the patient for potential side effects and offer practical coping strategies.
 - Ensure that the patient understands exactly what to expect from each drug.
 - Reassure the patient that side effects are usually minor, and are manageable.

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Starting Treatment (4)

- Practical Support
 - Adherence is enhanced if the regimen fits into the person's daily routine.
 - Ask the patient to decide on the best dosing times within the dosing limits.
 - Provide an illustrated schedule for taking the drugs at proper times.
 - Ask the patient to repeat schedule.

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Starting Treatment (5)

- Show samples of the medications
- Have the patient demonstrate use of each drug and time of administration
- Advise the patient how to handle any missed doses, including time range in which he/she may still take an ARV after a missed dose.
- Pediatric tip: Demonstrate how to give the medications.

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Starting Treatment (6)

- Assist the patient with planning ahead for changes in regular routine, e.g., travel. Problem-solve for different situations and problems.
- As available and appropriate for patient circumstances, encourage use of adherence aids:
 - Pill boxes
 - Alarm clocks
 - Cell phone alarms

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Starting Treatment (7)

- Adherence partner
The patient should involve a family member, partner, or friend to assist with the ARV medication regimen. At the initiation visit, DO NOT IGNORE THE ADHERENCE PARTNER: actively include this adherence partner in discussions about medications and adherence! However, a patient cannot ultimately be denied HAART due to lack of an adherence partner.
- Explain how the patient can access support from the clinic.
 - Clinic phone numbers, contact persons
 - Health care providers MUST be accessible to their patients.

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IMPORTANT

Patients need to understand:

- ARV treatment is NOT a CURE, but rather a life-long treatment to render HIV a chronic, manageable disease.
- HIV TRANSMISSION can still occur, and safe sex must be practiced consistently. If resistance develops, it can also be transmitted to others with unprotected sex.

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Ongoing Treatment

At EVERY visit assess:

- Medication regimen: what pills, when and how taken
- Doses missed: how often, why. Problem-solve with patient.
- Side effects – how to manage them
- Use of other medications, traditional medicine
- Pill counts and refill visits as indicators of adherence
- Positive reinforcement of patient efforts, and support for adherence challenges

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Ongoing Treatment (2)

- Questioning a patient about adherence requires tact and respect, in order to develop a long-lasting trust on the patient's part.
- Ask neutral, non-intimidating questions, which will invite the patient to be forthcoming about his/her level of adherence, e.g.:
 - “How often a month do you think you miss any of your medicines?”
 - “I know how difficult it is to remember to take medicine all of the time. How many times do you forget to take yours?”

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Ongoing Treatment (3)

- Whenever a patient admits to any degree of nonadherence, respond with kindness, understanding, and forgiveness, while still stressing the importance of adherence.
 - Scolding or brow-beating a patient about poor adherence will only cause the patient never to be honest with you again.
 - Whenever a patient admits to poor adherence, *always thank him/her for being honest*, and then work with the patient on ways to address the nonadherence.

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Special Issues in Pediatric Adherence

- Pediatric adherence problems often occur when only a single caregiver is fully aware of the child's medical needs, including the importance of strict adherence.
- There must be adequate support and understanding within the family about the importance of adherence.
- The following specific points must be assessed prior to the initiation of HAART:
 - What is the nature of the family, who cares for the child at various times, and who would be available to ensure appropriate care of the child if the primary caregiver is unavailable?
 - Who will be primarily responsible for giving the child medications and supervising adherence? If there are multiple caregivers, how will coordination between these caregivers be achieved?

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Pediatric Adherence (2)

Assessment prior to HAART (continued):

- What is the caregivers' knowledge of the medical regimen?
- Who will ensure medication adherence if the usual caregiver(s) is absent?
- What age-appropriate role will the child play in ARV adherence?
- What is the child's understanding of the medications and his/her HIV status?
- If the child is able to appropriately dose medications, what adult will be responsible for supervising the child?

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Adolescent Adherence

- The risk of non-adherence is *extremely high* in HIV-infected adolescents, and requires special care and interventions.
- Most HIV-infected adolescents have special psychosocial issues which often lead to adherence problems:
 - Denial and fear related to HIV diagnosis
 - Misunderstandings related to diagnosis and health needs
 - Lack of belief in the efficacy of ARVs
 - Distrust of practitioners and the healthcare system
 - Low self-esteem and unstructured, chaotic lifestyles
 - Limited familial and social support

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Adolescent Adherence (2)

- *The most critical aspect of providing appropriate care to HIV-infected adolescents is closely monitoring psychosocial health.*
- All ARV clinics should identify staff with interest in adolescent care who can provide continuity of care with HIV-infected adolescents. These staff members can form a therapeutic alliance with the adolescent, enabling him/her to handle challenges. These "continuity-of-care providers" should explore with the adolescent issues of sexuality, safe sex, substance abuse, barriers to adherence, and community support.
 - Ideally, an adolescent patient should have the same designated doctor at each visit, to ensure continuity of care and emotional/psychosocial support.

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Summary

- Never start treatment without a comprehensive adherence assessment.
- Educate the patient on all aspects of HIV/AIDS, treatment options, and outcomes.
- Be directive in counseling, to promote the goal of 100% adherence.
- Be accessible, approachable, supportive, and KIND.
- Monitor and counsel for adherence at EVERY VISIT.
- Pediatric and adolescent adherence requires intensive, ongoing interventions and follow-up.

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