Module 5: Adherence to Medication for Children and Adolescents

Session 1: Adherence to Medication for Children and Adolescents

Total Session Time: 1 hour 30 minutes

Learning Objectives

By the end of this session, participants will be able to:

- Explain medicine adherence
- Explain the importance of adherence
- Describe ways of preparing the patient, and/or parents/caregiver for life long medication
- Identify factors affecting adherence
- Describe the consequences of poor adherence
- Describe strategies relevant to maximize adherence in children and adolescents

Definition & Importance of Adherence

Adherence

Adherence means taking the correct dose of drugs at the correct time and in the correct way (such as with the right type of food or fluid). It also means looking after drugs to make sure they are safe and effective to use.

At an individual level, ARV treatment can allow one's immune system to recover so that illness is reduced, and health and quality of life is regained. For HIV infected patients, very high level of ARV adherence is required for the treatment to be effective and to prevent the emergence of resistant viral strains.

Medicine adherence is defined as taking doses of drugs and observing the treatment plan.
Factors supporting adherence to ARVs are:

- A supportive family and community environment
- Strong support groups of people living with HIV
- Food security and nutrition

Poor adherence leads to a higher risk of ARV resistance, resulting in the need for second line treatment which is more difficult to administer and costly.

ARV Adherence

ARV Adherence is an informed choice that involves the relationship between the child/caregiver and healthcare provider i.e taking the **Right Medicine,** with the **Right Dose**, at the **Right Time**, in **the Right Frequency**, in the **Right Way.**

Importance of adherence includes:

- Clients MUST understand that they cannot just take them how and when they feel like it!
- Clients must understand that they must take their medications even when they feel well
- The HCW must ensure that all clients understand this before starting treatment

Non adherence includes the following:

- Not taking the right drug
- Missing one or more doses of a given medicine
- Not observing the time intervals of doses
- Not observing the frequency
- Not observing the dietary instructions for the particular medicine

Taking the Right Medicine at the Right Time

- The right medicines and the right doses MUST be taken
- If not, the virus continues to replicate and resistance can develop

- There is usually a window period of about one to 3 hours

- Exact time of doses is crucial or else the viral load will increase and resistant virus emerge

Maintaining a certain amount of the medicine in the blood at all times is essential to prevent viral replication and resistance from occurring. Facilitator should come with real pediatric ART medicines and the dosage recommendation charts for better understanding.

The timing of the medicine doses is extremely important:

- When referring to a “window” period of about 3 hours, it generally means either three hours earlier or three hours later than normal
- When doses are missed or not taken on time, medicine levels in the blood fall, HIV suppression is reduced, allowing reproduction

In the Right Way

- Ignoring dietary restrictions may affect the amount of medicine absorbed
- If not enough of the medicine is absorbed, the amount of virus will increase and resistance is more likely to occur

The importance of following dietary restrictions when taking medications:

- In addition to getting the times, doses and medicine right, some medicines have dietary restrictions, such as to be taken with or without food.
- Not adhering to dietary restrictions can be like taking only half of a dose and for some medicines no dose.
- If not adhered to, the amount of medicine absorbed may be insufficient, meaning viral suppression is reduced.
- In ART all medicines have dietary requirements and must be adhered to– .g. "take with/without food"
- Give relevant examples e.g EFV Should not be taken with fatty foods.

The reason for the education is because adherence is the key to medications being as effective as possible. Support of the client is essential.

Importance of Adherence

Maintaining 100% adherence to ARVs is the single most important factor in ensuring successful outcomes:

- Maintains child's immune status preventing disease progression
- With some regimes, missing even a single dose in a 2 weeks can lead to resistance to medications and narrow treatment options

For successful ART outcomes, patients must take at least 95% of their pills/doses (i.e. achieve 95% adherence);

- Compare this to TB, where good cure rates can still be achieved with 80% adherence

95% Adherence Means:

- For medicines taken twice daily, no more than 3 missed doses per month
- For medicines taken once daily, no more than 1 missed dose per month

Importance of Preparing for Lifelong Medication

Adherence preparation should begin as soon as possible and before initiation of ART, but should not put the child at risk of disease progression or death through delaying the initiation of ART.

HIV is a **Chronic Disease** requiring lifelong therapy:

- There is no cure for HIV
- Medications taken incorrectly allow development of resistance
- Taking medications correctly is important for STAYING HEALTHY

- Children rely on a responsible caregiver for medication
- Responsibility for medicine administration is not necessarily to the parent
- The family caregiver changes over time such as house maid, mother, sibling, granny, peer, friend, etc.
- Formulations and dosages differ over time
- Motivation of child fluctuates over time

The following factors influence a child's adherence to treatment:

- Traditionally children do not take part in making decision. Children have no right whether to refuse or to take medications
- To educate children needs extra effort and skill. There is limited experience in counseling children for life time medications
- A child is growing & developing: needs, relationships, environment and priorities are changing.
- Medicines–pill/volume burden, taste, colour, frequency, smell, eating schedule-medicines that have requirements to be given with or without food
- Age of the child (changes in dosing, developmental changes)

Preparation for Adherence, factors Affecting Adherence & Consequences of Poor Adherence

Preparation for Adherence

Ways of preparing the patient, and/or parents/caregiver for life long medication include:

- Disclose child's status and need for life long treatment to responsible parents/guardian
- Identify responsible person for daily medicine administration
- Have a joint session with parent, family medicine dispenser and the child
- Conduct demonstration sessions on medicine dosages and administration

Important Considerations for Readiness to Start Treatment

- Understands importance of clinic visits and maintaining CTC 1 card
- Adheres to Cotrimoxazole and multivitamins
- Understand roles of different household members in medicine administration
- Relevant household members trained
- Household conditions for medicine storage are met

Assessment for Readiness to Start Treatment

In order to assess the readiness of patient to start treatment, the following questions should be considered:

- Are you ready to start ART?
- How long will the child need ART?
- Who will be giving the medicines?:
  - Has caregiver attended adherence sessions?
  - What time will medicines be given?
  - Does the caregiver work?
- What are some ARV side effects?:
  - What will be done if side effects occur?
- What will you do if child vomits after taking medication?
- What will you do if you forget to give your child medication at the right time?
- What are CD4 cells?
  - What is your child's CD4?
- Why is it important not to miss any doses?

The importance of assessing readiness and why one should never rush to treat:

- Before starting treatment, it is important to assess whether or not the child/caretaker will be adherent to the regimen
- If is not ready to be in treatment, the child may not benefit from the ARVs and resistance may occur
- It is important to understand that it is often necessary to have multiple meetings before treatment is initiated
- Promoting adherence begins prior to starting treatment
- If difficulties and challenges are discussed beforehand then the caretaker is given more time to consider any life style changes, interventions and strategies needed that may assist in adherence
- This way, children/caretakers are involved in their treatment from the very beginning and know what to expect

CD4+ cells also called T helper cells are types of T-lymphocytes and these are immune cells which coordinate the function of other immune cells.

It is important not to miss any dose because missing doses leads to incomplete viral suppression resulting into decrease of CD4 cell count, growth and development faltering, reappearance of OIs and progression of disease leading to increased morbidity and mortality.

Assessing Adherence in Children

- Assessment of adherence should be a concern of every child's health care provider
- Should be performed whenever there is a visit to a health centre in order to identify children who need adherence support

- Assessment may be difficult, due to children and parents self reporting;
  - Social desirability of children and parents to report complete adherence may make assessment invalid
- During follow up visits to clinic needs to include interviewing family care provider about actual missed dosages last week/month;
  - Omitting more than one dose in 10 days implies <95% or suboptimal adherence
- Always insist on adherence each visit to the child, parent and household/family care provider
- Always insist to bring medications at every visit and do pill count /syrup measurement so as to calculate adherence percentage

Adherence should be assessed at each visit, and parental, caregiver and child issues addressed to support adherence.

When assessing for adherence, the following steps should be taken:
- **ASK** about specific barriers to adherence such as new person in the household like an in-law, mother is too ill to give medication, poor palatability of medication etc.
- **ASK** for other examples:
  - How do the people involved affect adherence? Who are they?
  - How does timing affect adherence?
  - What other challenges to adherence can you think of?

NOTE that lifelong adherence is extraordinarily challenging.

*Refer to **Handout 5.1.1: Assessing Adherence in Children** on **page 233** for more information on assessing adherence in children*

Activity on filling in the adherence chart

- Use the formulas below:

$$\%\ of\ pills\ missed = \left(\frac{no.\ of\ pills}{total\ no.\ of\ pills\ prescribed}\right) \times 100$$

$$\%\ adherence = 100 - \%\ of\ pills\ missed$$

*Refer to **Worksheet 5.1.1: Adherence Chart Activity** on **page 235** for more information*

Factors Affecting Adherence in Children

Adherence in children depends on the 3 main factors described as:
- Child related factors
- Care taker/parent related factors
- System related factors

Child related factors include:
- Living environment
- Age
- Disclosure status
- Medicine regimen:
  - Smell, dosing, volume, pill burden, palatability

- Health status of child:
  - Common childhood illnesses and mood
  - Developmental milestones

Programmatic issues can also affect paediatric adherence and must be considered as programmes expand to provide paediatric ART. Problems with adherence for children, their caregivers and adolescents (in particular those who are in transition of care) should be anticipated; they are encountered at every level of the health care system involved in providing ART.

Continuous access to a supply of free ARV medicines as well as the development of well-functioning systems for forecasting, procurement and supply management are essential components of paediatric treatment programmes.

The limited formulations currently available for children present significant barriers to optimal adherence. The development of formulations appropriate for use in infants and young children is therefore strongly encouraged.

Family/caretaker related factors are:
- Stigma, unexpected travel, cultural beliefs, education level, various caregivers over time, mother employed
- Storage, fridge
- Peer pressure, school, sport
- Parents / caretaker HIV and AIDS status
- Relationship between parent/caregiver and child
- Not involving actual medication administrator, e.g. maid

System related factors include:
- Patient-care giver-clinician relationship:
  - Non friendly clinic environment for kids
  - Poor communication and understanding
- Contradicting information from doctor, nurse, pharmacist
- Laws and policies in place

The care setting:
- Children and adolescents should be given motivation to return to the care site and remain in care.
- A welcoming and comfortable care environment that can offer flexible and creative incentives can motivate children and adolescents to become involved in their care.

Concerning communication:
- Regardless of what the caretaker/child tells you, work to project concern and respect not just by what you say but how you say it
- Asking specific, open-ended questions to facilitate client sharing allows for them to respond with more than a nod or just a “yes” or “no”

Non Disclosure as a Cause of Non-Adherence
Caregivers are often concerned with the disclosure of HIV status to other family members, friends or schools, thus restricting the child’s options for seeking support.

Therefore, an understanding of how the developmental stage of the child influences the extent to which he or she will cooperate with the regular administration of medicine helps to guide planning and support for the process. Failure to disclosure to the child may cause non adherence as follows:

- This is commonly seen in children.
- Child is either left with the child minder or grandparents who have no idea about the child's HIV status.
- Sometimes deliberate efforts are made to deceive the caregiver e.g. told that the medication is either for flu or cough
- Importance of continued medication not explained

Consequences of Poor Adherence

Failure to disclose to the child can lead to poor adherence to drugs which in turn may cause the following consequences:

- Incomplete viral suppression resulting into decrease of CD4 cell count/percent
- Growth and development faltering
- HIV related illnesses and OIs may reappear
- Progression of disease leading to increased morbidity and mortality
- Emergence of resistant viral strains; Development of ARVs resistance (especially with adherence of 60-90%)
- Shift to future treatment options such as second line which is usually less easily available and more difficult to adhere

Adherence is related to the clinical, immunological and virological responses to therapy in infants and children.

- Resistance refers to the ability of the HIV virus to mutate or change its structure in such a way that it loses its sensitivity to a particular medicine
- Resistant HIV can function and grow despite the presence of antiretroviral agents
- The point to be aware of here is that skipping or missing doses may result in increased viral load and the virus changing its structure.

Remember: Good adherence has the best chance of success!

Strategies Relevant to Maximize Adherence in Children and Adolescents

Strategies for Successful Adherence among Children

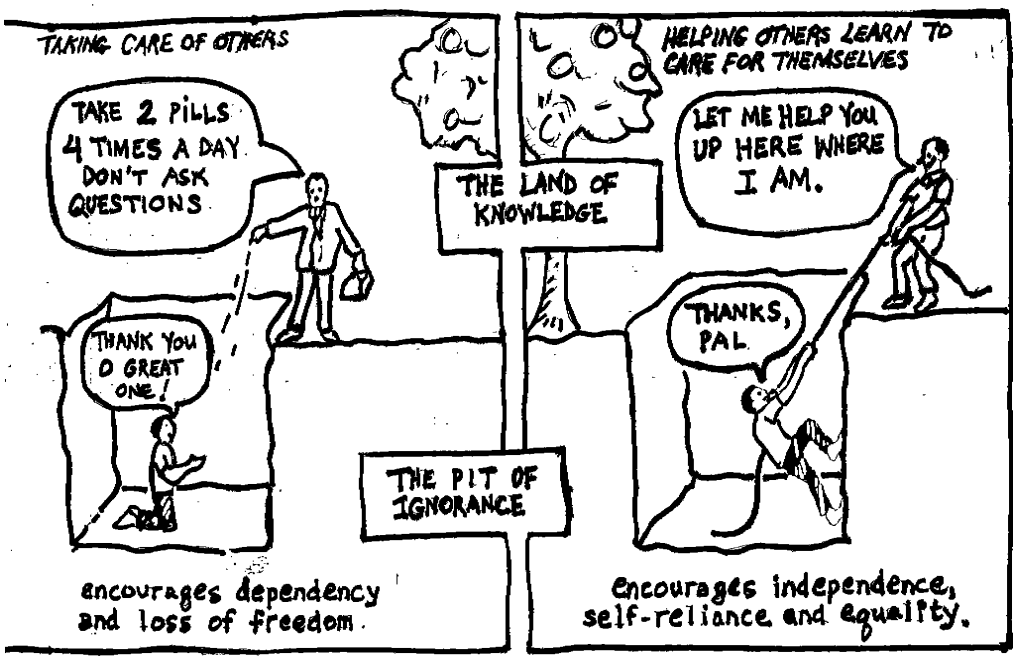
The successful treatment of a child requires the commitment and involvement of a responsible caregiver. This may be particularly complicated if the family unit is disrupted as a consequence of adverse health or economic conditions. Mothers of HIV infected children are frequently HIV-infected themselves and the care of the children may be less than optimal because of the mothers' compromised health. In addition, some strategies for successful adherence among children may include:

- Before **ANY** medications are started, every patient must be assessed for treatment READINESS with all potential barriers identified and addressed
- Never rush to treat, always assess carefully
- Strategies for adherence **MUST** be household or family oriented
- Adherence counseling takes time and effort
- Use of checklist and SOPs
- Adherence must be addressed at **EVERY** patient visit

- Review strategies regularly: to meet the changing needs of the growing child
- Work as a team: doctors, nurses, pharmacists, counselors all to reinforce adherence
- Identify one household caregiver who gives medication to child and should attend clinic as well

Strategies for Successful Adherence among Children

This cartoon below shows the difference between taking care of others vs. helping others learn to care for themselves.



NOTE: Preparing clients for adherence encourage empowerment, independence, and self-reliance.

Common challenges in adherence and strategies to improve in daily clinic practice

In some settings you may be able to change a specific medicine or formulation if the problem is relatively recent and confined to the characteristics of a single drug. In other cases inadequate adherence may have gone on long enough to result in treatment failure and the need for an entirely new regimen. Examples of challenges that the patient has no control over include; impassable roads during the rainy season, political instability, disaster, etc.

If adherence is significantly impaired, it may be necessary to stop the current regimen while identifying and addressing adherence barriers. This may prevent development of (further) resistance.

Child Not Taking Medications

Challenge	Strategies
A parental report of the child not taking his/her medications	• Obtain a detailed history to identify specific causes of his/her broad complaint • Make available information in the primary caretaker's language to address the complaint

Medications Make Child Sick

Challenge	Strategies
A parental report of the child becoming nauseous and vomiting after taking medications	• Administer medications with food if not contraindicated. • Administer medications with liquid to help reduce gastric irritation. • Request assistance from the school nurse if nausea & vomiting mainly occur in the a.m. before school. This may only be done with family's permission.

If child spits up or vomits medicine, that dose should be repeated if vomiting occurred in < 30 minutes from time the medicine was given. If vomiting occurred in > 30 minutes from time the medicine was given do **not** repeat the dose. The medicine can be mixed with different liquid or soft food. In both cases, the next dose should be given according to the normal schedule.

Fear of Medication Harming the Child

Challenge	Strategies
A parental report of adherence in the face of deteriorating clinical & immunological status in the child; parent anxious that the ARV medication will harm the child	• Obtain refill history from primary pharmacy • Utilize visiting nurse/HBC provider services to assist with adherence assessments • Utilize directly observed antiretroviral therapy (e.g., visiting nurse, HBC provider)

Regimen/Dosing Confusion

Challenge	Strategies
A parent becomes confused about which medications are being given due to multiple names for medications	• Provide parent with written schedule of medications. This illustration should include both brand and generic names and some description of the medications in a language that the child and caregiver can understand • Utilize colour-coded labels with a matched colour-coded calendar • Where possible elicit additional support from another family member or other community resource person

Adherence in Adolescents

For perinatally infected adolescents on life-long HIV-suppressive therapy:

- Faced with treatment imposed on them
- Often lack of early disclosure
- Challenge of parental authority
- Wish of more direct involvement in their own care and treatment

Those starting treatment need to be ready to adhere to prescribed medication regimen

HIV-infected adolescents are especially vulnerable to specific adherence problems based on their psychosocial and cognitive developmental trajectory. Many HIV-infected adolescents face challenges in adhering to medical regimens for reasons that include:

- Denial and fear of their HIV infection;
- Misinformation;
- Distrust of the medical establishment;
- Fear and lack of belief in the effectiveness of medications;
- Low self-esteem;
- Unstructured and chaotic lifestyles;
- Mood disorders and other mental illness;
- Lack of familial and social support;
- Absence of or inconsistent access to care or health insurance; and
- Incumbent risk of inadvertent parental disclosure of the youth's HIV infection status if parental health insurance is used.

Favorable Circumstances for Adherence in Adolescents

- Adequate support
- Stability in one's life
- Beneficial and early disclosure
- Change in health status or lab parameters
- Familiarity with people responding well to similar therapies
- Familiarity with someone who is sick or who died recently
- Access to a supportive clinician discussing options
- Nonjudgmental health provider

Factors that may improve adherence to ART for adolescents living with HIV include:

1. The adolescent (individual characteristics and stage of development)
   - access to information that corresponds to the adolescent's maturational stage;
   - treatment tailored to the adolescent's stage of development;
   - information communicated in a straightforward way;
   - a relationship of trust and respect with health workers;
   - ART adapted to the adolescent's lifestyle (e.g. will the adolescent take medication in school?);
   - adolescents involved with and consulted on changes in treatment (therapeutic alliance).
2. Their environment (family, peers, health services, community)
   - support of siblings, parents/guardians, peers, support group, treatment supporter;
   - consistent care and support from a range of sources over time;
   - regular assessment for side effects and adherence in an appropriate manner;
   - simplified therapeutic regimen;
   - access to support groups led by peers who have successfully implemented and adhered to ART themselves.

Factors Affecting Medicine Adherence among Adolescents

Adherence among adolescent depends on the number of factors including:

- Depression;
  - Individuals who are depressed lack the motivation to carry on with life's activities
- Drug abuse:
  - Substance use makes it difficult for individuals to adhere to treatment

    - Alcohol use increases risk of ARV medicine toxicity
- Unstable living conditions
- Lack of support
- Lack of readiness and refusal

Programmatic issues can also affect paediatric and adolescent adherence and must be considered as programmes expand to provide paediatric ART. Problems with adherence for children, their caregivers and adolescents (in particular those who are in transition of care) should be anticipated; they are encountered at every level of the health care system involved in providing ART.

Continuous access to a supply of free ARV medicines as well as the development of well-functioning systems for forecasting, procurement and supply management are essential components of paediatric treatment programmes.

The limited formulations currently available for children present significant barriers to optimal adherence. The development of formulations appropriate for use in infants and young children is therefore strongly encouraged.

Strategies for Enhancing ARV Adherence Among Adolescents

Having a good support system and feeling connected to others gives feelings of hope and acceptance. Therefore, in order for adolescent to adhere to ARV drugs the following strategies should be enhanced:

- Consider practicing medicine adherence with vitamin pills and Cotrimoxazole-prophylaxis before starting the ARV
- Explore with the adolescents challenges they experience in taking the medicines and work out strategies to address them
- Develop a good relationship with the adolescent so that they see you as their partners in health: The importance of having a relationship with the client include:
    - Early diagnosis of complications can also delay HIV disease progression
    - When clients are involved in their care and you see them on a regular basis, they are often able to avoid acute illness
    - Having a positive relationship helps make strengthen communication, which may make it easier for client to speak about issues.
- The member of the C&T-team with the best relation to the adolescent should take the lead in the counseling
- Regimens that fit into the adolescents life as much as possible;
    - Let the adolescent know that they need to continue taking the drugs even when they are feeling unwell or feeling well
- Positive approach to treatment that nurtures the adolescent's belief in their success
- Use of simple regimens – a once or twice daily regimens likely to work best:
    - Adolescents are more likely than anyone else to discontinue a regimen on their own if they encounter any difficulties
    - Involve the adolescent when discussing treatment options
- Give information proactively, in appropriate language and in writing because adolescents may not ask questions on their own
- Use real life examples to illustrate as adolescents often think in concrete terms
- Explain to young people what to expect while on therapy and how to manage side effects and adherence problems

- Adolescents should be encouraged to discuss their problems with their care providers/person they trust

Help the Adolescent Develop an Individual Strategy for Adherence
Encourage the Adolescent to:
- Establish a routine for taking medicines
- Place in coloured boxes or place coloured stickers on medication to distinguish between medications or when they are to be taken
- Keep the medicines where they can see them in the morning and evening
- Take the ARV medicines at the same time every morning/evening
- Write notes and stickers to remind them to take the medicines
- Keep a diary of how they are taking their medicines and to review it with the care provider
- Plan ahead to take ART when they are away from home
- Plan for sudden events that change the normal routine and therefore should plan to always have a few tablets with them
- Identify a treatment partner if possible;
    - Although adolescents who are living alone may find this difficult, the strategy has been successful in adults

Other strategies that can be used with patients to enhance adherence include:
- Overt reminders e.g. Watch, Timer, Cell phone alarm, Tie in with daily activities etc.
- Storage of pills
    - e.g. place them somewhere you see every day, but out of direct sun exposure
    - Place in coloured boxes or place coloured stickers on medication to distinguish between medications or when they are to be taken
- Peer Support Groups: Emphasize that support groups encourage honesty and exploration. Open discussions can reduce stigma and isolation

Key Points

- Adherence is taking the **Right Medicine**, with the **Right Dose**, at the **Right Time**, in **the Right Frequency**, in the **Right Way**
- Adherence is more than simply following instructions, It requires commitment and knowledge
- Involving the caretaker/child in decision making improves adherence
- Supporting relationship between the child/ adolescent, family, friends of child/ adolescent and HCWs improves adherence
- Provide necessary services to the parent/care giver escorting the child to promote good adherence
- Asses adherence every visit
- Good adherence (>95%) has the best chance of treatment success

Handout 5.1.1: Assessing Adherence in Children

The continuous assessment and support of adherence are vital components of a proactive approach to ART. The assessment of adherence should be a concern of every health care provider participating in the care of children. It should be performed whenever there is a visit to a health centre in order to identify children in need of the greatest support for adherence. The measurement of adherence may, however, be difficult, particularly in children.

Quantitative methods are generally employed (asking children or caregivers how many doses of medication have been missed during the past 3, 7 or 30 days) but the responses may not reflect true adherence as children and caregivers learn the social desirability of reporting complete adherence. Qualitative evaluations of adherence can more effectively identify barriers to optimal medication-taking but can be more difficult and time-consuming for the health care providers as well as the children and/or their caregivers. Qualitative evaluations generally focus on obtaining descriptions of impediments to adherence or problems encountered. Furthermore, the assessment of adherence can be complicated by diverging reports between children and caregivers, as well as by the limited availability of information when the caregivers bringing children to clinics are not responsible for supervising ART administration (164). Reviews of pharmacy records as well as pill counts can provide valuable information about adherence. Viral load measurements can be used to assess adherence to medication but are unlikely to be widely available in low-resource settings at present and are an expensive way to monitor adherence.

Source: ANTIRETROVIRAL THERAPY OF HIV INFECTION IN INFANTS AND CHILDREN IN RESOURCE-LIMITED SETTINGS: TOWARDS UNIVERSAL ACCESS

Worksheet 5.1.1: Adherence Chart Activity

Instructions:

- In small groups, work together to fill in the blanks in the adherence chart below.
- Use the formulas provided to calculate the % of pills missed and % adherence for each row.
- Be prepared to share and discuss in plenary.

$$\%\ \boldsymbol{of\ pills\ missed} = \left(\frac{\boldsymbol{no.\ of\ pills}}{\boldsymbol{total\ no.\ of\ pills\ prescribed}}\right) \times \mathbf{100}$$

$$\%\ \boldsymbol{adherence} = \mathbf{100} - \%\ \boldsymbol{of\ pills\ missed}$$

Example: Below you can see the calculations from Row 1 in the table.

$$\%\ of\ pills\ missed = \left(\frac{1}{60}\right) \times 100 = 2\%$$

$$\%\ adherence = 100\% - 2\% = 98\%$$

No. of Missed Pills out of 60	% of pills missed	% adherence
1	2%	98%
2		
3		
4		
5		
6		
7		
8		
9		
10		
15		
20		