

Counselling Training Manual

in Support of Pediatric ART



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Foreword

“We are getting the ART services for adults, but what about our children?” – This is the concern of the mothers from the VMM supported HCBCS and the pain that is reflected in this question is repeated many a time in the community.

The United Nations General Assembly affirmed its commitment to the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010. They called upon international and national bodies, the public and private sectors, civil society, people with HIV and communities affected by HIV/AIDS to work closely together to achieve this. By the end of 2005, only two million people were able to access antiretroviral (ARV) treatment (mostly adults) out of a total of six million people estimated to be in need of treatment.

The urgent need to increase treatment access to CLHA and the growing awareness of the critical need for communities to be involved in education, preparation, support for ARV treatment and a Pediatric counselling manual are vital. Children and caregivers need to learn about ARV therapy so that they understand the total range of issues involved and can accurately pass on information to those who need it in their communities. This includes not only people who are taking, or will need to take, ARV treatment themselves but also all those within the community who have a role in informing, supporting and advocating for treatment.

The success of ARV treatment depends on achieving high levels of adherence, sustaining protective behaviours of parents and children and reducing stigma at the personal and community levels. Inadequate adherence to treatment can compromise a child’s health by enabling rapid increase in the amount of HIV in the blood and allowing the virus to change in ways that make ARV treatment less effective or stop working.

However, sustaining adherence to lifelong treatment, reducing HIV/AIDS-related stigma and sustaining protective behaviour will all require much more than reliable provision of ARV medicines. There must also be effective community and individual education about ARV treatment, including how to take and adhere to treatment; how to manage drug side effects; how to prevent HIV transmission and how to access supportive care. Communities also need information on issues such as equity of access and criteria for enrolment into ART programmes. All of these will increase community knowledge and understanding of HIV and ART, help to increase uptake of voluntary counseling and testing (VCT) and ARV treatment, and will support individuals with their treatment and help to reduce stigma and discrimination. Key community leaders and structures can provide vital support for successful provision and use of ARV treatment.

The vast and wide array of Counselors working with the HIV/AIDS infected and affected across the nation needs capacitated in Pediatric Counseling too. In this context the need to have a practice manual to take the counselors to delivery mode is all the more imperative. This particular work aims at improving the Counselors skills in the knowledge, attitude domains to work effectively in the area of pediatric counseling. Further this work also helps the counselors to carry forward their initiatives of involving the community people and more pertinently the entire civil society to embark on a multi-pronged strategy for this multidimensional problem.

This manual supports the counselors to provide necessary counseling in the multi- specialised teams at the ART centers comprising of Medical officers, counselors, lab technicians, pharmacist, nurses etc., where the counselor/s role is to provide ART treatment education and adherence counselling apart from maintaining records for the purpose of CMIS managed by NACO.

The present work gives the road map and the stage-by-stage process of pediatric counseling along with areas such as:

- Treatment education
- Strengthening mechanisms to support and promote adherence, prevention and stigma reduction.

Successful community engagement in ARV treatment programmes and increased social capital among children with HIV and the wider community play a unique role in the continuing efforts to combat HIV/AIDS.

Abbreviations

AIDS – Acquired Immunodeficiency Syndrome
ART – Antiretroviral Therapy
ARV - Antiretroviral
CBO – Community Based Organisation
CLHA – Children Living with HIV/AIDS
CMIS - Centralized Management Information System
DBS – Dry Blood Spot
GO - Government
HIV – Human Immunodeficiency Virus
HCBCS – Home and Community Based HIV/AIDS Care and Support
ICTC – Integrated Counselling and Testing Center
LIP - Lymphoid Interstitial Pneumonitis
NACO – National AIDS Control Organisation
NGO – Non Government Organisation
OI – Opportunistic Infection
OPD – Out Patient Department
ORS – Oral Rehydration Solution
PCP – Pneumocystis Carinii Pneumonia
PLHA – People Living with HIV/ AIDS
PPTCT – Prevention of Parent to Child Transmission
TB - Tuberculosis
TB DOTS – Tuberculosis Directly Observed Treatment Short course
VCT – Voluntary Counselling Testing
VMM – Vasavya Mahila Mandali
WHO – World Health Organisation

Introduction

Manual for Counselors in Support of Pediatric ART is essentially designed as a practice manual in delivery mode and supplements NACO's 12 day training Manual which is focused on adult PLHA. The training within NACO's Manual includes:

- Antiretroviral Therapy: Counselling and medical aspects
- The Purview of Counselling in HIV/ AIDS home- based care
- The role of diet and nutrition in the management of PLHA

Pediatric Counseling support is an important component in continuum of care for positive living of an orphan/vulnerable children living with HIV/AIDS. Counselors should recognize the fact that the treatment of pediatric HIV infection poses additional adherence challenges for children and families due to repeated morbidity and mortality. The Pediatric Counselor should facilitate rigorous adherence to antiretroviral medication regimens to achieve and maintain undetectable viral loads. Since the care of the sick child is a challenge to the caregiver due to stigma and discrimination, it affects the caregivers' perception towards a child's health and adherence. The child's basic right to live has to be made clear to the care givers through counseling and here comes the role of the Pediatric Counselor.

The diagnosis and management of HIV in children is a complex issue where Counselors should recognize certain challenges and considerations that are unique to children such as:

- Young children have immature immune systems and thus are susceptible to more frequent and severe common and opportunistic infections.
- Due to the persistence of maternal antibodies, a positive rapid HIV test is not definitive in the diagnosis of children below 18 months. However, a negative test is useful because it usually excludes infection acquired from the mother, so long as the child has not been breastfed.
- Normal CD4 counts are higher in young children than in adults and decrease with age reaching adult levels around the age of 6 years. The absolute CD4 count depends on age and so cannot be used in the same way as for adults to determine progression of infection.
- ARV drugs dosage in children need to be adjusted to weight as the child continues to grow.
- Counselling children for disclosure of their HIV status, discussing about ART, support adherence to ART requires a special effort and skills in communication and the expertise of caregivers.
- All children who have been exposed to HIV, whether classified as HIV exposed / or possibly exposed or confirmed as symptomatic HIV / confirmed HIV infection, require regular follow up and reassessment in order to determine their individual care and support needs.

Pediatric Counselors should note that if a child is diagnosed as HIV infected, he or she need not be kept on ART. The decision to put a child on ART depends on the progression of the disease. Whereas HIV infected adults may be asymptomatic for a period of up to 10 years or more, in children the disease progresses more rapidly and depending on when the infection is acquired. Half of HIV-infected infants will develop severe symptoms and die within the first two years of life if they are not treated with ARVs.

The rate of progression of disease and the continuous growth of the child makes it necessary to provide close follow up and constant re-assessment of the child through regular clinical assessment and ARV initiation at the right time. HIV can have a detrimental effect on a child's psychological well-being and health. This will be reflected in their behaviors, emotional growth and development and effect their social and family interactions. They will often develop various coping mechanisms due to changing family dynamics. The increase in the orphans and child headed families is a challenge to provide care, support and treatment. Pediatric Counselor should have in depth knowledge to understand the dynamics of the person and the predicament for initiating effective interventions. The detailed discussion on the development stages is intended for this purpose.

Further, the family often experiences economic deterioration which leads to school drop outs, child labor and loss of childhood. Food insecurity and trafficking are also outcomes which are prominent in low socio-economic families.

In this pediatric counselling Manual the skills and tools necessary for building resilience within children and their caregivers are included. Support systems intended to strengthen the family and community, articulating safety nets for children, healthy coping mechanisms to best cope with feelings and emotions and methods of adherence to medication are presented in detail to help the Pediatric Counselor to offer quality services in pediatric ARV treatment.

This Manual aims at a progressive evolution of counselling process to a child and care giver by the counselor. Hence there is continuity from one session to the other leading to adherence to ARV. The skills of pediatric counselling are basic to deal with HIV/AIDS and care of the sick child which leads to complete adherence, so the Manual started providing counselling skills followed by knowledge on HIV/AIDS among children and care of the sick child. The first three modules are essential for adherence that is dealt in the module - four.

The *Counseling Manual in Support of Pediatric ART* is focused on children living with HIV/AIDS and includes:

- **Module 1 - Pediatric counseling** deals with principles and methods of working with CLHA, techniques of pediatric counseling and the process of counseling the CLHA and caregivers.
- **Module 11 - HIV/AIDS in children – Basics** deals with modes of transmission to children, infant feeding, importance of testing and progression of the disease in children.
- **Module 111 - Care of the sick child** deals with medical issues: OI in children and side effects to ARV and the home care management, Nutrition and counseling, Water, sanitation and Hygiene for CLHA
- **Module 1V - Adherence to ARV** treatment deals with the assessment of the child, adherence and follow up of the incomplete adherence.

Audience of the module

Counselors

- Counselors in ART centers
- Nurses in ICTC
- Medical Social workers in Pediatric OPD
- Counselors working with NGOs

Beneficiaries

- CLHA attending ART centers
- Care giver : Parent / Guardian

This Manual was developed with the field experiences of Vasavya Mahila Mandali and its network of NGOs in Andhra Pradesh in Home and Community Based HIV/AIDS Care and Support with a child centric approach with the technical support from WHO country office, India.

The feed back from three sessions with field staff including the program managers and the adult support group members gave realistic views and experiences which are incorporated into the Manual to develop practical, hands on experience and user friendly sessions. The inputs on experiences of adults on ART especially regarding the barriers to adherence and disclosure are taken into consideration while developing this Manual. The siblings of the CLHA shared their feelings of the constant sickness of their loved ones and expressed views on the adherence and counseling techniques.

The focus group discussions with CLHA on ART and their caregivers have provided valuable inputs for adherence and the barriers. The medical team at ART centre, Guntur has shared the practical issues related to adherence and care of the sick child. The content of the Manual was shared with eminent medical professionals in public and social sector and their inputs were incorporated. As this Manual is going to be used all over India, the food habits from the various parts of India are taken into consideration by having interactions with NGO representatives from different states. The recipes were developed by nutritionists working with child care programs in rural and urban settings. Some of the existing literature was reviewed and adapted to the Indian context.

All the illustrations in the group counseling cards / information brochure/interactive games were done by a children support group member from a relocated urban slum in Vijayawada, Andhra Pradesh, to have participation of the children in developing and designing the tools. The story was named as “The Bam Bam Virus” by the children.

METHODOLOGY

The training methodology used in this manual is highly participatory. An interactive approach that takes the existing knowledge of the participants as a starting point is adopted so that they are truly involved in the learning process. As far as possible, the training is made enjoyable and entertaining, making serious information accessible and easily understood. Question and answer sessions are used more to help participants learn and make use of new information within a short span of time. The facilitators’ attitude is crucial in this kind of training. Some participants may start the training feeling that the issue is a complicated one and that they will not be capable of understanding it because they are not health professionals. Hence the Counselors are reminded to cultivate and encourage openness and willingness to share the experiences of the participants, with respect, which will encourage them to participate in learning actively. Judgmental attitude on the part of facilitators will block the learning process and needs to be discarded to get matured as an effective trainer.

The activities deliberately favour the use of materials that can be reproduced at low cost by organisations in their community work.

Some practical advices for Facilitators

- Ask participants to sit in a circle or semi-circle, never in rows or behind tables like at school or university.
- Move tables out of the way so that participants and Facilitators (therefore ideas and learning) can move freely.
- Never start to explain something new without checking first if any of the participants can explain it. Encourage group dynamics by asking participants to correct and supplement each other’s responses. Facilitator will be surprised at how much knowledge the participants already have.
- Facilitator is not there to tell the participants how little they know but to show them how much they know and to add to their existing knowledge.
- Call on the practical experience that some participants may already have, whether they are health professionals, people on treatment or caregivers. Concrete examples given by participants will have far more impact than long, theoretical explanations.
- ‘Facilitator is a trainer not a teacher.’ Facilitator is not there to impress the participants with his/her knowledge but to facilitate their learning.
- The materials facilitator use is there to help him/her to provide better explanations. If these are not going down well with the participants, use ones own imagination and create different support materials.
- Facilitator’s sense of humour is the best tool.

A multidisciplinary team experienced in ARV treatment issues should facilitate the training. The ideal number of Facilitators is two. All facilitators should be present throughout the training course because the modules are all linked to each other. At least one facilitator (but preferably all facilitators) must be experienced in using participatory methods. One facilitator with clinical experience in ARV treatment is essential, but you could also have facilitators who have already been involved in adherence support or treatment education.

Each module includes different progressively evolved sessions that contain

- **Aim:** The outcome of the session
- **Methodology:** Each session contains interactive Power Point Presentation, brain storming, role plays, games, group counseling cards, songs and Story
- **Time:** Appropriate time is allotted to each session
- **Materials Needed:** To keep the materials available prior to the session
- **Notes to Facilitator :** Facilitator can follow the lead with the notes
- **Activity:** A detailed procedure was mentioned to follow during the session.
- **Essential Information:** This section is giving key information to be told to the participants.
- **Power Point Presentation:** This contains the slides for the facilitator to use in the interactive PPT
- **Handout:** Contains additional reading material for reference

Tools in the Manual

Group counseling cards: 11 cards are included with a visual picture on one side and the instructions on the back side. These cards are to be used during counseling sessions at ART centers.

Vitamin cards: Use 8 cards with pictures and text on sources of vitamins during counseling sessions.

Interactive Games

Participatory games for the Counselor to organize during the training sessions with children and caregivers.

Snake and ladder game

Four thematic game boards for the children and caregivers to play while at ART center are part of the manual. This is an accepted game model by all ages and can be played easily and do not require expertise.

Information Brochure

This take home message is to be given to the caregiver and children after explaining it to them. This contains do's and don'ts and recipes for the children of different ages.

My ART Calendar

Child friendly calendar is developed to give to each child on ART so that the child will paste a sticker every time after taking the medication. The counselor has to explain it to the child / care giver and ask them to bring for the follow up visit to ART centre so that this will make counselor to assess the adherence.

The Bam Bam virus story

This story deals with the HIV/AIDS/ ART, care giving, self care, disclosure and grannies taking care of grand children. This is child friendly story with attractive pictures of animal characters.

Song

A song on care of child living with HIV/AIDS that can be used while a group of children are at ART centre.

PAEDIATRIC COUNSELING

Session Time 2 hours 20 minutes

Session-I	Working with CLHA – 30 minutes
Session-II	The Techniques of Counseling children- 60 minutes
Session-III	Counseling Process – 40 minutes
Session-IV	Review of the session – 10 minutes

Introduction

Counseling is a process of empowering people to combat varied situations. Psychotherapy through counseling, which is a wonderful modern day intervention, provides opportunities for those seeking help to live more satisfying and happy lives.

Counselors lend a professional 'ear' to listen to the problems of the counselee and do not tend to label them. The counselors have to listen quietly and work with the counselee in articulating various options and to overcome the impediments. .

This practice manual helps the counselors to couple counseling with psychotherapy for most purposes. Even though there is a good deal of difference between the two, these are overlapping activities with some differences. But both these activities denote a professional relationship between a trained counselor and a client or a group of clients, where psychological theories are applied to help the clients overcome their personal problems.

Counselors should very much understand the fact that in the lives of children living with HIV/AIDS and their caregivers, the counselor is most important in guiding them by creating trust, relations they are missing and also an anchor to ART/ VCT/ pediatric departments/ NGOs. Counseling of children is very challenging and is much more difficult to deal with a chronically sick child who is stigmatized/orphaned/living alone in the world. The acceptance of the counselor by the counselee is crux of the counseling process and it is only possible when the counselor acts as a mentor of the counselee.

Session- 1 Working with CLHA

Aim of the session

At the end the session, participants will be able to :

- Understand the values of working with Children Living with HIV/AIDS (CLHA)
- Learn the methods of disclosure of HIV status and CD4 results to the child and caregiver
- Learn to focus on the perception of death by the child

Methodology

- Question & Answer session
- Interactive Power point presentation
- Brain storming
- Tools utilization

Time 30 minutes

Materials needed

- Values of working with CLHA written on a Flip chart
- Stickers
- LCD
- Group counseling cards
- Game - Name Juggle
- The Bam Bam Virus - Story 5 : The Brave Grand Mother Kantha

Notes for the Facilitator

- The participants may know the values of working with CLHA but it needs to be stressed as they are going to do counseling of vulnerable children.
- Restrict the technical words while facilitating the process.
- Encourage the participants to be interactive by using tools and questions and answers
- The participants may be having reservations in disclosing the HIV status and CD4 count to the child and the caregiver. So the methods and the implications of disclosure should be freely discussed.
- Perception of death by the child has to be discussed by the participants as the participants (counselors) may have an idea of adult perception but the child's perception must be understood.

Activity 1 - Name Juggle

Among the counselors to make them play the game which can be used at ART centre to familiarize the children to each other. Show the Game card and explain the process of conducting the game by following the instruction given on the backside.



Activity 2 - Values Of Working with Children Living With HIV/AIDS

1. Ask participants to write one value of working with CLHA on a sticker and place it on the chart
2. Let each participant explain the value they have presented.
3. Explain the values of working with CLHA stressing on the confidentiality by using the Power point slides

Essential information

VALUES OF WORKING WITH CHILDREN LIVING WITH HIV/AIDS

Counselors should put a constant effort in conforming to the following values while they work with children to ensure the right kind of interventions to help children cope with positive living.

1. Children have the right to “**confidentiality**” which needs to be protected and respected.
2. Children have “**likes and dislikes**” that need to be understood and respected.
3. Children should not be “**discriminated**” based on age, gender, behavior, socio-economic status, or disposition of psychology or health. They should all be treated equally.
4. Children have “**curiosity and aspirations**” that differ from child to child; these need to be acknowledged and they need to be inspired and guided.
5. All children have “**potential, abilities and skills**” which should be worked with and developed.

6. Children's **"self-esteem"** is very fragile so they need to be handled with care and encouragement.
7. Children have the **"right to freedom"** which should not be suppressed. They should be guided through discussion and understanding about what is good and bad, rather than being told.
8. Children have **"emotional needs and feelings"** which need to be understood and rightly interpreted and provided for.
9. The needs of children affected by AIDS such as love and affection need to be **"responded to within the community"** rather than through institutions. This should be encouraged and resourced wherever possible as it helps enable sustainability.
10. Children have the ability to **"make decisions"** and should be given opportunities to do so.

Activity 3 - "Remember your childhood"

Ask the group to remember one incident in their childhood which caused grief and impacted on them. Give them the lead that they have to discuss their feelings of anger, aggression, responses to peer/parental pressure.

Ask the trainees what they have learnt through this activity?

This activity is to make them realize the various emotions the child must be going through.

- Explain about the essence of disclosure using the Power point slides.
- Question and answer session on perception of death in one word
 - What death means to you?
 - What is the impact of death in long term?
 - What is after death?
- Power point presentation on perception of death by the child

Essential information

Child's Perception of Death

1 - 2 years

Links death with sleeping and thinks that dead people will wake up.

Fear of separation from parents.

3 - 4 years

Do not think of death as permanent but more as a temporary separation.

Children may feel responsible for death due to their powerful imagination.

They believe that if they think hard enough about it the dead person will come back.

5-8 years

Start accepting death as a final separation.

Afraid to see their sick parents die and thus to be abandoned.

Worry about their own death.

9-10 years

Children have learnt that all forms of life die one day.

They start to feel sorrow, grief and loss.

They are more interested by the mystery of death.

11-12 years

React strongly to death.

They start to be interested by what happens after death.

Death is accepted as part of life.

Talking to children about death and grief

- communicate openly, honestly and factually
- Acknowledge the child's coping mechanisms – Denial and blame
- Ensure that they are not alone, and have support outside of counseling
- Give them time to think about death and express their emotions and thoughts
- Discuss questions about the child's perception in relation to their religion (NEVER say that HIV/AIDS or death is a form of punishment from God)

Activity 4 - Disclosure

The Bam Bam Virus - story 5: The Brave Grand Mother Kantha. Explain to the Counselors that how to tell the story which gives the information on the disclosure of HIV infection, understanding HIV/AIDS and the importance of communication within the family.



- Question and Answer session
 - o What impressed you in the story?
 - o What is the important issue in the story?
 - o What do you think about the disclosure process in the story?

Essential information

Reasons for disclosure

The counselors should know and ensure that

- Children have the right to know about their health, so that they can practice self-care, thus lifting the burden and subsequent possible burnout of parents, and allowing their autonomy in decision making and care
- To provide the child with coping mechanisms to face the HIV and subsequent treatment
- Makes adherence to treatment more tangible and sustainable as treatment gives them a sense of hope.
- Children who have their illness hidden from them have higher rates of dejection
- Anxiety is the main reason why children abstain from disclosure; anxiety however is present within the illness regardless of disclosure. Studies have found that most feel that disclosure has benefited them, many feel relieved to know what is happening to them.
- If the illness is not disclosed, the health professional/ client relationship will be hindered, as trust may not be established, and the patient may feel things are being hidden from them

There are two types of disclosure

Partial Disclosure

In partial disclosure the name of the virus or illness is never directly named. It aims to describe what's happening to the body and what treatment help to resolve. The children gain information about reference points in their body, and what is happening to their body, which will initiate discussion with the child.

Within partial disclosure the counselor will

- Explain the importance of treatment to be taken and its effects upon microbes and the body.
- Explain the progression of the disease as he is not feeling sick at present, it does not mean that he does not have the disease, or that he won't fall sick in the future.
- Explain prevention methods of HIV: condoms usage in older children and also early treatment
- Let the child identify the symptoms he is suffering / has suffered and to link them to his disease process.
- Describe the microbes acting on the defence mechanism and his reduced immune defence.
- Explain the importance of medical and laboratory follow up for a better life.

Complete Disclosure

Complete disclosure names the virus and the disease. This will lead to subsequent questions about how the virus was contracted and leaves the topic open to discussion about vertical transmission and prevention. Complete disclosure often allows the child to mature more quickly and be more autonomous in their decision making about the disease.

Within complete disclosure the counselor will,

- Name the disease: HIV infection and AIDS
- Explain the general modes of transmission: Vertical transmission and the other modes
- Tackle the questions of sexuality and prevention: Condom use in older age group of children and PPTCT services in preventing the vertical transmission.
- Distinguish between contradictory messages received in school education sessions on health, HIV / AIDS and the educational messages heard during consultations

Choosing which method is appropriate for the child

Which method of disclosure is chosen will be dependent upon the developmental stage of the child and the family's readiness to accept the information. This decision should be made in consultation with the parents / care givers.

Working with parents/care givers through the stages of disclosure

There are numerous stages involved in working with parents/care givers to come to this decision:

- Identify the current modes of communication in the family: Identify the person who is very close to the child and disclosure in the presence of that person is less traumatic to the child
- Try to find realistic solutions to improve those modes of communication
- Discuss the importance of disclosure
- Prepare parents for disclosure and discuss what is planned for the child after disclosure
- Recognize the difficulties involved whilst confirming it's necessity for the child's wellbeing
- Decide with the parents exactly what will be said to the child
- Discuss with the parents how they will go about telling the child to keep their illness a 'secret', or who they will be allowed to share it with.
- Parents / Care-givers must anticipate the difficult questions associated with disclosure – How did you get the disease? Are you and I going to die?
- Propose role plays to practice disclosure
- Be present when disclosure is performed
- As a last resort perform disclosure on the parents behalf

Follow up of disclosure is essential. Remember that disclosure in children is an ongoing process. The initial disclosure may be hindered by the child's ability to understand or their age related understanding of information. As they advance in age, or their illness progresses, more information may be required, and more questions will arise.

Barriers to disclosure

The effective recognition of barriers to disclosure by the counselors helps resolve the obstacles of counseling and initiation of interventions. Hence counselors should understand and address the issues such as

- Guilt
- Embarrassing questions that follow
- Fear of rejection from the child
- Fear of abandoning the child, as the parents may die
- Children symbolize hope and future, parents do not want to ruin their dreams.
- Parents want to protect their children from anxious or dejective reactions
- Parents do not want to submit them to the rejections of family/ community
- Parents feel that there is no urgency as the child is still well
- Parents feel helpless on how to go about it
- Parents and/ or health care professionals are concerned of the trauma caused due to disclosure.

Golden rules for counselors in dealing with disclosure

- Communication must be clear, truthful and empathetic
- Information should be imparted in a manner that the child can understand. Both the child and caregiver should be present in hearing this information as it enables them to discuss it at home.
- Emotional and psychological responses to disclosure and solutions include denial, blame, guilt, anger, fear and shock.
- Give them time to accept the facts.
- Explore the reasons for their reaction
- Educate them about the disease to further dispel any myths
- Try to get them to focus on the future and the bigger picture.

Hand Out**Developmental Stages of Childhood****Nature of Children**

Children learn by playing and trying out things for themselves by observing and emulating what others do. Children are curious. They want to find out how they can change and affect their environment.

- Children try out new skills and experiment, even from the first months. Although children need to be told many things, they learn a lot from doing things themselves.
- **PLAYING:** Play is children's work. Learning to use an object helps to develop physical or motor skills, and the ability to think and solve problems.
- **EMULATING:** Children also learn by imitating others. If a caregiver wants a child to eat a different food, she or he needs to show the child by eating the food herself. If the caregivers want the child to be polite and respectful, they need to be polite and respectful to the child.

Child Development**Cognitive and psycho-affective development and impact of the disease among children – role of caregiver****Child age from birth to 2 years Sensory –Motor stage****For children below 18 months****Cognitive and psycho-affective development and impact of the disease**

- The child does not know how to communicate or to express what he feels.
- Parent/caregiver do not know much about how he lives with his disease
- The child does not understand the disease - he lives it.

- Reflection of disease: The child can feel pain. His suffering will be expressed through crying and agitation. If pain continues, the child will avoid looking at adults. The child can quickly go from crying to laughing as soon as the pain stops.

What caregivers should do

- Carers cannot make the child understand the reason for treatment nor the physical manifestations of disease. So facilitate the continual presence of a parent or care giver.
- Be attentive to, evaluate and treat pain. Reassure the child by taking into consideration that he cannot express himself in words. Look at him, smile at him, speak to him and wrap him up.

For children between 18 months and 2 years**Cognitive and psycho-affective development and impact of the disease**

- The children mainly make use of their senses and motor capabilities to experience and interpret their environment by recognizing the caregivers and initiates social contact (smiling when they see the parent)
- If they cannot see or touch an object they stop looking for it. The characteristic of this stage is '*thinking by doing.*'
- **Trust vs. mistrust:** The child is responding to the environment and their needs. If the child has a healthy, loving environment they will quickly develop trust in their care giver and those around them.
- The child perceives the disease as an external constraint that he can oppose. He can react strongly to the consequences of his illness and the disruption to his routine. The causes of the disease are invisible and casual links are not understood. For example, the pulmonary physiotherapy is interpreted as stopping the child from playing and not clearing his lungs.

- The child does not anticipate future deterioration or treatment.
- With the progressive acquisition of language, the child becomes capable to express pain in other ways apart from crying, although the latter is still the main mode of expression.
- When disease occurs early in the child's life he lives with it without asking questions, it's like "wearing glasses".
- The child's thoughts are very egocentric, everything revolves around him.
- Identifies with care givers and likes to imitate them, forms image of self, can be further away from caregivers, frequently overwhelmed by feelings.
- Plays role in 'make believe play', follows simple game rules, can share and take turns, needs independence, will test authority, can identify differences in self and others.
- Protects self and stands up for their rights, concerned with what behavior brings reward and punishment, conscience still relatively unformed.
- **Autonomy vs. shame:** The child begins to exert their autonomy. This is not always in keeping with their environment and often results in tantrums, stubbornness and negativity.

What caregivers should do

- Install routine and ritualise treatments by respecting the child's routine as much as possible.
- Explaining the disease is not useful, as the child does not understand what is happening to him. Adult explanations are irrelevant to his understanding and perceptions of disease.
- Give the child as much autonomy as possible to take away the constraints of disease. Give him choices such as "Would you prefer a story before seeing the doctor?".
- Help parents to resist the controlling the child and trying to impose upon them. Parental anxiety and guilt often express themselves through excessive permissiveness. Saying "no" is necessary in certain situations as for all children of this age. The psychological development of the child will be harmed if all is permitted because of his illness.
- Be attentive to, evaluate, and treat pain.
- **Initiative vs. guilt:** In this stage the child learns to take initiative and begins to have imaginative thought. If the child is not given room to explore and assert this initiative, they will succumb to the feeling of guilt and will continue to depend unduly on adults.
- The child is able to name his external but not his internal organs. He sees his body from the outside and is unable to represent the interior.
- The child's vision of his disease is fragmented (limited to pain areas) and from time to time (when he has pain)
- The child is not susceptible to rational explanations and is satisfied with vague notions.
- From 3 to 4 years the child has animist thoughts, things around him are alive and "that chair hurt me". There is a casual and artificial reason for everything. For example, the world is man made, and "the mountains where the man put the stones" or the "river that the man filled up with water". A period of incessant "Why".
- The child has no notion of time and lives his disease from day to day. He does not project into the future. When the disease occurs early in the child's life he lives with it without asking questions, it's like "wearing glasses."
- The causes of disease are invisible. The child does not think in terms of "what, why, how" but simply associate disease with any other phenomena "X". This is in no way trying to look for a cause or to

Child age from 3 to 6 years Preoperational stage

Cognitive and psycho-affective development and impact of the disease

- Good balance and coordination, refined motor skills can draw a refined square and write a few letters, can complete a puzzle, talks in sentences and is understandable, has developed likes and dislikes, understands cause and effect, expresses ideas, asks questions.

understand what is happening to him. The developmental stage is that of magical thoughts and no casual links are established. He is a victim of events that master and triumph over him. He may feel guilty about his disease and feel that he is sick because he did not obey, that he was naughty, or because he did not eat all his dinner. He thinks that his disease is punishment for his bad behaviour or thoughts.

- When we tell the child that he “has to take treatment to stop getting sick” he retains the “has to” and cannot anticipate what “getting sick” means. From 4 years of age he may understand preventing symptoms that he has already experienced; “take the good medicine so you don’t cough any more”. The child does not understand the medical care and follow up. Being weighed, measured and having blood taken may be interpreted as menacing and disturbing acts. The child confuses between fear and pain and expresses them in the same fashion (crying).
- The child thinks of death not as something definitive but as a temporary separation. Given his powerful imagination, the child may feel responsible for the death of others.
- The child’s thoughts are egocentric and he only can envisage things from his own points of view. If he knows he has HIV he thinks that everyone else knows it, can see it and is aware of his disease.
- The child tries to please the parents and caregivers. Having been brought up to respect adults, he generally adheres to what he is told by them by having confidence and obeys without doubts. This is even truer when there is a good quality parent-caregiver relationship and when the parents adhere to their prescribed treatments.
- An action is good if satisfying a felt need or rewarded and bad if punished.

What caregivers should do

- Install routine and ritualize treatments and respect the child’s routine as much as possible
- Reassure the child and relieve him of guilt if necessary.
- Take away the constraints that the disease represents by giving the child a sense of autonomy. Offer him

choices such as “would you prefer a story before taking a tablet?”

- Use imagination to transmit ideas about the disease and treatment - stories/songs/giving examples
- Respect the child’s imagination and lack of concept of limits that are helping him to grow. For example, never say to a CLHA “you will never be able to run” when he talks about the desire to run and be a sportsman.
- Give information relevant in the short term, as at this age it is difficult to think more than 3 or 4 nights ahead.
- Establish a caregiver-child relationship. Even if the child does not understand everything he should be the centre of the therapeutic relationship.
- The adult’s word is “truth”. Do not lie to the child.
- Help parents to resist the control the child tries to impose upon them; parental anxiety and guilt often express themselves through excessive permissiveness. Saying “no” is necessary in certain situations as for all children of this age. The psychological development of the child will be harmed if all is permitted because of his illness

Child age from 7 - 9 years Concrete operational stage

Cognitive and psycho-affective development and impact of the disease

- The child begins to think logically. They can solve conversation tasks.
- **Industry vs. inferiority:** The child learns more formal skills in life such as relating to peers, playing games with rules
- If the child in previous stages has emerged with autonomy and initiative their learning improve quickly and they become industrious. Inferiority come as a result of not mastering these skills and increasing learning skills.
- Coordination and strength through well developed motor power can develop new skills frequently.
- Highly verbal, asks fact oriented questions, can understand abstract ideas, learns to think systematically about concrete objects, learns concept of past and future.

- Independent and self assured, likes affection from adults, identify and label feelings, distinguish between wishes, motives and actions.
- Participates in community activities, enjoys working and playing with others, develops friends, can be alone, learns to achieve and compete, imitates and identifies with same sex adult.
- Begins to experience conflict between values of parents and peers and has a strong sense of fairness where rules are important and must be followed
- The concepts of being sick and having to take treatment are accepted. The child can understand the disease affecting him.
- Schooling helps the child to organize his thoughts and his reason.
- It is useful to talk about short term landmarks like next New Year/ next holidays/his next birthday rather than 'rest of your life'
- Till the age of seven years, the child will continue to be marked by colorful and representational thought processes - "Will the little beasts in my body wake up while I'm asleep?"
- The child has some capacity to imagine internal human organs. However, the child thinks that the brain is only for thinking and his arms and legs move on their own.
- The child's desire for mastery and understanding ensure good exchanges with his environment and help him understand what he is going through. The child starts to question his surroundings (parents and caregivers).
- Treatment may be problematic as the representation of HIV disease is complex for asymptomatic children. As the child cannot feel the HIV in his body and has no symptoms the disease lacks landmarks. It is difficult for the child to understand his disease and treatment given the abstract nature of the disease.
- Significant protective factors predicting the way the child will adapt to disease in adolescence include; the acquisition of self-esteem through social

activities, games and sports, putting some distance between himself and the family (investing elsewhere), and notions of autonomy.

- The first real fear of death is felt. The child understands three very important things about death; it is universal, irreversible and its cause is not linked to (imaginary) thoughts.

What caregivers should do

- Give the child information about his disease, as he needs landmarks. Comparison should be used to explain bodily functions that he can understand - the heart is a pump, the stomach is a breadbasket, cells are bricks.
- Bring up the potential gravity of his illness whilst keeping up realistic hopes.
- Without provoking them, answer or encourage the parent(s) to answer the child's questions about death. Encourage the parents to disclose.
- Help the child to get organised in his daily routine, integrating the disease.
- It is important to consider the child as an active primary stake holder.
Promote contact with other young people with HIV disease so that the child feels comfortable.

Child age from 10 - 12 years Formal operational stage

Cognitive and psycho-affective development and impact of the disease

- The child considers many possibilities to any given condition and able to use planning to think ahead and can recognize and identify problems.
- They can state several alternative hypotheses, execute procedures to collect information about the problems to be studied, and test the hypotheses.

- **Identity vs. identity diffusion:** The child, now an adolescent, begins to question who they are. An adolescent who feels sure in their identity will become self-confident and certain, whereas an adolescent whose identity is diffused will often carry feelings of self doubt, and low self esteem. Increasing orphaning in HIV/AIDS families demands strategies to address identity crisis in a more contextual manner.
- Develops sexual characteristics and has sexual drives. The child needs self care, personal hygiene, Menstruation, body odor
- Able to think, able to reason, generate general principles and test them against evidence, capable of introspection, growth in ability to think abstractly and utilize imagination in problem solving.
- Develops sexual identity, develops independence, likely to show extreme mood swings, less dependent on family for affection and emotional support, strives to define self as separate individual, often feels misunderstood.
- Enjoys many social activities, heavily reliant on peers, tries to conform to group norms, has close friendships and emotional attachments, experiences conflict with parents, experiments with sex-role expectations and standards
- Challenges the value of home, develops a personal morality code, what becomes important is whether the behavior confirms to the behavior of others, not its inherent rightness or wrongness, belief that good behavior is maintained by some presence of authority.
- Abstract thought occurs around 10 to 11 years of age. Therefore the mechanisms (physiopathology) can be understood.
- Concrete thought. The child can understand causal links and that several causes can act together to have a specific effect.
- The child can describe and explain the symptoms of HIV disease on different organs and their function. He can express hypotheses as to the causes of the disease.
- The child is more and more conscious of the control he can have over the disease. He has desires of mastery and of autonomy that allow rich exchanges and the slow and progressive taking of responsibility.
- The representation of HIV disease is complex for asymptomatic children. As the child cannot feel the HIV in his body and has no symptoms the disease lacks landmarks.
- Divisions in representation of his disease and denial with respect to his disease complicate the child's care.
- If HIV disease limits the child's ability to invest in relationships outside of the family circle, it affects his acquisition of autonomy.
- Significant protective factors predicting the way the child adapts to disease in adolescence include; the acquisition of self-esteem through social activities, games and sports, putting some distancing between himself and the family (investing elsewhere), and notions of autonomy.
- Time spent with friends is a source of pleasure.
- The child gradually becomes conscious of the chronic nature of his disease through daily treatment and the repetitive aspect of his care. Ideas of the temporality and disease "for life" that can't be cured are only completely understood at around 15 years of age.

What caregivers should do

- From around 11 years of age, give information about the disease, explain in detail using physiology.
- Bring up the potential gravity of his illness whilst keeping up realistic hopes.
- Encourage the parents to perform complete disclosure.
- Help the child to get organized in his daily routine, integrating the disease.
- Encourage investment in activities outside of the family circle.
- Promote contact with other young people with HIV disease if the child so wishes.
- It is important to consider the child as an active primary stakeholder. Provide temporal landmarks that make sense such as "to enter into adult life".

Psychological responses among children

Psychological responses among children - Dejection

Symptoms

- Feel miserable and sad
- Lacking energy
- Small tasks seem difficult
- Don't want to socialize
- Difficulty in thinking clearly
- Can see little hope for the future, Irritable, angry and anxious at times
- Difficulty in sleeping

Management

- Allow the child to talk about their feeling
- Ask the child what they think /would make them feel better; help them to adopt these changes where relevant.
- Normalize the situation for the child
- Explain that it is temporary
- Ensure that the child has support and friendships with which s/he can talk and engage in recreation with
- Discuss ways in which the care giver can support and care for the child's dejection
- In serious cases, or if the dejection persists for 8 months or more refer the child to a psychologist or psychiatrist.

Psychological responses among children - Anxiety

Symptoms

- Abdominal discomfort
- Diarrhea
- Dry mouth
- Rapid heart beat
- Tightness in chest
- Shortness of breath
- Insomnia
- Difficulty in concentrating

Management

- Ask the child why they think they are feeling anxious
- Discuss their responses
- Try to find solutions to the causative problems
- Normalize the feeling
- Try using relaxation techniques (such as deep breaths, lying down, going for a gentle walk, stretching out the chest)
- Discuss techniques that can be used in the future to ease the feeling; discuss who could help
- Discuss techniques that can be used in the future to ease the feeling and who can help

Psychological responses among children - Anger

Symptoms

- Outlet of verbal or physical abuse
- Feeling hot and flustered
- Irrational thought patterns
- Frequent disagreements
- Shaking limbs
- Headaches
- Chest feels tight
- Tense muscles

Management

- Try to find reasons for the anger and possible solutions, assess where it's coming from.
- Assess whether the anger is part of a negative thinking pattern that has encompassed their life
- Ask the child about feeling angry; where they think it comes from and how they respond.
- Ask the child if there were times before when they had been angry, but had been able to calm down.
- Look for other calming ways such as taking a deep breath, talking about the problem, spending some time alone.
- Explain to the child how their anger may be affecting others around them and ask them whether they think that is ok (do not blame them for this)
- Imbibe some positive thinking and positive reinforcement tactics. Between sessions ask them to document the anger – what caused it, what was their response, and what made them calm down. This will not only help the counselor in the next session, but will help the child to understand his own anger.

Psychological responses among children - Fear

Symptoms

- Tightness in chest
- Tightness in throat, Lack of energy
- Difficulty sleeping
- Lack of appetite
- Restless over activity
- Treasuring objects

Remember some fears are normal in children – e.g. strangers, being away from parents, ghosts, monsters, sleeping alone

Management

- Fear is a very natural response to a chronic illness, and will progress through numerous stages as the child's health improves or becomes worse
- Make sure they are supported through this by friends, and family
- Religious guidance can also be of benefit where relevant (this should be the child's choice)

Considerations for Counseling the Children

Ambiguity

- In a motivating situation, when the counselor is eliciting responses from several subjects, it is called an ambiguous situation as the counseling relationship appears vague / ambiguous to the client.
- The counselor generally structures the situation. In initial sessions, it is important to clarify the roles of the client and the counselor, so that each knows exactly what their relationship will entail, and what the sessions will seek to achieve.

Responsibility

- It is important to share the responsibility between the client and counsellor.
- The counsellor must maintain a reasonable level of emotional distance in retaining a professional relationship.
- The counsellor must be empathetic to maintain healthy self-care practices.
- The counsellor must also enable the client to become self empowered and allow them to take the weight of shared responsibility between the caregiver and the child.

Value, Belief and Attitude Change

- It is important to be aware of the individual client's beliefs in order to maintain objective practice.
- The personal beliefs of the counselor should not influence or judge the client in any way, and subjective practice should be maintained at all times.
- In many situations clients are plagued by value conflicts. When these value conflicts occur the counselor should help resolve them by clarifying the issues, overcoming the confusions of the client and adopting an attitude of unreserved acceptance.
- Displaying the options or different avenues of conflict in diagrams can be a useful tool while working with children.

Understanding

- Understanding is essentially the perception of another's attitudes, meanings and feelings.

In a counseling situation reiterating or summarizing the client's statements can be a good way of making sure one has understood them correctly by reflecting, paraphrasing and discussing emotions.

Privacy/ confidentiality

- Respect for a client's privacy must be upheld at all times. Their files must be stored and marked confidential, and their details should not be discussed with anyone else unless consent is given.
- Be sure to make confidentiality clear to the client at the beginning of your work with him/ her to enable them to feel more comfortable about the process which leads to trust building and to be more forthcoming with personal information.

Counseling tips on dealing with children's feelings

- Explore any underlying fears or feelings that may be causing the child's denial, anger, guilt and shock
- Acknowledge the child's fears and explain how these fears are normal for any child.
- Give information in a simple manner about how living positively can prolong the child's life.
- Encourage the child to focus on the future
- Help the child and the family to communicate openly with each other; and let the child believe in sharing their feelings with others; especially people close to them.
- Allow the child to work through their feelings at their own pace.
- Try to find instances when they were able to find solutions or ways to cope with their problems. These instances can be used as examples of how to solve problems or distress in the future
- Suggest practical ways for the child to express their feelings safely. These might include crying, drawing, sharing with peer group, hitting a pillow; singing a solo. Find a form of technique suited to the child.
- Encourage family therapy, so that the child feels supported
- Provide a safe environment for the child to express emotions. Involve in the counseling process the person that matters most to them.

Disclosure of HIV/CD4 Status

Disclosure requires a well thought out, prepared and empathetic approach. It must be done sensitively and necessary follow up must be foreseen and adhered to. It is important to note that legislation regarding disclosure to a child is very grey in India. As a first rule disclosure should be done with the consent of the parent/caregiver.

Upon disclosure there are numerous factors to consider:

Cognitive development of the child

Perception and understanding of causes of the disease

To minimize misunderstandings the counselor and care giver should work with the child's level of understanding and build from there, keeping in mind their level of comprehension and developmental stage. A child's knowledge is often fragmented; counselor must ensure that these gaps are filled where relevant. Take into account previous learning and the misconceptions that may be present.

Guilt and distress associated with the disease The origin of the disease is central to the creation of meaning of the disease in the child. They may attribute blame, feel guilt and distress if they are unsure why this has happened to them. The sadness felt by the parents and seen by the child may also be a source of guilt for the child. The parent's ability to confront and accept the disease will have a large impact on the child.

The child's perception and self image The onset of opportunistic infections, and the association of the child to that of his sick or deceased parents often harms and alters the child's self esteem. They will notice the difference between them and healthy children and will often feel inferior.

Grief anticipation and anxiety Perception of death evolves with age. The child will be confronted by the fear of his own death, and that of his parents. This fear can be unbearable at times, particularly in the case where a child has already had one parent die. HIV should be

discussed as a 'potentially fatal chronic infectious illness'. Even though treatment provides hope, there are uncertainties within it and therefore uncertainties and anticipation for the future.

Current support structures in their life / Family relationships Close family bonds and open modes of communication will enable and facilitate thorough and productive understandings of, and abilities to cope with, the disease. These bonds need to be assessed by the counselor and worked with or built upon. Orphans and semi-orphans need to have considerable care.

Coping mechanisms of the parent/ Parental guilt HIV transmission is marked by two main forms; that of mother to child transmission in which guilt is often felt; and that of sexual relations which is often a subject of taboo. These factors make disclosure difficult in most cases. Parents may try to protect their child and will use defense mechanisms such as lies and denial. There may also be the double trauma for a parent, discovering their own disease and that of their child's at the same time. When feeling guilt parents will often have trouble exerting authority, or they may become over-attentive.

Secrecy and confidentiality in the child (who he can and cannot tell) - "The secret stops being a normal event and becomes pathological when we cease to be its guardian and become its prisoner." Often parents will hide the child's disease behind other illness' which allows them to justify the doctors' visits and medication. The weight of this secret becomes a heavy burden for the family and grows with time. There is also the risk that the child will find out by overhearing or some other means which has a negative impact on the child. When the child has been told of his illness but is unable to tell anyone else about it, this often can feed his imagination if he doesn't understand why secrecy is of importance. They will often feel confusion, isolation and distrust.

Ability to cope and adhere to treatment Coping with the disease and the additional burden of treatment schedule may be difficult for the child and the caregiver as the difficulty is not only with the treatment but social, cultural, economic and personal beliefs should be considered while conducting counseling sessions.

Session 2 The Techniques of counseling children

Aim of the session

At the end the session, participants will be able to :

- Understand the role of counselor in Pediatric counseling by knowing the abilities of one self, what a counselor should do and what not to do.
- To equip with the participants with techniques of pediatric counseling.

Methodology

- Question & Answer session
- Interactive presentation
- Usage of tools
 - Interactive game 16: Words Search
 - Song
 - Role play

Time 60 minutes

Materials needed

- Flip chart
- Stickers
- Cards
- LCD
- Tape recorder
- Song cassette

Notes for the Facilitator

- The participants may be trained in the counseling techniques in relation to adults in previous trainings but focus on the pediatric counseling techniques should be understood.
- Restrict the technical words while facilitating the process.
- Encourage the participants to be interactive by using tools like role plays and questions and answers

Activity 1 – Qualities and Abilities of Counselor

- Ask participants to write one point on a card on each of the following within 2 minutes:
 1. Ability of the counselor
 2. What a counselor should do
 3. What a counselor should not do
- Hold the card in front of them.
- Let each participant explain their point.
- Present the Power point slides with explanation and discuss

Essential Information:

Abilities of the counselor

Counselors require the following traits for effective practice:

- **Sensitivity:** Open mindedness, sensitivity in manner, understanding and subsequent responses
- **Listening skills:** The ability to listen as well as talk
- **Empathy:** Empathy, warmth and non-judgment; it is possible to understand someone without agreeing with them
- **Nurturance:** The will and disposition that allows for comfortable and welcoming relations; the desire to assist and nurture people
- **Establishing connections:** The manner which allows the client to feel comfortable, that they are being listened to, and that they can work together as a team with trust and respect

Counselors should uphold confidentiality at all times

Activity 1

What a Counselor should do? 4

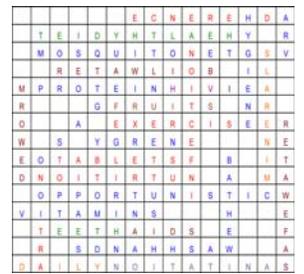
- Show the child that the counselor love him/her
- Talk to the child. Get a conversation going with emotional expressions, gestures and sounds
- Follow the child's lead
- Praise and appreciate what the child manages to do
- Help the child to focus attention and share experiences
- Help the child to make sense of their world
- Help the child widen their experiences
- Help the child learn rules, limits and values

What a Counselor should not do? 6

- Make decisions on the child's behalf
- Judge children
- Interrogate children
- Blame children
- Lecture children
- Make promises they cannot keep
- Impose their own beliefs

Activity 2 - Word Search game

Take the word puzzle and explain to the counselors how it is to be used at the ART centre and make them to practice. This "Word Search" provides an opportunity for older children to follow the leader and develop trust on the buddy. This can be facilitated by counselor when children are at ART centre to develop rapport with them and also it builds trust on the counselor which is a very important relation for the child and the counselor for success of the treatment.



Essential Information:

Counseling techniques

Creating trust and rapport with the child

Join the child on the floor, or in play, to ensure that the child feels comfortable with you. If the parent or caregiver is present in the session make sure to include them also, but make sure that the child does not feel excluded from an "adult conversation." This creates trust between the child and the counselor.

Attentive listening

Often the counseling relationship focuses on the problems expressed and gives little attention to the strengths and resilience of the child. Listen for both the problems and the strengths, as strengths offer great insight into ways of coping and provide avenues for resilience to be upheld and maintained.

Reflecting, paraphrasing and discussing emotion

Helping a child talk about their feelings is a major part of counseling.

- Reflecting - repeating back the feelings to the child
- Undistracted listening - Appreciating the child's emotions and finding the right words to reflect those emotions back to the child.
- Counselor keeps a list of 'emotion words' to give expression to the child's feelings.

Scaling questions: The emotions or problems are to have a scaling to be done to appreciate the child's issues.

Open and closed questions: The questions can be open or closed to get clarity in the thought process of the child

Skilful and purposeful inquiry: Questions are to obtain information and also can be used to:

- **To find out what silence means** – The child may relate silence to death as they are exposed to death in the family at regular intervals and people may be talking about the death of the child in front of him
- **To help the child focus** – Questions can focus the child on the issues to be stressed like- do not tell the child about ART/HIV/AIDS, but question them what they know about these issues. The child focuses more on what you want to tell after we allow them to answer the questions.
- **To encourage the child to do more self-examination** – Instead of telling the child “you are not taking the drugs regularly” (it amounts to accusation), ask the child to tell why are you not taking the drugs regularly? (it gives the space for the child to examine itself the reasons)

- **To follow a hunch** - Counselor may get a hunch and this should be followed up. The child may become very quiet and the care giver may have changed from mother to an aunt. The hunch is that the mother is very sick or passed away. So the counselor has to concentrate on the crisis management.

Non-verbal interactions

- The sitting arrangement itself influences the interaction. The child needs to be in the touching distance to the counselor.
- The child speaks and the counselor might raise an eyebrow, causing the child to hold something back.
- The counselor might say something that the child feels is critical. Her facial muscles tighten. The counselor notices and considers what he has said.
- Gestures, eye and facial expressions, posture and other invisible signals all are forms of communication between the child and counselor.

Activity 3 - Techniques of counseling**Role play of counseling skills on different focus areas:**

Case study: Rajiv, a boy of 10 years has just been diagnosed HIV positive. He feels scared and alone and doesn't know what to do next.

5 minutes: 2 from the participants should volunteer to do roles of Rajiv and counselor to practice their counseling skills on Rajiv case – i.e. creating trust and rapport, listening, reflecting on emotions, open and closed questions, use of effective body language. Other participants will give feedback on the role play and discuss ways in which they could improve them.



- Introduce the group to the counseling cards and explain how they are to be used. Break off into small groups and practice using the cards.

Activity 4 – Interactive tool for counseling

- Interactive counseling techniques using Power point presentation
- Break the group into 5-6 member teams and ask them to develop an interactive tool for children on HIV and ART/Stigma in the community/Healthy living/Disclosure
- Present the games developed and discuss

Essential Information:**Interactive counseling tools**

Communicating tools with children in an interactive way are,

- Drawing
- Storytelling
- Drama and role play
- Play/ games
- Child friendly Counseling Environment
- All the participants should participate in interactive session.
- Take care of ‘gate keepers’

Activity 5 – Song

Make the counselors to practice the song so that they can make the children to sing when they are at the centre. Once they learn they in turn teach other children at community which gives a message on self care and acceptance of treatment.

Handouts**Pre-Art Counseling For Children**

In India all children below the age of 18 must have parent/ guardian consent before HIV/ CD4 test can be performed.

Children should never be rushed into making decisions, especially when dealing with something as personal and important as testing for HIV/CD4. In a pre-ART session, a child may come alone or may be accompanied by a support person, such as a parent or friend. As a counselor, you should follow the steps:

- In pre ART counseling, the counseling should be based on the maturity and understanding level of the child; this will not necessarily correspond with the child’s age.
- Create a friendly and private environment. If caregivers are present and the child is comfortable with that, proceed. If the child is not comfortable, ask the adults to wait outside.
- Gain the child’s confidence and trust so that the child can speak freely about him or herself, the family and HIV and AIDS.
- Explore the child’s feelings about being in the session and address any fears the child might have.
- Assess the child’s knowledge and understanding of HIV/AIDS and ART and find out what else the child / care giver wants to know.
- Answer the child / care giver’s questions accurately and honestly, but remember that the information you provide must be appropriate to the child’s age and level of development.
- Explain the testing procedure accurately. Explore and try to address any worries, fears and anxieties that the children might have about the process. Do not lie in trying to protect them (such as promising that the needle will not hurt).
- Explain the possible results of the test – CD4 results and the qualification for ART initiation and what adherence to ART means for the child.
- Discuss who will receive the results, how they will be given and who will provide support, especially if the result shows the child is qualified for ART.
- Stress the benefits and importance of coming back to collect the medicines every month.

ART Counseling For Children

In ART session, a child should not be rushed into receiving the medicines, but should be gently supported to accept the truth of taking the medicines life long. One or more sessions should be offered to a child to cope with the facts. As a counselor, you should:

- Remember that if the child has come alone, caregiver consent is required to proceed.
- As with pre-ART counseling, gain the child's confidence and trust so that the child can speak freely about him or herself, the family and HIV and AIDS. Also, try to create a friendly and private environment.
- Check if the caregiver who was previously identified to provide support is present if not ask the child about the caregiver as the family dynamics change in HIV families frequently and ensure that the caregiver has sufficient adherence knowledge.
- Briefly re-assess how much of the information given in the pre-ART session has been retained and understood by the child and caregiver.
- Assess if the child is ready for ART. Check any barriers to adherence the child/caregiver have and explore any fears.
- Allow the child some time to react. Be supportive throughout the reaction period, allowing tears, silences, anger and despair.
- Answer the child/caregiver's questions. If the child asks for further information, provide it yourself or refer the child to another person who can help them.
- Be aware of the children's level of energy and concentration. If they are ready to receive more information and support at that session, continue. If not, arrange another session to be held in the near future.

Counseling Techniques

There are certain skills that a counselor must have to work effectively with children. These skills ensure that the counselor will listen to the child and respond in an appropriate way keeping the abilities of counselor for positive interaction.

Creating trust and rapport with the child

It is important to approach a child living with HIV not as someone with an infection, but as a human being within his environment with a part of his life behind him and the rest of his life before him. Each child has desires and hopes for the future and wishes to give meaning and direction to their life. It is important to recognize these and work with them to establish a trusting, working partnership. Talk to the child according to their needs, not in the manner that is most suited to you. To make contact we use dialogue and body language; this must be warm, open and engaging in order to gain a child's trust and allow them to feel comfortable enough to work openly with you.

Key point:

Join the child on the floor, or in play, to ensure that the child feels comfortable with you. If the parent or caregiver is present in the session make sure to include them also, and see that the child does not feel excluded from an "adult conversation." This creates trust between the child and the counselor.

Attentive listening

Attentive listening means listening to the child without being distracted. A counselor must learn to focus while listening to a child. The keys to attentive listening are awareness and determination. When the counselor becomes aware that her mind has drifted away, she should realize this and refocus on the child. If the counselor's mind drifts away and she loses track of what the child has been saying, it is acceptable to say, *"I'm sorry, I lost my concentration. Would you kindly repeat what you just said?"*

Key point

Often the counseling relationship focuses on the problems expressed and gives little attention to the strengths and resilience of the child. Listen for both the problems and the strengths, as strengths offer great insight into ways of coping and provide avenues for resilience to be upheld and maintained.

Reflecting, paraphrasing and discussing emotion

Helping a child talk about their feelings is a major part of counseling. If the child can understand and be open with their feelings, then they can appreciate how this affects their life, both positively and negatively.

Key point:

- One of the best ways to help a child appreciate and understand feelings is to use a technique called **reflecting; repeating back the feelings to the child**. This reflection enables the child to feel that they have been heard and understood and aids the child in associating particular feelings with descriptive emotional words.
- It also gives the child an opportunity to correct the counselor when she doesn't understand the feelings. This technique requires **undistracted listening, as well as skill in appreciating the child's emotions and finding the right words to reflect those emotions back to the child**. The child may reflect about his mother's health and may not express his inner feelings. So tell the child not to be 'sad' but to cope up with the situation. This gives an expression to the emotion the child is feeling. The child gets relieved that the emotion is understood by the counselor.
- It is suggested that the counselor keeps a list of 'emotion words' – sad, happy, joy, yummy, bad, sour, good, and others, to help the child articulate how they are feeling; one should be careful however to ensure that the child is not led in their responses.

Scaling questions

Sometimes children will have difficulty in articulating the severity of emotions.

Key point:

- In these cases scaling questions can be useful. For instance, "if **10 is very upset** and **1 is not upset at all**, what number were you when your mother/care giver yelled at you?"; "And what number are you right now?"
- Another tactic is to ask the child how their body was feeling at that point of time. For instance, "when your mother/care giver yelled at you, did your body feel hot; did you feel flutters in your stomach; was your heart beating fast?"

Open and closed questions

In order to obtain greater detail from the child's response open questions are useful. Open questions are those which cannot be answered as 'yes' or 'no' and require an explanation.

Key points:

- "How did you feel when that happened?", requires an explanation

Closed questions are useful for obtaining specific answers; a time, date which can be answered with "yes" or "no"—

- "When that happened did you feel angry?"
- "Did you take your ART this morning?"

Skilful and purposeful inquiry

When you are counseling a child, each question has a purpose. The counselor should have a clear understanding why he/ she have asked each question. Questions are one of the best tools a counselor has.

Key points:

Questions are to obtain information and also can be used to:

- **To find out what silence means** – The child may relate silence to death as they are exposed to death in the family at regular intervals and people may be talking about the death of the child in front of him
- **To help the child focus** – Questions can focus the child on the issues to be stressed like- do not tell the child about ART/ HIV/AIDS, but question them what they know about these issues. The child focuses more on what you want to tell after we allow them to answer the questions.
- **To encourage the child to do more self-examination** – Instead of telling the child “you are not taking the drugs regularly” (it amounts to accusation), ask the child to tell why are you not taking the drugs regularly? (it gives the space for the child to examine itself the reasons)
- **To follow a hunch** - Counselor may get a hunch and this should be followed up. The child may become very quiet and the care giver may have changed from mother to an aunt. The hunch is that the mother is very sick or passed away. So the counselor has to concentrate on the crisis management.

Non-verbal interactions

The Counselor and child, within their interactions will influence one another. A clear understanding of body language is very important in the counseling of children.

Key points:

- The sitting arrangement itself influences the interaction. The child needs to be in the touching distance to the counselor.
- The child speaks and the counselor might raise an eyebrow, causing the child to hold something back.
- The counselor might say something that the child feels is critical. Her facial muscles tighten. The counselor notices and considers what he has said.
- Gestures, eye and facial expressions, posture and other invisible signals all are forms of communication between the child and counselor.

If a counselor misses these, she/ he will be overlooking many underlying messages, and therefore it is important to be perceptive to this. It is also important to note however that body language can be misleading, and like verbal communication must be questioned and considered rather than judged as absolute truth.

The body language of the counselor should be welcoming and warm. Simple gestures such as sitting at close proximity, smiling at appropriate times, looking interested and occasionally touching the child, help to reassure them and let them know you are there with good and compassionate intentions, and that you can be trusted.

Case example:

You are counseling a child who claims she is independent-minded and truthful. But during counseling visits, she keeps her eyes down and her shoulders hunched. You see a contradiction between the child's words and the way she holds her body. You watch her behavior and feel skeptical about her words. An appropriate response would be to comment: “*Maya, you say many good things, but your body is saying something different. While you talk about how strong and independent you are, you look a little nervous.*”

The skilful counselor understands that many messages are silently delivered.

Interactive Counseling Tools Drawing

Drawing helps enable the child to open the 'hidden cupboards' in their life and articulate their emotions without having to use words. Choose a topic for the child to draw that is related to the subjects you need to cover for instance, if you are trying to assess the child's family relations, you would ask them to draw a picture of all the people who live in the house. The drawing and the expressions within it can then be used to discuss the family further. The adherence barrier can be drawn by the child and the same can be discussed.

Storytelling

Children have attitude to answer direct questioning or to listen to lecturing on issues, particularly ones that are painful to them. Stories that tell of situations similar to theirs help the child to feel less alone and that they are understood. Familiar stories allow children to relate to them easily. At the end of the story, encourage the child to talk about what has happened in the story, what they have learnt, and whether they had similarities to the character in the story. Ask them to tell a story of their own. This is very useful in group counseling.

Drama and role play

Drama gives children the opportunity to voice concerns that they may have, express their emotions, and learn about a certain topic or emotion and how to best deal with it. It can help to instill principles in them (for instance, taking medication everyday, or the feeling of being supported by friends when they are sick) and open avenues for discussion. It need not be a drama in full but expressions of bitter taste, sadness, joy —

Anticipating problems through hypothetical scenarios with the care giver and child

- What would you do if...vomiting, refusal, fever, rashes other? Present these questions to the child and the care giver. Ask them for their responses and then prepare them by enabling solutions to these problems. i.e. find a backup plan
- Hypothetical scenarios have to start from the initiation of ART as the first months are the most difficult time for the child and the care giver. The reversal of immunity starts and the child may feel very sick and the care giver may stop the drug thinking that "the costly /government drugs are not good for the child." The reality is that the child's immunity is improving and so the child is going through the motions of fevers and a 'bad' patch. "Feeling worse in order to feel better."

Play/ games

Play is an important way for children to interpret the world and express themselves. When using play in therapy it is important to observe and not obstruct what they are doing. The counselor can use different toys (some made, e.g. plastic humans and animals, and some unmade, cardboard boxes, string, sticks, snakes and ladders board) to interact and ask questions about the child's life.

Session 3: Counseling Process

Aim of the session

At the end the session, participants will be able to :

- Get equipped with the process and modes of counseling the children/caregivers at ART centers.

Methodology

- Question & Answer session
 - Interactive presentation
 - Usage of tools : Buddy Game

Time 40 minutes

Materials needed

- Flip chart
- Stickers
- LCD
- Games
- Group counseling cards

Notes for the Facilitator

- The counselor should be made aware that the process and modes of counseling of children involves the caregivers also and so the counseling for adults and children should be integrated with a focus on children.
- Counselor should give practical examples while doing the session for better understanding to practice the tools.
- Restrict the technical words while facilitating the process.

Activity 1 - Steps in Counseling

- Ask participants to write the steps involved in the counseling process on a sticker and place it on the chart.
- Discuss the process with the help of Power point slides and explain.

Essential Information

Steps in The Counseling Process

Preparation

The first contact: Making the first contact is very crucial as the impression lasts for long time.

Preparation should include: creating goals, preparing the necessary information, to assess the **readiness** on the part of the child and the caregiver to accept ART, identifying the motivation and the barriers for ART.

Creating Trust and rapport by spending time to make them feel comfortable with you, the environment and the counseling relationship.

Role Clarification and confidentiality: the expectations and roles of counselor, child and care giver has to be clarified.

Expressing and assessing the problem

Problem focus: Obtain a clear picture of the client's psychological and social disposition. Focus on supports they currently have, coping mechanisms, livelihood and the family relations.

Strengths of the child and care giver:

Remember to focus on the strengths of the child also, as strengths will offer great insight into ways of coping and dealing with the problems like ART adherence etc. Work at the child's own pace and give them room to breathe, to cry and to ventilate their feelings. Gently coax them through this and understand that for each child this stage will take different amount of time and will require different levels of intervention.

Addressing the problem and setting goals

Focus on the solutions should be on how to live more healthily with adherence to ART, or create stronger and closer relationships. It can be beneficial to write a list of goals to be completed between Pre ART sessions for example:

Day 1 – talk to my mother/care giver about HIV/CD4 test

Day 2 – complete a CD4 test at the ART center

Day 3 – contact the counselor to discuss the results of the test and what that will mean and the follow up to the result

Follow up sessions include:

- ART counseling including the medication schedule and the possible side effects at the time of initiation
- ART and follow up counseling on adherence and identification of barriers to adherence to ART at each session.

Summarizing and termination of each session.

Summarize the session, making sure the child is clear on information discussed and the goals set. Give a compliment to the child about his/her participation

In Pediatric counseling on ART adherence and care giving, the process of counseling is long term and so knowledge building and counseling can be planned prior as the sessions are fixed in each month. Linkages can be developed with NGOs/ positive networks/ CBOs and other stake holders to provide better care for the child and the care giver.

Activity 2 – Modes of counseling in relation to pediatric counseling

- Ask participants to brainstorm on the modes of counseling and prioritizing them in relation to pediatric counseling.
- Present the Power point slides and explain

Essential Information

Modes of Counseling

1. Individual consultations

Child

The challenges

- Children’s attention needs to be held through their active participation
- Educational objectives need to be attained and adapted methods need to be used
- Children are sometimes turbulent and difficult to be “controlled”,
- The counselor may feel a failure in conducting the session as the children loose concentration fast.

Caregiver

- To negotiate the process of disclosure of the HIV disease to the child.
- To identify the factors of non adherence and the attitudes of family.
- The caregiver versus adherence to ART for the child
- Working with parents includes the possibility of role-plays with hypothetical scenarios to prepare them for questions that the child will ask them.

2. Group consultations

With children: 10-15 children can be grouped as buddy groups or children support groups as they visit the ART center on the same day for medicines every month. Group counseling can be done effectively with these children as they love to be in a peer group rather than in isolation. Their comfort levels are higher in the peer group. The sharing of experiences in adherence to ART is beneficial in the group sessions.

Challenge:

- There is a temptation to attribute responsibility to a particular child “that one’s a horror, not interested, not involved”.
- The group may be difficult to control
- Different age groups should be dealt separately
- Sensitivity towards beliefs and practices related to culture/religion/region

Age specific issues:

In older children it is appropriate to bring up questions in relation to sexuality and the use of condoms.

For parents/ Care-givers

- To get realization among the caregivers that they are not alone in this situation
- They should help themselves to accept problems they encounter
- Parents will reassure each other through the sharing of life experiences.

These sessions should be facilitated by a counselor on various themes like disclosure, testing the children, ART and adherence and care giving. Diverse discussion methods may be employed; two common examples being the round table and role-plays. Any method favoring participants' free expression is potentially useful in group sessions.

Combined sessions with child and caregiver

- As the caregiver and the child are partners in treatment, educational work and follow up on treatment and adherence are always done with both
- Everyone has heard exactly the same information, which helps promote communication and discussion in the family.

The counselor may also be a role model for parents in how to discuss, explain, and speak honestly with the child. The generation gap can be reduced as the 'secret' is out and the care giver and the child feel free to discuss about the treatment at home.

Activity 3 - Buddy Game

Practice the game as mentioned in the game chart and also show the picture as shown in the front. This game aims at building the trust for children among the family and peers.

**Handout****Steps in the Counseling Process****Preparation**

The counselor should gain as much information about the client as possible prior to the first session with them. This can be obtained through case history reports, pre-counseling interviews and any other means relevant. In the beginning of counseling, the counselor and the child are strangers to one another so need to spend some time getting to know each other and to find a level on which they are comfortable. For a counselor, it is very important to know how to make contact and to be aware of his/ her own feelings and thoughts, and how he/ she can be available to the child.

The first contact

- **Making the first contact is very crucial as the impression lasts for long time.**
- Some children in their first contact present as chaotic, angry, full of anxiety, vulnerable and unwilling to engage and communicate.
- It's quite normal that a child's voice breaks with emotion or fades away.
- A withdrawn body posture is also often seen.

Key points

- The first interview is the beginning of the actual contact between the child and the counselor. Usually the child approaches the counselor cautiously. He is unsure of what is going to happen. Thus much of what takes place during the first interview is concerned with the probing and, if possible, with the identification of the problem.
- At this stage the counselor must be careful not to invade the personal emotions of the child. It is good to support the senses and boundaries of the child. Promises should not be made like "do not worry, you are going to be healthy" to a very sick child, which the child realizes as a lie and the child loses trust.

- Preparation should include:
 - creating goals for the session
 - preparing the information necessary for the counseling session and anticipating what is required of themselves and the child
 - The counselor should remind him/herself of both the long-term and short-term goals of the relationship and of the major issues that have come up.
 - Having refreshed his/ her memory, she can encourage discussion or make better comments. This creates continuity between sessions.
 - **Readiness** on the part of the child and the caregiver to accept change as in some cases individuals may not realize that their habits are undesirable or bad for their health; in others they may be apathetic or scared to embrace new things.
 - Another obstacle is motivation, both in finding and maintenance of it. Sometimes an Individual may desire change, but he is helpless because he does not know whom to approach or does not have the time or other resources to seek help. These factors need to be addressed in the initial session, and followed up throughout the counseling process.

Creating Trust and rapport

Upon the first meeting with a client it is important to establish their trust and spend some time making them feel comfortable with you, the environment, and the counseling relationship.

Role Clarification

The counselor should clarify the counseling relationship; what their role is, what the child's role is, and what can and cannot be expected of the relationship. They should also explain issues of confidentiality in the first sessions only to create a strong relationship.

Expressing and assessing the problem

Problem focus

The client should then be given time to explain the problem(s) facing them and express the feelings related to that. Within this the counselor should try to obtain a clear picture of the client's psychological disposition and a more holistic outlook of their life.

- What supports do they currently have?
- Aside from their problem how are they coping generally in life?
- Are they employed?
- Do they have a family?

Strengths of the child and care giver:

Remember to focus on the strengths of the child also, as strengths will offer great insight into ways of coping and dealing with the problem. Work at the child's own pace and give them room to breathe, to cry and to ventilate their feelings. Gently coax them through this and understand that for each person this stage will take different amount of time and will require different levels of intervention.

Addressing the problem and setting goals

Once the period of catharsis and problem assessment has been given due time you can begin to address the ways in which these problems can best be dealt with. In collaboration with your child try to find ways in which they can feel better about the situation, and find solutions.

For instance, this may be that they just want to talk about it more; it may be that they want to learn how to live more healthily, or create stronger and closer relationships. These are all goals for the future which give hope to the child and build a structure to the counseling relationship. It can be beneficial to write a list of goals to be completed between Pre ART sessions for example:

Day 1 – talk to my mother/care giver about HIV/CD4 test

Day 2 – complete a CD4 test at the ART center

Day 3 – contact the counselor to discuss the results of the test and what that will mean and the follow up to the result

Follow up sessions include:

- ART counseling including the medication schedule and the possible side effects at the time of initiation
- ART and follow up counseling on adherence and identification of barriers to adherence to ART at each session.

Summarizing and termination of each session.

As you move toward the end of the session, a client may be a bit bewildered by the amount of information to take in and remember, or they may be feeling emotional having shared personal information for the first time. At this point it is important to:

- In Pediatric counseling on ART adherence and care giving, the process of counseling is continuous and the rapport building is effective. The knowledge building and counseling can be planned prior as the sessions are fixed in each month. Linkages can be developed with NGOs/ positive networks/ CBOs and other stake holders to provide better care for the child and the care giver
- Any relevant information materials should also be distributed.

In cases where they have become particularly emotional during the session, ensure that they have a support person to take them home, or to be there upon their arrival.

- Prepare them for leaving taking time to compliment them on what they've just engaged in.
- summarize the goals that have been set Summarize the session, making sure the child is clear on everything that was covered

Modes of Counseling

1. Individual consultations

For children

Individual consultations may be offered from the age of 4-5 years. A meeting with the parents usually allows the definition of objectives: give the child an opportunity to speak about his disease, how he lives with it and what he thinks about it.

This kind of meeting is often well accepted by parents. The child will be able to confide in someone who is neutral and is not anxious, stressed, sad or depressed about the child's illness, and will thus speak more freely. The child feels "negative waves" very strongly, and often does not speak or ask questions freely.

Individual consultations are preferred to group sessions for small children (less than 8 years of age) and at the time of starting ARV treatment.

For caregiver

Essentially, individual consultations with caregivers are to negotiate the process of disclosure of the HIV disease to the child, to identify the factors of non adherence and the attitudes of family. Nonetheless, as said above, caregivers need time to be able to express them selves, and this must not be neglected for the child's equilibrium. The caregiver is one of the key factors of the child's overall well being and more specifically in their adherence to treatment. Working with caregiver includes the possibility of role-plays with hypothetical scenarios to prepare them for questions that the child will ask them.

2 Group Consultations

For children

Group Consultations are particularly pertinent post disclosure around 9-10 years of age.

These groups allow support and sharing of experiences, but also permit sharing of concerns.

Moreover, given that children are generally unable to announce their disease in their environment (school, friends), participation in support groups is an opportunity for them to speak with HIV affected peers and to participate in social activities. The groups thus serve as emotional support system.

Group sessions also permit the counselor to tackle the questions of adherence and the difficulties in taking drugs every day when one is feeling sick. In older children it is an appropriate environment to bring up questions in relation to sexuality and the use of condoms.

- Group size: maximum 8 children of roughly the same age (all aware of their status).
- Short highly interactive sessions are preferred (maximum 1 hour).
- Use life experiences. For example, on the subject of adherence: “and you, how do you manage at home to remind yourself to take your treatment?” – Lead questions like use of calendars/ drawings should be given if the ideas are not flowing.
- Role of the Counselor: consists of ensuring that each participant is able to formulate his own ways of thinking and doing things. He reformulates issues that are brought up so as to stimulate awareness, synthesize the debates, and refocus the discussion back to the theme.

The challenges of counselling

- Children’s attention needs to be held through their active participation
- Educational objectives need to be attained and adapted methods need to be used
- Children are sometimes turbulent and difficult to be “controlled”,
- The counselor may feel a failure in conducting the session as the children loose concentration fast.
- There is a temptation to attribute responsibility to a particular child “that one’s a horror, not interested, not involved”.

Counselors working in these sessions must be able to self evaluate and self criticize, and also be capable of analyzing situations encountered from an educational point of view and subsequently readjust the sessions with creative ideas and methodologies.

For parents

Group sessions for parents have the aim of permitting parents to realize that they are not alone in living with this situation and that there are other families asking themselves the same questions. They should help themselves to accept problems they encounter such as those they think will be posed by disclosure/ ART and adherence/ care giving to the child. Parents will reassure each other through the sharing of life experiences.

These sessions should be facilitated by a counselor on various themes like disclosure, testing the children, ART and adherence and care giving. Propositions may be at the request of parents or suggested by team members. Team members are privileged witnesses in their work with the families and children, and accordingly observe the difficulties that families are experiencing.

Diverse discussion methods may be employed; two common examples being the round table and role-plays. Any method favoring participants’ free expression is potentially useful in group sessions.

Combined sessions with child and caregiver

As the parents and the child are partners in treatment, educational work and follow up on treatment and adherence are always done with both parents and the child.

With respect to disclosure, consultations with the parents and the child present will permit the counselor to say the same thing to all at the same time. Thus everyone will have heard exactly the same information, which helps promote communication and discussion in the family. The counselor may also be a role model for parents in how to discuss, explain, and speak honestly with the child. The generation gap can be reduced as the ‘secret’ is out and the care giver and the child feel free to discuss about the treatment at home.

Session 4: Review**Aim of the session**

To review the session on pediatric counseling

Methodology

Brainstorming with the participants

Time 10 minutes

Materials needed

Charts and pens

PPT slides on the issues dealt during the session to recap the information to evaluate the session

Notes for the Facilitator

The Facilitator should get unbiased information on the session through interaction. If the Facilitator feels that the participants respond better if an evaluation form is provided then the idea can be followed up.

Activity

- Question and answer session:
 - what is most useful information in the session
 - Is the content relevant?
 - Is the handout useful for the future reference?
 - How is the facilitation?
PPT slide with activities

HIV/AIDS IN CHILDREN -BASICS

Session Time : 30 minutes

Session-A HIV/AIDS IN CHILDREN – BASICS – 20 minutes

Session-B Prioritizing the information and review -10 minutes

Introduction

This module contains the basics of HIV/AIDS with a focus on children and the time allotted to this module is minimal as it is assumed that the counselor has been trained in basic HIV/AIDS knowledge in previous training. This module aims at recap on information on HIV/AIDS and bring in the relationship of the knowledge in a child focus.

Due to the devastating effect of HIV/AIDS on children, there are more than two million children living with HIV/AIDS in the developing world and children account for 13 percent of all new HIV infections globally. In addition, currently more than 15 million children worldwide have lost one or both parents to AIDS and it is projected that one out of every five children in the hardest hit countries will be orphaned by 2010. Children living with HIV have clinical, social and emotional needs that are distinct from adults and other OVC.

The term “**Pediatric AIDS**” applies to children as old as 12 years of age. Because children are still growing, so are their immune systems. Thus, HIV does more harm, quickly in many children than in most adults. Some children who are infected with HIV in the womb or during birth may become very ill right away, even within the first month of life. Up to half of HIV-infected children are seriously ill by two years of age. Others appear healthy for years before symptoms develop.

Our treatment goal in HIV infection is to slow HIV from making copies of itself. This goal is reached when viral load goes down (ideally to undetectable) and CD4 cell counts go up. Ideally, ART should be given to any infant younger than 12 months of age as soon as a diagnosis of HIV infection is made, regardless of symptoms or CD4 cell count. Any child who is experiencing HIV-related symptoms such as poor growth, developmental problems, or serious infections, or whose CD4 cell count shows damage from HIV, should begin treatment as soon as possible. Infants and young children normally have higher CD4 cell counts than are observed in adults, so they can develop serious HIV associated complications even though they may have adult-normal CD4 cell counts.

Management of childhood illness is an essential part of the family care model in HIV/AIDS treatment and care. The established guidelines for the integrated management of childhood illness must be expanded to include treatment of HIV/AIDS in order to properly train pediatric care providers. With more resources and training, ART Centers will be better prepared to serve the children attending ART.

Session 1: HIV/AIDS in Children - Basics**Aim**

At the end the session, participants will be able to :

- Acquire knowledge on the Basics HIV/AIDS in children
- Be Familiarized with the interactive tools

Methodology

- Interactive Power point presentation
- Question and answer session
- Demonstration of tools

Time: 20 minutes

Materials needed

- LCD
- Charts and pens
- Power point presentation
- Reading Material
- The Bam Bam Virus: story 1 - Understand the HIV
- The Bam Bam Virus: story 2 -The Bam Bam virus is difficult to spread
- Interactive Game: 11 Snake and Ladder- Let us climb up the ladder of health through adherence, nutrition, hygiene and sanitation

Notes for Facilitator

It is recommended to have a medical doctor as a co-facilitator with specific experience in participatory methodology. The medical issues are not included in the training module, as this module is not meant for medical personnel. The time required for this session is less as the group knows about HIV/AIDS basics in adults and so the virus structure and the related topics are excluded.

Even if the facilitator thinks that participants already understand the essential information, it is important to use this activity as a preparation for the following activity. It is essential to understand about HIV in children to ensure adherence to ART.

Limit the use of scientific terms or technical jargon as much as possible. If you use technical words, always check if participants understand them and explain them in simple language before you continue. Avoid putting off participants' doubts and confusing explanations and encourage them to seek clarification.

Activity 1 - Basics of HIV/AIDS in children

Interactive Power point presentation on basics of HIV/AIDS in children. The questions are,

- What are the risk factors of transmission of HIV to children?
- What is the advice to be provided on breast feeding to the HIV positive mother?
- Why some children born to HIV positive mothers are dying before 24 months of age?
- What are the tests for confirming HIV among children?

Essential information

- Half of HIV positive children in India are dying before their second birthday.
- In vertical transmission, the risk of transmission of HIV to child is highest during delivery.
- The factors contributing to transmission of HIV to child from mother depends on: stage of HIV in mother, usage of condom, ART treatment to mother, general health status of mother, mode of delivery (normal / caesarian section)
- The risk of feeding practices – exclusive breast feeding or complementary feeding versus mixed feeding. Breastfeeding should be stopped and the Infant feeding formulae should be started at once as mixed feeding increases the risk of transmission.
- Informed choice on breast feeding should be practiced.
- PCR testing for children below eighteen months can save the child as the interventions for treatment can start early to prevent the progression of disease.
- Caregivers/guardians of orphans should be counseled in relation to disclosure of HIV and initiation of ART.
- All children living with HIV/AIDS and children born to HIV positive mothers should be provided with Cotrimoxazole prophylaxis
- Follow up of all exposed children born to HIV positive mothers is mandatory till they are tested non reactive to HIV

Activity 2

The Bam Bam virus story 1: Take the story book and section one which is on Understand the HIV. This gives information relating to HIV in humans, treatment and also myths in the community on HIV.



Activity 3



The Bam Bam Virus Story 2: Continue with the second story on “The Bam Bam Virus Difficult to spread”. This section presents the information of the feelings associated with being infected with virus. The counselors while telling the story use the two way communication by asking children the questions which will make them to keep themselves in the situation.

- o Question and Answer session
- o What impressed you in the story?
- o What are the important issues in the story?
- o What do you think about the virus and spread?

Activity 4

Practice Interactive Game: 11 Snake and Ladder- Let us climb up the ladder of health through adherence, nutrition, hygiene and sanitation. The counselor can use this game at ART centre with children and care givers.



Handout

Statistics of HIV/AIDS among children:

The estimated total number of HIV infections in India was 3.5 million in the year 1998 and 5.134 million in 2004. The estimated number of children living with HIV/AIDS in India is 202,000 as per UNAIDS report published in July 2004. Though children represented only 6% of all people living with HIV/AIDS as of December 2005, they accounted for 18% of the 3.1 million AIDS deaths in 2005. Only 40,000 or 4% of the one million people now on antiretroviral treatment are children. This means that one in every six AIDS deaths each year is a child, yet children represent less than one of every twenty-five persons getting treatment in

developing countries today. Half of HIV-positive children die undiagnosed before their second birthday as they are not tested by PCR which is expensive and not available widely in the public health sector.

Virus structure

Refer to NACO counseling module 5: sub module 1: Antiretroviral therapy- counseling and medical aspects.

Transmission

The modes of HIV transmission among children:

- Vertical Transmission
- Sexual transmission especially in children exposed to sexual abuse as in the case of children living on the streets and children in vulnerable situations.
- Blood transfusion
- Needles used by intravenous drug users, needles reused without sterilization and use of un-sterile instruments.

Vertical Transmission

Parent to child transmission occurs when a HIV positive mother passes the virus to her baby during pre & post natal period. The overall risk of transmission among women with HIV is estimated at approximately 15 to 35% if no preventive measures are taken. In developed countries the transmission is about 14%-33% while in developing countries it is higher up to 43%. Knowledge on risk of vertical transmission is essential and helps in developing the preventive measures through counseling.

Vertical transmission		
During pregnancy 25%-35%	* During delivery 70%-75%	After delivery Exclusive Breast-Feeding 5-15%

* Reasons for high transmission during delivery

During delivery, contractions of the uterus lead to the pushing of blood from the placenta to the baby. Also the passage of the baby through the birth canal exposes the baby to the virus as the baby comes in contact with mother’s blood.

The high and low risk factors in transmission

Factors related to the Mother

- **Stage of infection**
 - If the woman is in the advanced stages of infection at the time of pregnancy, the risk of transmission is more due higher viral load.
 - If the woman acquires infection just before / in the first weeks or in the later months of pregnancy, the initial spike in viral load at the time of infection may increase the risk of transmission to the child.
- **Re-infection:** Re-infection during pregnancy and breast feeding increases the risk of transmission due to the increase in the viral load in the woman.
- **Breastfeeding pattern:** Exclusive breastfeeding has been found to present a reduced risk over mixed feeding, which is widely practiced in India.
- **Duration of breastfeeding:** Longer the duration of breastfeeding – more is the risk of transmission.
- **Disease of the breast:** Ulcers/ cracks on the breast increase the risk of transmission to the child.
- **Viral, bacterial, or parasitic placental infections** may also increase the risk of transmission.

Factors related to Child

- **Oral ulcers:** Oral ulcers enhance the risk for transmission due to the increased possibilities of the virus entering the child's body.
- **Gastro-intestinal illness:** A weakened gut may facilitate routes of entry for the virus found in breast milk in a baby who is on the breastfeeding.

Factors related to Intervention/treatment

- **Antiretroviral therapy to the mother during pregnancy and to the child after birth (PPTCT intervention):** This can significantly reduce the risk of transmission during pregnancy and delivery.
- **Cesarean section:** This can significantly reduce the risk of transmission, but is limited to availability of medical expertise and also the health status of the mother.
- **Invasive procedures:** Avoidance of invasive procedures during delivery can significantly reduce the risk of transmission.

Feeding practices in India

In India it is a privilege of the mother to breast feed the baby, which is culturally accepted. In HIV positive mothers it is a challenge not to breast feed the baby as she is questioned and provoked for not feeding the baby by the neighborhood. So we have to be sensitive in counselling the mother regarding feeding practices.

Breastfeeding options

- Exclusive breastfeeding
- Exclusive breastfeeding with early cessation
- Using wet nurses
- Expressed and heat-treated breast milk feeding

Replacement feeding options

- Infant feeding formulas available in the market
- Home-prepared modified animal milk

Informed choice

The mother is provided with knowledge regarding the risk of breast feeding and also options in the feeding of the baby. In the current infant feeding recommendation for PPTCT in India, HIV positive women are counseled on feeding options to make an informed choice on how they are going to feed their infants. The two options are:

- Exclusive breastfeeding for the first 6 months for women opting to breast feed.
- WHO and NACO recommend that HIV positive mothers avoid all breastfeeding when replacement feeding is:

• Acceptable	• Affordable
• Feasible	• Sustainable
• Safe	

HIV testing in children

1. PCR test

PCR testing is the standard test for diagnosing HIV in children below 18 months. PCR testing is not only essential for monitoring and improving efficiency of PPTCT programs, but also for early identification of HIV infection in children to improve access to systematic quality care and treatment. The **Dry Blood Spot (DBS) procedure** is a method of PCR testing.

2. Antibodies testing

Antibody testing can be used from 12 months of age by when maternal antibodies will be generally declining. A negative antibody test at 12 months of age is a good indication that the child is HIV negative. However, in a breastfed child the test would have to be repeated three months after stopping of breastfeeding.

Issues related to HIV/CD4 testing of children

Key issues in testing of children are ...

- The parents may not be in a position to accompany the child
- The child may be an orphan who lost both the parents
- The child living with a granny who is old and is unable to accompany the child to VCT/ ART centers
- Extended family members are not willing to take the child for testing
- Children living on the streets are not having guardians
- Children from the child headed families do not have anyone above 18 years in the family to be a guardian.

Dealing with vulnerable children

In the absence of the legal guardians, various stake holders in the community has to take a constructive role, keeping in view of the importance of early identification for early intervention / treatment.

- It is important to ensure sensitization of at least one family member to accompany the child
- Community volunteers/ adult support group members/ positive networks to be proactive in

identifying and taking care of the children living with HIV/AIDS

- NGO representative can take a temporary responsibility to facilitate the testing done especially for the street children, orphans and children from child headed families.
- Strategies to be developed in VCT centers for testing of children with or without guardian by developing linkages with local NGO/CBO/ Positive networks.

Progression of HIV among children

There are two forms of progression of HIV infection among children:

- **Rapid progressors** - who usually show signs of HIV from around three to six months of age. Most of these children die before the age of two years, usually from Pneumocystis Carinii Pneumonia (PCP) and other respiratory infections.
- **Slow progressors** - **Around** 60% of CLHA are slow progressors. They remain relatively asymptomatic until the age of three years and start presenting with mild infections. They can live longer if treated for the Opportunistic Infections (OI).

Follow up of children born to HIV positive mother

Follow up of the infants born to HIV positive mothers starts at 6 weeks of age through case history documentation.

Session 2: Prioritizing the information and Review

Aim

At the end the session, participants will be able to :

- Prioritize the information to be told in six situations mentioned in introduction.
- Review of the session

Methodology

- Participatory discussions among the participants
- Brain storming session

Time 10 minutes

Materials needed

Charts and pens
Stickers

Notes for Facilitator

The Facilitator should be able to guide the participants to participate in the group activity as the needs of the people may differ in the given region. At the end of the session the points of counseling on basics of HIV/AIDS among children has to be stressed as per the six situations.

Activity

The counselors prioritize the information to be told in six situations on a chart and stickers in small groups consisting of 5-6 participants or brain storming of the total group.

Slide 1 with six situations

1. Pre ART counseling for child
2. Pre ART counseling for caregiver
3. ART counseling for child
4. ART counseling for caregiver
5. Follow up counseling for child
6. Follow up counseling for caregiver

Slide 2

Show this to participants and explain that they have to prioritize the information to be told in six situations in a table.

Focus person	Pre ART session	ART session	Follow up session
child			
caregiver			

Slide 3

Get information from the participants for reviewing the session

Review of the session

- The relevance of the content
- What parts are more useful or not useful?
- The facilitation process
- Usefulness of counseling tools

CARE OF THE SICK CHILD

Session Time : 2 Hours 25 minutes

Session A	Care of the sick child at home –Medical	- 45 Minutes
Session B	Care of the sick child at home- Nutrition-	60 Minutes
Session C	Water, Hygiene and Sanitation	- 30 Minutes
Session D	Review	- 10 Minutes

Introduction

One of the responsibilities of Counselors is to improve the care givers' capacities in providing care to a sick child. This module deals with the details of caring the sick child's needs and ways to facilitate the caregivers' involvement in the caring process with appropriate inputs.

The CLHA are heavily reliant on the care givers for daily care, treatment and support. It is important that the child feels secure, nurtured and loved within their environment. Many of the side effects of ART and minor opportunistic infections can be managed at home by identifying them as early as possible. The caregiver and older children should be equipped with knowledge on OIs for effective treatment and to improve the quality of life.

Malnutrition is a one of the important issues for CLHA. Even at the early stages of HIV infection, HIV demands heavily on the body's nutritional status. The risk of malnutrition increases significantly during the course of the infection. Though good nutrition cannot cure AIDS or prevent HIV infection, but it can help to maintain and improve the nutritional status and delay the disease progression. A healthy and balanced diet will help to maintain body weight and fitness by improving the immune system – the body's protection against infection. Body weight is an important indicator of health status in CLHA.

Many of the conditions associated with HIV/AIDS affect food intake, digestion and absorption while others influence the functions of the body. Most of the symptoms of these conditions (e.g. diarrhea, weight loss, sore mouth and throat, nausea or vomiting) are manageable with appropriate nutrition and care. Good nutrition will reinforce the effect of any medication taken.

Factors related to water, sanitation and hygiene affect children's right to quality of health in many ways. Although water and sanitation facilities in communities are increasingly recognized as fundamental for promoting good hygiene behavior and children's well-being, many communities have very poor facilities. Conditions vary from inappropriate and inadequate sanitary facilities to the outright lack of waste disposal and safe water for drinking. Access to potable water supply and a latrine is a basic need, especially essential for those living with HIV/AIDS. Unsafe water can be fatal to those delicate immune systems. A nearby and reliable supply of water for households helps those infected to stay healthy. Policy makers, programme planners and managers, donors and field workers need to treat HIV as a chronic disease and plan for better water supply, sanitation and hygiene to counteract the vicious impacts on people's day-to-day health, work, income and dignity.

Men, women and children with HIV/AIDS infection are highly susceptible to opportunistic infections. Most of these are related to poor water supply, sanitation and hygiene leading to Diarrhoea and various types of skin diseases. The risk of getting vector borne diseases like Malaria is also greater and is worsened by poor drainage creating mosquito breeding places in and around the communities.

When CLHA have better access to treatment and basic services and hygiene education, they can live longer and continue to help their family and the Nation at large. Unfortunately, majority of those infected do not know about their HIV status and most do not want to get tested because of stigma and the lack of access to treatment. One can stay healthy for a very long time if they ensure that they live in a healthy environment.

Session 1: Care of the Sick Child at Home – Medical

Aim

At the end the session, participants will be able to :

- Enhance the knowledge on taking care of Opportunistic Infections at home.
- Acquire knowledge on ART medicines and their common side effects
- Understand the interactive tools to identify the side effects

Methodology

Play way method
 Power point presentation
 Practicing the group counseling cards
 Practicing the games

Time: 45 minutes

Materials Needed

LCD
 Charts and pens
 Group Conselling Card 2:
 Children should know what drugs they are taking
 Group Counseling Card 9:
 Self Care – Child Must Take Care Of Himself
 Bam Bam Virus: Story 4: The Bam Bam Virus and Protective Clothes

Game:

- Protected Child
- Things I do everyday
- Save The Baby Elephant
- Interactive Game 13: Snake and Ladder
 “Medicines twice a Day Keeps the Pain Away”

Notes to Facilitator

Facilitator needs to moderate the participants as they may loose focus while playing. The information shared should be right and the incorrect information should be rectified. The tools should be tried as they are to be used by the counselor. Facilitator guides the participants towards issues related to ART drugs and side effects. Only the most common side effects and home care tips are dealt with and the medical knowledge is purposively limited to the requirement of counselors.

Activity 1 – OI management

- Tug of war between caretakers and OI:
 - a. Everyone stands in two rows facing each other.
 - b. One row represents OI and the other home care providers.
 - c. OI row participants tell one symptom and the home care team gives a tip on management.
 - d. The same symptoms can be seen in many diseases so they may be repeated but the tips have to be different like nausea can be due to medicines or indigestion or jaundice. The tips are different so the teams should be made aware of the fact that the symptoms may be few but the diseases may be many.
 - e. This continues till they are exhausted with symptoms of OI
 - f. When facilitator feels that the information shared is wrong then he should ask others to correct the information.



- Interactive Power point presentation gives methodical information
- Demonstrate then allow time for practicing how to counsel using counseling card 9: Self Care – Child Must Take Care of Himself. Follow the instructions on the backside of the card by showing the picture.



- Demonstrate then allow time for practicing how to counsel children using interactive games.
- The Bam Bam Virus: Story 4: The Bam Bam Virus and Protective Clothes- This section gives information about how to protect oneself from germs. It also demonstrates that those with the virus can live normally with others



Essential information

- Awareness on common OIs is important to deal with CLHA at home
- PCP is the most common OI among children below 1 year of age
- Recurrent bacterial infections like Pneumonia, ear infection, sepsis, skin infections, muscles, bone infections and brain infections are common among CLHA
- Extra pulmonary TB is more common among children compared to adults.
- Oral thrush below 6 weeks of age is normal but if seen after 6 weeks it can be taken as a hallmark of HIV in the child
- Diarrhea is the most common problem and can be treated with good home care
- The symptoms of disease component and the side effect of ART are difficult to distinguish and so pediatrician care is needed.
- The self care habit in caregiver is to be imbibed
- Continuous Medical care and psychological support is necessary for the CLHA.
- ART Medicines given to children are dispensable tablets and the dosage depends on the weight of the child
- ART medicines dosage should be followed according to the guidelines of NACO.
- If the child is not able to take the tablets, the tablets can be dissolved in the boiled and cooled water.
- The ART medicines as suspensions are also available for very young children
- ART is not an emergency drug so take time to counsel the care giver and the child in 2-3 sessions before initiating ART for better adherence.
- The common side effects to ART are: fatigue, Lack of interest, Diarrhea, Skin Rashes, Peripheral neuropathy, Anemia, Nausea, vomiting, Weight loss
- The common ART medicines are Lamivudine, Stavudine, Nevirapine, Efavirenz and Zidovudine

Activity 2 - ART side effects management.

- Ask the participants:
 - What are the pediatric ART medicines available at ART centers?
 - What is a side effect?
 - When do side effects happen if a person is taking ARV?
 - Why is it important to talk about side effects with child and caregiver on treatment?
- Explain to the group regarding the available medicines and the way to make the suspensions and to store the drugs. Discuss about which side effects are common or less common, and what effect they might have on a child's health.
- Group Counselling Card 2: Children should know what drugs they are taking – to familiarize the children and caregivers with the drugs by practicing with the counselors during the session. 
- Point out side effects that are specific to one drug and note them on the chart.
- Case study: present a case study on the child having side effects and then ask the participants to do a role play on the side effects and the support from the family and the community. Enact as a counselor explaining the side effects and giving advice to prevent and alleviate them to a child and also the caregiver.

After each role play, ask the members of the other groups to comment and suggest how the advice could be improved or changed. If there is no enough time for all the groups to act their role plays, ask one or two groups to perform their role plays and then ask the other groups to describe briefly what their role play would show and the key issues they would portray.

Activity 3 - Games

Depending on the size of the group and time availability the facilitator can make the counselors to practice the games by following the instructions



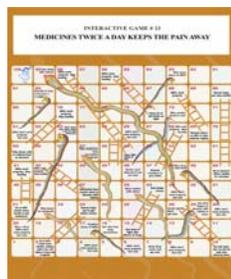
Protected Child Game

Things I do everyday Game



Save The Baby Elephant Game

Interactive Game 13: Snake and Ladder “Medicines twice a Day Keeps the Pain Away”



Handout

Care of the sick child at home – Medical

As the CLHA have frequent infections, the caregiver should learn to deal with the situation at home and also when to take the child to hospital. The home care tips should be told to the child and caregiver during counseling sessions, so the counselor should be equipped with basic knowledge on OI in children.

Common OIs in children and care at home

Pneumocystis Carinii Pneumonia (PCP): It is a common AIDS - defining illness among children below the age of one year with a high mortality rate of about 35%.

Symptoms: Fever, Increased heart rate, breathlessness and severe Cough

Homecare Tips

- Cotrimoxazole should be given everyday.
- If fever is very high, do lukewarm water sponging
- Child to be kept in inclined position to relieve breathlessness
- Immediate medical attention is needed.

Recurrent bacterial infections and home care tips

Pneumonia: Lung infection is common among CLHA with fever, breathlessness and needs immediate medical attention

Sepsis: A serious infection of blood with high fever, toxicity and unconsciousness, which needs immediate medical attention.

Abscesses and skin infections: Boils and rashes on the skin are seen in CLHA. Frequent cleaning of the skin wounds with lukewarm water and soap is advised. If the boils are bleeding, the care-giver should wear gloves while cleaning the wounds.

Bone/ joint infections: Painful Swelling of muscles, joints and bones is common that needs immediate medical attention. Use hot water bag on the swelling.

Ear infection: Common among children in general, but more so in CLHA. At home, care should be taken during bath to avoid water entering the ear. Oil should not be instilled into the ear. Dry the ear at least 3 times daily. Roll clean absorbent cloth. Place it in the child's ear and remove it when wet. Replace it with a clean one and repeat these steps until the ear is dry.

Meningitis and Encephalitis: Brain infections present a very sick child who is unconscious or having fits. This child needs immediate medical attention. Turn the head of the baby to one side to avoid blocking of airways with vomit or secretions. Do not keep sharp objects near the child as the child may throw a fit and injure him/herself.

Tuberculosis (TB)

48% of children with HIV have TB. Extra pulmonary and miliary TB are more common among children when compared to adults.

Suspect TB if the child has:

- Fever for more than 2 weeks
- Cough more than 2 weeks
- Ongoing weight loss or poor weight gain is easily visible among children.
- Pneumonia not responding to antibiotics
- Recent glandular enlargement
- Contact with adult who has Pulmonary TB

Home Care Tips

- Refer the child to TB DOTS programme/ Chest diseases OP.
- Child to be kept in inclined position to relieve breathlessness
- ART medication to be discussed with the ART Medical Officer as the protocol may be changed keeping in view of interaction between ATT and ARV

Herpes zoster is rare in immunocompetent children and if it occurs in a child, then HIV infection should be suspected. Blisters on one side of the body in one area with pain are the hallmark of the disease. The common belief of relief with 'mantra' will not work. It needs immediate treatment. Past infections are seen as scars in the area.

Diarrhoea

Diarrhoea if more than two weeks is chronic

Home Care Tips

Oral rehydration solution (ORS) should be given. The extra fluid necessary in addition to the usual fluid intake is:

- Up to 2 years: 50 to 100 ml (half a glass) after each loose stool
- 2 years or above: 100 to 200 ml (one full glass) after each loose stool
- Give frequent small sips
- If the child vomits, wait for 10 minutes. Then continue, but more slowly
- Continue giving extra fluid until the diarrhea stops
- Get Immediate medical attention

The children become dehydrated easily. Severe dehydration is seen as loose skin, sunken eyes and reduced urine output.

Oral thrush (Oral candidiasis)

Recurrent oral Candidiasis is one of the clinical indicators of HIV infection in infants beyond 6 weeks of age. (HIV negative children less than six weeks of age also can have oral thrush)

Children have creamy white curd like patches with red underlying mucosa in the mouth, palate and tonsils.

Home Care Tips

- Treat mouth ulcers twice daily
- After washing the hands of the care giver, a clean soft cloth is wrapped around the finger which is dipped in salt water and the mouth of the child is cleaned.
- Paint the mouth with Gentian violet (GV) solution
- Wash hands again
- Continue using GV for 48 hours after the ulcers have been cured
- Antifungal mouth paint can be used
- Give Paracetamol for pain relief

ARVs and Home care management of side effects

Nausea common for Zidovudine

- This is common and self-limited.
- Treat symptomatically – give oral fluids, continue eating and give rest.
- If persist for more than two weeks or worsens, take the child to ART center.

Headache common for Zidovudine or Efavirenz

- This is common and self-limited side effect.
- Give Paracetamol
- If persists for more than 2 weeks take the child to pediatrician / ART center.
- Assessment for meningitis by pediatrician.

Diarrhoea common for Stavudine

- Give Oral Rehydration solution
- Reassure patient that if due to antiretroviral therapy, the child improves in a few weeks.
- Follow up in two weeks
- If no improvement is seen take the child to pediatrician.

Fatigue common for Zidovudine

- Fatigue is tiredness that does not go away when the patient rests. It can be physical or psychological.
- Consider anemia especially if on Zidovudine
- Check hemoglobin.
- Fatigue commonly lasts 4 to 6 weeks especially after starting Zidovudine.

Anxiety, nightmares, psychosis, depression common for Efavirenz, (lasts < 3 weeks).

- Give at night; counsel and support
- Call for advice or refer if severe depression or suicidal or psychosis.

Blue/ black nails common with Zidovudine

- It is harmless.
- Reassure.

Skin Rash common for Nevirapine

- Dry / wet rash
- If generalized or peeling of skin is seen take the child to hospital immediately.

Fever this could be a side effect or an opportunistic infection, or immune reconstitution syndrome

- Check for common causes of fever.
- Call for advice or refer

Yellow eyes (jaundice) Common for Nevirapine

- Immediate medical attention is needed

Abdominal or flank pain Common for Stavudine

- Immediate medical attention is needed as it can be due to Pancreatitis

Anemia common for zidovudine

- Paleness of tongue, eyes, nails
- Low hemoglobin (<8 grams)

Tingling, numb or painful feet/legs- Peripheral neuropathy Common for Stavudine

- If new or worse on treatment, refer. Physician may consider changing the ART.

Cough or difficult breathing Common with Immune Reconstitution Inflammatory Syndrome

- Occurs within weeks of starting ART.
- Take the child to ART center/pediatric OPD.

Changes in fat distribution-Lipodystrophy Common for Stavudine.

- It is a condition where a collection of fat changes the body shape. This occurs in adults taking ART, but the experiences in children have not yet been documented.

Session 2: Care of the Sick Child at Home – Nutrition**Aim**

At the end the session, participants will be able to:

- Understand how HIV/AIDS affects the nutritional status of CLHA
- Identify the necessary components for a healthy and balanced diet for CLHA and HIV positive mothers
- Identify strategies to maintain good nutritional status of CLHA.
- Provide appropriate dietary recommendations for CLHA on ART and side effects.
- Identify dietary practices and barriers to good nutrition.

Methodology

Play way method
Interactive Power point presentation
Brainstorming session

Time: 60 minutes

Materials needed

Presentation: Power point, charts and posters.
Group Counseling Card 3: Essential activities for health of child with HIV/AIDS
Group Counseling Card 4: Effects of HIV/AIDS on nutrition of Children
Group Counseling Card 5: Importance of Good nutrition For Children with HIV/AIDS
Group Counseling Card 6: Elements of Healthy and Balanced Diet and Nutrition Counselling
The Bam Bam Virus: Story 3: The Bam Bam Virus and Secret Weapon
Vitamin Cards – Eight cards
Games:
○ Iron Chef
○ Vitamin Reunion
○ Battle in The body
○ Interactive Game 12: Snake and Ladder “Reach An Apple”
○ Interactive Game 15: Puzzle

Notes to facilitator

- Nutrition for CLHA is a cross cutting issue for the quality of their lives.
- In discussions distinguish the difference between Food in-take and Absorption of food
- Barriers are region specific, so the counselors should be encouraged to discuss and to add to the list / to make the list of their own.
- Nutrition counselling is an important aspect of ART adherence.

Activity 1 - Myths and misconceptions about food

- Ball toss game / brainstorm:
 - Everyone stands in a circle.
 - Trainer holds the ball and names one good source of protein or muscle-building foods/ carbohydrates/ vitamins/ minerals/ low cost locally available food then tosses the ball to someone else in the circle.
 - Next person also names one example of a good source of protein or muscle-building foods/ carbohydrates/ vitamins/ minerals/ low cost locally available food.
 - Ball keeps getting tossed around the circle.
 - When trainer feels ready, s/he can change the category and start again.
- Brainstorm
 - Common food-related myths and misconceptions.
 - Write on flip chart and discuss. (provide accurate information)

Activity 2 – Potential barriers to nutrition

1. Brainstorm and small group work about potential barriers.
 - a. Brainstorm in plenary about potential barriers to good nutrition.
 - b. Write them on flip chart.
 - c. Divide participants into 4 groups.
 - d. Ask each group to address X number of barriers and come up with possible solutions.
 - e. Ask each group to present their solutions.
 - f. Discuss in plenary.
2. Brainstorm about common food-related myths and misconceptions
3. Show, then allow time for practicing how to counsel using counseling cards and other tools.
 - a. existing dietary practices worksheet
 - b. meal planning worksheet/food drug timetable
4. Show, and then allow time for practicing how to counsel children using interactive games.

Activity 3 - Nutrition counseling

Nutrition counseling with group counseling cards to be practiced by the counselors in the session to become familiarize with the process.

- Group Counseling Card 3: Essential activities for health of child with HIV/AIDS



- Group Counseling Card 4: Effects of HIV/AIDS on nutrition of Children



- Group Counseling Card 5: Importance of Good nutrition For Children with HIV AIDS



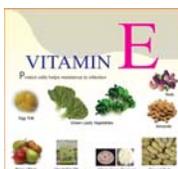
- Group Counseling Card 6: Elements of Healthy and Balanced Diet and Nutrition Counselling



- The Bam Bam Virus: Story 3: The Bam Bam Virus and Secret Weapon- This story deals with the human organs and body mechanisms that protect the body, and fight against the germs. Make the counselors to familiarize with the story so that they can fluently use it with children.



- Vitamin Cards – Eight cards: Make the counselors to practice in the session by showing the card and explaining the sources and get the feed back from other participants.

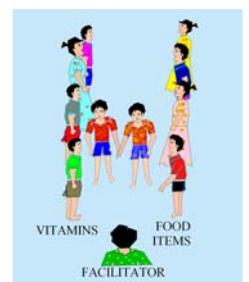


- Games: A number of games are suggested, depending on the availability of space, time and size of group, the games can be practiced and used as per the instructions provided in the card.

Iron Chef Game



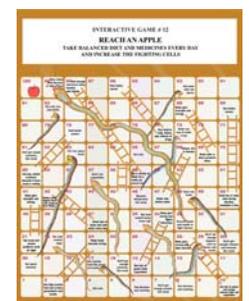
Vitamin Reunion Game



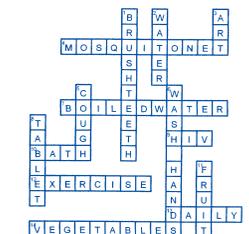
Battle in The body Game



Interactive Game 12: Snake and Ladder "Reach An Apple"



Interactive Game 15: Puzzle



Essential Information

- HIV/AIDS has an effect on nutrition through reduced intake and also reduced absorption which leads to weight loss
- Additional nutritional needs of children living with HIV/AIDS should be understood
- Malnutrition and HIV/AIDS are related in India due to food insecurity for CLHA who are vulnerable.
- For infants, start with cereals or rice before introducing vegetables or fruits from the age of six months. Use a very thin consistency when starting semi-solid foods, slowly thicken consistency, Avoid mixing with breast milk and fruits should be fully ripe.
- Balanced diet with a variety of macro and micro nutrients should be advised
- Food can interfere in the efficacy of some ARVs.
- The minor side effects of ARVs can be managed at home
- Information on individual and traditional food and diet practices in the home should be considered.
- Listing the Food-related myths and misconceptions with child and care giver is important.
- Potential barriers to achieve good nutrition and feasible options are region specific.
- Prioritizing the low cost, locally available nutritious foods
- Easy to prepare recipes depending on the local availability.
- Nutrition counseling as early as possible increases the quality of life of CLHA.

Handout**HIV/AIDS and nutrition****Effect of HIV/AIDS on Nutrition**

HIV/AIDS has a strong impact on nutrition and nutrition has an impact on the progression of HIV infection in CLHA. HIV/AIDS reduces the nutritional status of a child by reducing food intake, absorption and digestion of food which can lead to malnutrition. Another mechanism by which HIV/AIDS contributes to malnutrition is by impairing the immune function and quickening the progression to AIDS. In ill nourished CLHA, the disease progression is rapid.

HIV/AIDS reduces food intake

Children with HIV/AIDS often do not eat enough because:

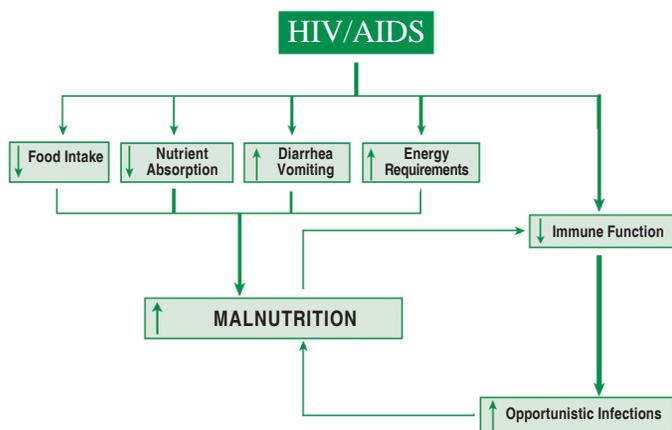
- The illness and medicines taken may reduce the appetite and modify the taste of food.
- Symptoms such as a sore mouth, nausea and vomiting make it difficult to eat.
- Tiredness, isolation and depression reduce the appetite and the willingness to make an effort to prepare food and eat regularly.
- Economical constraints of the family.
- Negative attitudes of care givers in providing food for CLHA.

HIV/AIDS reduces the absorption of food

Food, once eaten, is broken down by process of digestion into nutrients. These nutrients pass through the gut walls into the bloodstream and are transported to the organs and tissues in the body where they are needed. One of the consequences of HIV and OIs is that since the gut wall is damaged, food can not be absorbed properly. Diarrhea is a common occurrence in CLHA. When a person has diarrhea the food passes through the gut so quickly that it is not properly digested and fewer nutrients are absorbed.

HIV/AIDS affects weight

When a child does not eat enough food or the food eaten is poorly absorbed, the body draws on its reserve stores of energy from body fat and muscles. As a result, the child loses weight and becomes thin and emaciated



Need for Healthy and balanced diet for CLHA and Mothers

A healthy and balanced diet includes adequate food intake including a variety of foods and all essential nutrients which are needed for CLHA.

- **Proteins**
Body building foods available in legumes, and animal products, Beans, peas, lentils, groundnuts, Soya beans
- **Carbohydrates**
Energy foods available in rice, wheat, maize, millet, sorghum, barley, potatoes, sweet potatoes, yams, Banana
- **Fats**
High energy foods, Butter, lard, margarine, cooking oil, cream, Ghee, coconut cream, oilseeds, Fatty meat, fish, Curds and cheese

- **Vitamins and minerals** – protective foods yellow, orange, red or dark green vegetables and fruit are good sources of vitamins.
 - Sources of vitamin A- Green leafy vegetables, pumpkin, green peppers, squash, carrots, yellow peaches, apricots, papaya and mangos, Good
 - Sources of vitamin C to fight infection, Tomatoes, cabbage, oranges, grapefruit, lemons, guavas, mangos, pineapples

Low cost, locally available foods

The sheer size of the Indian subcontinent combined with the diversity of foods available necessarily leads to region-specific cuisines and a vast range of food practices. Children and caregivers should be provided with information on low cost locally available foods within their culture and food customs.

Complementary feeding

For children born to HIV positive mothers mixed feeding should be avoided and the switch over to complementary feeds is sudden and so more care should be taken.

Complementary foods, which include cooked semi-solid and solid foods, should particularly include proteins, iron, vitamins, as these are frequently found to be deficient in the diet of young infants.

Food such as cereals, pulses, fruits and vegetables are introduced slowly, one food at a time. The foods should be cooked, mashed and mixed with formula/buffalo/ cow milk to a thin consistency. No salt, sugar or seasonings should be added. When the baby accepts one solid feed for at least a week, a second kind can be introduced.

Tips for preparing food:

- Start with cereals or rice before introducing vegetables or fruits.
- Use a very thin consistency when starting semi-solid foods, slowly thicken consistency.
- Avoid mixing with breast milk
- Fruits should be fully ripe.

Complementary Foods

Use local utensils to show amount

Age	Texture	Frequency	Amount at each meal
From 6 monts	Soft porridge, well mashed vegetables, meat, fruit	2 times per day plus frequent cow/buffalo milk	2-3 tablespoonfuls
7-8 monts	Mashed foods	3 times per day plus frequent cow/buffalo milk	Increasing gradually to 2/3 of a 250 ml cup at each meal
9-11 monts	Finely chopped or mashed foods and foods that baby can pick up	3 meals plus 1 snack between meals plus cow/buffalo milk	3/4 of a medium size cup/bowl (250 ml)
12-24 monts	Family foods, chopped or mashed if necessary	3 meals plus 2 snacks between meals plus cow/buffalo milk	A full medium size cup/bowl (250 ml)

Gain Weight

Weight gain is particularly important for those children who are already underweight and malnourished. Underlying malnutrition must be addressed along with the additional nutritional demands caused by HIV/AIDS. Strategies for gaining weight include:

- Eat more food by eating larger portions or eating more frequently.
- Eat more staple foods such as rice, maize, millet, sorghum, wheat, bread, potatoes, sweet potatoes, yams and bananas.
- Increase intake of beans, soya products, lentils, peas, groundnuts and seeds such as sunflower and sesame.
- Include all forms of meat- poultry, fish and eggs as often as possible. Minced meat, chicken and fish are easy to digest.
- Eat snacks regularly between meals. Good snacks are nuts, seeds, fruit, yogurt, carrots, potato chips, ragi cakes and ground nut cakes
- Introduce more dairy products such as full-cream milk, sour milk, buttermilk, curd and cheese into the diet.

- Add sugar, honey, jam, syrup and other sweet products to the food.
- Make meals as attractive as possible by giving different types of food preparation.
 - It is important to regain the weight lost as soon as possible and to restore the body's nutritional reserves.

Exercise to improve well-being and build muscles

- Exercise is especially important for maintaining the health of CLHA
- It helps strengthen and build muscles that store energy and protein that the immune system needs.
- It can make the child feel more alert, help relieve stress and stimulates appetite.
- Exercise should not be tiring or stressful; gentle muscle-building exercise is recommended.
- Going to school, playing, doing household chores, walking, running, swimming and dancing are all suitable.
- Children living with HIV/AIDS need to make an effort to find the exercise that they enjoy and that suits their situation.

ARV and Nutrition

Food or drinks to be avoided or taken in small quantities by children on ART

Alcohol containing tonics reduces effectiveness of ARV

Coffee/tea increases fluid loss and interferes with absorption of nutrients.

Undercooked meat / raw eggs cause food borne diseases

Eating too much garlic reduces the effectiveness of Saquinavir-ARV drug.

Nutritional management of common ARV side effects

These are some simple ways to manage the side effects and encourage children to eat.

- **Loss of appetite-** take small, frequent meals
- **Change or loss of taste-** Use flavor enhancers such as salt, spices, or lemon in cooking. Provide a variety of foods that child can relish. Brush the teeth and clean the tongue every morning and night.
- **Constipation-** Eat high fiber foods such as whole cereals, fresh vegetables, fruits, beans, drink plenty of liquids, exercise regularly and avoid processed foods - refined flour and polished rice.
- **Diarrhea-** Drink plenty of fluids (more than 8 glasses of fluid with salt per day), fruit juices, small and frequent meals containing soluble fiber like bananas during and after illness.

Avoid many foods and drinks that can make diarrhea worse or compound the effects of diarrhea including: fried or oily foods / whole, unrefined grains and cereals / green, unripe and acidic vegetables and fruits such as tomatoes, pineapple and citrus fruits / milk if it cannot be tolerated / coffee, tea / spicy foods / gas-producing foods such as beans, cauliflower, cabbage, sprouts; onions and green peppers.
- **Fever-** Drink plenty of buttermilk / fruit juices with a pinch of salt / energy rich food.

- **Dry mouth-** use more soups and other liquid preparations / use chewing gum / rinse mouth with clean warm water / avoid hot and spicy foods.

- **Flatulence (gas)-** Can be avoided by not eating gas-forming foods like beans, cabbage and cauliflower.

- **Nausea or vomiting-** Eat small quantities of food, fluids should be taken after meals and in limited quantities during meals / eat in sitting position and rest between meals / smell fresh orange, lemon peel or drink lemon juice in hot water or herbal or ginger tea. Foods and activities that may worsen nausea and vomiting include: having an empty stomach; preparing food and eating fatty, greasy and/or very sweet foods.

- **Pale tongue/hands/fingernails (signs of anemia)**
Eat foods like animal meats, dark green leafy vegetables / fruits, jaggery and millets like Ragi, Take iron/ tonics. Make sure the child is treated for Malaria and worm infestation.

Nutrition Counseling

Nutrition counseling is an important component of pediatric ART adherence counseling. Nutrition education at an early stage gives child and caregiver a chance to build up healthy eating habits. Topics that should be discussed in nutrition counseling include:

- General nutrition information
- Individual and traditional food and diet practices at home
- Food-related myths and misconceptions
- Low cost, locally available nutritious foods
- Easy to prepare recipes
- Potential barriers to achieve good nutrition
- Food choices for individual treatment schedules to manage food-drug interactions (foods to take/avoid)
- Nutritional management of side effects

Common food and diet practices

Many dietary and food practices are passed down in families for generations. To change unhealthy long-standing customs or practices it requires knowledge building and support by the counselor. Some examples of dietary practices that should be encouraged include:

- Drink water/fluids everyday especially when the child suffers from diarrhoea / fever
- Eating fruits, green leafy vegetables everyday.
- Avoid Overcooking vegetables
- Affordable, Accessible, low cost plant proteins
- Limited usage of oil and salt
- Washing the vegetables before cutting

Potential barriers and solutions

Many factors can affect a child or caregiver’s ability to provide adequate nutrition for the child. Counselors should help children and caregivers in identifying options in participatory manner.

Barriers	Options
<p>Economic</p> <ul style="list-style-type: none"> • Financial resources • Inability to maintain sanitary, water, food or home conditions 	<ul style="list-style-type: none"> • Provide referrals or linkages to other organizations or services that may be able to help
<p>Social/cultural</p> <ul style="list-style-type: none"> • Food-related practices, taboos, myths and misconceptions • Food allocation in home resulting in inadequate amounts especially for girl child • Stigma-related factors • Orphaning and migration 	<ul style="list-style-type: none"> • Dispel myths and misconception • Prepare separate meals for child. • Talk to those stigmatizing against child or caregiver. • Suggest joining support groups and work toward reducing stigma and discrimination.
<p>Physical</p> <ul style="list-style-type: none"> • Inability to eat due to sickness or side effects • Inability to prepare food and snacks (i.e. illness of caregiver) • Inability to exercise regularly (can be for many reasons, not just physical. i.e. time, space) 	<ul style="list-style-type: none"> • Review nutritional management strategies to alleviate ARV side effects • Discuss option of asking others in family or community to help prepare food. • Home remedies by the care givers
<p>Environmental</p> <ul style="list-style-type: none"> • Availability of food (i.e. seasonal) • Constraints due to natural calamities (floods, cyclones, fire accidents), conflict, war, domestic violence or other environmental factors 	<ul style="list-style-type: none"> • Discuss variety of food sources that provide adequate nutrition for the child. • Linkages with organizations for preparedness and services
<p>Other barriers raised by child/caregiver</p>	<p>Discuss with the ART doctor and arrive at solution</p>

Session 3: Water, Hygiene and Sanitation

Aim

At the end the session, participants will be able to :

- Acquire knowledge on the importance of water, hygiene and sanitation for CLHA

Methodology

Brainstorm

Power point presentation

Practicing the counseling cards

Time: 30 minutes

Material needed

LCD

Flip chart

Markers

Group counselling Card 8: Water, Hygiene and Sanitation

Interactive Game 14: Snake and Ladder: Drinking Safe Water, Washing and keeping Clean are Our Habits

Game: Battle in the Body

Notes to the facilitator

Facilitator should take care of the casual approach of the participants and care givers about impact of water, hygiene and sanitation on the health of CLHA.

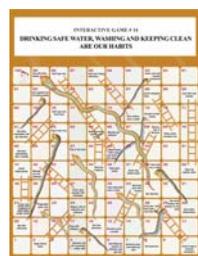
Conscious efforts must be put towards recognizing the importance of the topic and understanding the use of this particular topic.

Activity 1 Water, Hygiene and Sanitation

- Brainstorm about general hygiene precautions for CLHA
- Brainstorm about food related precautions for CLHA
- Counseling card 8: Water, Hygiene and sanitation. Practice the cards during the session as per the instructions provided on the back side of the card.



- Interactive game 14: Snake and Ladder: Drinking Safe Water, Washing and keeping clean are Our Habits. Make the counselor to be aware of the game so that they can use it at ART centre with children and care givers.



- Game: Battle In the Baby- Follow the instructions on the card and familiarize with the game so that the counselors will use it with children at ART centre.



Essential information

- Good access to safe water and sanitation is indispensable for CLHA and for the provision of home-based care.
- Drinking safe water can prevent water borne diseases.
- Food should be prepared carefully to avoid contamination with germs and toxins.
- Food hygiene measures have two aims – to prevent contamination in preparation areas and to prevent germs multiplying in cooked food.
- Raw food should be avoided in the feeds and also contact with raw foods should be avoided.
- Meat and fish should be cooked well while eggs should not be eaten raw.
- Personal hygiene of the child and the care giver reduces infections.
- Disposal of waste by burning is very important.
- Vector borne diseases like Malaria can be avoided by using insecticide treated mosquito nets.
- Avoid contact with person having TB.
- Avoid direct contact with wounds of other persons.

Handout

Clean and safe water

Good access to safe water and sanitation is indispensable for CLHA and for the provision of home-based care. Children with suppressed immune systems need safe water and sanitation facilities to reduce the risk of opportunistic infections.

Children on ART must have access to clean and safe drinking water when taking medicines. Drinking plenty of safe water replaces fluids lost through AIDS-related diarrhea. Clean and safe water is essential in dissolving the ARV tablets and the preparation of replacement feeds when mothers choose not to breastfeed.

- Drink boiled and cooled water
- Use safe clean water from protected sources such as treated piped water supplies, boreholes, gravity feed schemes and protected wells. If the water is not from a protected source, it should be boiled before consumption.
- Care must be taken during collection and storage and use clean containers to prevent contamination. Water containers at home can easily become contaminated by dirty cups and hands that have not been washed. When children drink contaminated water they become sick.

Food safety and hygiene

Germ as well as the toxins cause sickness. If they get food poisoning, they will lose weight and become even weaker, which lower the body's resistance further. The attitudes of people towards proper hygiene and sanitation are to be improved.

Hygienic food handling and access to safe foods are imperative. Most food poisoning can be prevented by following some basic rules of hygiene like to prevent contamination in food preparation areas, to prevent germs from multiplying in food and causing food poisoning.

Hygiene in the kitchen

- Keep all food preparation areas clean and use clean dishes and utensils.
- Wash vegetables and fruit with clean and safe water.
- Cover food to prevent both flies and dust from contaminating the food.
- Keep rubbish in a covered bin and empty it regularly.

Cooking and storage of food

Germ multiply more quickly in warm food. Storing food in a refrigerator or cool place slows down this growth. Cooking on a high heat can also kill most germs. Food should be eaten as early as possible after cooking.

- Store fresh food in a cool place or refrigerator where available.
- Do not throw away the boiled water from vegetables as the essential vitamins are lost.
- Serve food immediately after cooking. Do not leave the food standing at room temperature before eating.
- Do not store raw and cooked foods together - use containers
- Avoid storing leftovers unless they can be kept in a refrigerator or a cool place. Do not store them for more than one or two days and always reheat them at a high temperature.

Preparing baby food

- Always wash your hands with soap and clean utensils thoroughly.
- **Raw food contains bacteria.** Raw food materials should be avoided in HIV positive children and adults.
- Feed baby within two hours of preparing the food.

Animal foods

- Cook meat and fish well; meat should have no red juices.
- Wash utensils and surfaces touched by animal products with hot water and soap before preparing other foods.
- Keep meat and fish separate from other foods.
- Eggs should be hard boiled. **Do not eat half-boiled eggs, raw eggs, cracked eggs or any foods containing raw eggs.**

Hygiene and sanitation

Personal hygiene and safety

- Always wash hands with clean water and soap before and after preparing food or eating, after coughing / nose blowing / using the toilet / touching any pets or animals / before and after coming in contact with a sick person. Dry hands on a clean cloth or towel.
- Cover all wounds especially on the hands to prevent contamination of food during preparation and handling.
- Reduce risk of exposure to vector-borne diseases. Sleep under insecticide-treated mosquito nets to avoid Malaria.
- Cover your nose and mouth when coughing or when someone is coughing nearby to avoid contacting Tuberculosis
- Avoid contact with other people's open wounds to avoid transmission of HIV.

Disposal of soiled linens

- Soak soiled (blood, vomit, other bodily fluids or excretions) linen and underclothes in bleach for 30 minutes and wash with soap and hot water.
- Dry clothes in the hot sun to kill the germs
- If they cannot be washed, then dispose them by burning. Do not dispose of soiled linens in dust bin.

Disposal of human waste

- Avoid open defecation
- Use a latrine and keep it clean and free from flies / Keep the surroundings clean

Session 4: Review

Aim

At the end the session, participants will be able to :

- Review the session on care of the sick child

Methodology

Brainstorming with the participants

Time 10 minutes

Materials needed

Charts and pens

Power point slides

Notes for the Facilitator

The facilitator should get unbiased information on the session through interaction. If the facilitator feels that the participants respond better if an evaluation form is provided then the idea can be followed up.

Activity

- Question and answer session:
 - What is most useful information in the session?
 - Is the content relevant?
 - Is the handout useful for the future reference?
 - How is the facilitation?
- Power point slides

ART and Adherence

Session Time : One hour 35 minutes

Session A	Assessment of the child	- 30 minutes
Session B	Adherence to ART	- 40 minutes
Session C	Incomplete Adherence	- 15 minutes
Session D	Review	- 10 minutes

Introduction

Anti Retro Viral therapy in India is a recent happening and presents numerous challenges especially on issues of sustainability. Keeping children on ART is a much more challenging task as the process involves many stakeholders. Adherence is a critical issue in treatment process in India as health seeking behaviors are relatively less and inadequate.

One should be aware that the process of adherence assessment should begin before therapy is initiated and incorporate into every visit. A comprehensive assessment should be instituted for all children in whom antiretroviral treatment initiation or change is considered. Evaluations should include nursing, social, and behavioral assessment of factors that may affect adherence by the child / family and can be used to identify individualized needs for intervention.

Assessment should focus on establishing a dialogue and a partnership in treatment management. Specific but open-ended questions should be used to elicit information about past experience and concerns about antiretroviral therapy, since caregivers may have taken these medicines or heard about them from others.

Interviews / pictorial/ textual assessment tools should be used to identify factors that make it difficult for children to receive treatment as prescribed as well as those that make it easier to administer medicines as the literacy rate is poor in many states of India. When assessing readiness to begin treatment, it is important to obtain explicit agreement with the treatment plan, including strategies to support adherence.

Regular monitoring of adherence is essential to early identification of problems and can reinforce the importance of treatment as prescribed. Useful methods include self-reports, refill checks and pill counts.

Strategies for ensuring adherence have to be developed for the child, family, health care provider and NGOs keeping in view the context and conditions in the community. Some of the strategies have been described in the hand outs.

Counselor supports CLHA in achieving 100% adherence to ART by applying pediatric counseling tools in conveying the message on HIV/AIDS in children, ART and care of the sick child.

NETWORKING WITH VARIOUS STAKEHOLDERS IS THE KEY TO SUCCESS OF ADHERENCE TO ART AMONG CHILDREN.

Session 1 : Assessment of the child

Aim

At the end the session, participants will be able to :

- Assess the Child living with HIV/AIDS

Methodology

- Interactive Power point presentation
- Question and answer

Time: 30 minutes

Materials needed

- LCD
- Charts and pens
- Power point presentation
- Handout
- Group Counselling Card 11: Stake Holders
- Growth Chart

Notes for Facilitator

Facilitator guides the participant towards importance of assessing the child before ART initiation and on documenting the information.

Activity 1 – Assessment of the child

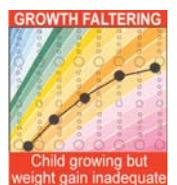
- Interactive Power point presentation on the Assessment of child and the groups of children
- Discussion on the practices of counselor during adult sessions regarding ART adherence and correlate with the child focus by asking them the questions like:
 - What information is collected at ART centers before starting the child on ART?
 - What are the necessary tests for initiating ART to a child?
 - Do you maintain documents like case studies?
 - As a counselor how do you assess the child?

Activity 2 - Group counseling cards

Group Counselling Card 11: Stake Holders- Show the card and ask the participants about the stakeholders involved in adherence of CLHA. Follow the instructions on the card and get the feed back and then present the other side of the card to provide information.



Growth Chart: Explain the growth chart and ask the feed back from three participants about how do they use in the ART centre with children / care givers. Mid arm circumference is a better indicator of growth of the child.



Essential Information

- Assessment of child before ART initiation
- Document the information
- The categorization of CLHA

Handout**Assessment of the Child**

ART in children has to be initiated only after a thorough assessment of the child and the family. As treatment has to be continued for a lifetime, the family should be made aware of facts regarding ART. Most mothers or caregivers may not have the necessary information but effort should be made by the counselor and health care providers to provide as much information as possible.

Data collection is followed as per NACO guidelines**Documentation - Information card**

An information card and detailed records are necessary for each child with the details of mother and the child included. This information is useful for assessment, documentation, follow up and research. The Information card for the infant is to be issued in PPTCT centers immediately after the delivery / at ART centers upon the first consultation.

In assessing the child and their likelihood of adherence to ART, it is important to consider the following factors:

Information of child

- Cognition/ personality and behavioural traits
- Developmental stage
- Support systems in their life- financial, psychosocial and family
- Care givers' belief in treatment
- The level of disclosure that has been bestowed upon the child, and their understanding of that
- Degree to which they have accepted the disease
- Whether they are symptomatic or asymptomatic/ present symptoms and concerns of the patient/ Infections past and present especially TB, PCP
 - Ability to question and articulate procedures and concerns
 - Past history of ART and details
 - Nutritional assessment
 - Emotional assessment
 - Co-existing OI and treatment – Is the treatment from NGO/ GO / self financed as it is going to have a direct impact on their adherence. People attached to NGOs have a greater chance of follow up when compared to self reporting.
 - Cotrimoxazole prophylaxis
 - Birth weight
 - Testing for HIV
 - Feeding information- breast feeding practices/mixed feeding/artificial feeding alone
 - Developmental milestones

Information of Maternal health:

- Maternal health status during pregnancy
- Condom usage during pregnancy to avoid re-infection
- Type of delivery – normal/assisted/caesarian
- CD4 count / viral load in mother
- OI in mother
- Family history of tuberculosis – sputum positive / sputum negative
- History of treatment completion which shows the attitudes of the family

Logistical assessment:

The logistics of the care giver arrangement, the procurement of medication, and factors containing transportation, finances, etc need to be considered, when assessing a child's adherence to ART. Increased orphaning and care givers' attitude will have a large impact on adherence to ART

Considerations include:

- Distance to the ART center
- Compliance of the care giver
- Economic status

Methods of assessment

Methods of assessment include interviews, questionnaires, behavioral observations and preliminary / external data obtained from other health professionals. When working with children interactive tools are used in obtaining information.

Groups of children on ART

Dealing with children on ART requires categorization of children into 3 groups according to their age for practical approach:

- **1st group: Below 6 years** who are dependent on their parent/guardian and so the focus of counseling will be on the care giver.
- **2nd group: 7 – 12 years** who can understand the issues but still need care givers help in treatment. The focus is on child as well as the care givers
- **3rd group: Above 13 years** the child can understand the importance of the treatment. Hence, one to one counseling can be applied for child along with care giver.

Session 2: Adherence to ART

Aim

At the end the session, participants will be able to :

- Understand the importance of adherence to ART

Methodology

- Interactive Power point presentation
- Question and answer session

Time: 40 minutes

Materials needed

- LCD
- Charts and pens
- Power point presentation
- Handout
- Tool: My ART Calendar
- Group counseling card 1: ARVs Can Help Children Live Normal Lives
- Group Counselling Card 10: Importance of Regular Visits to Medical Professionals

Notes for Facilitator

Facilitator guides the participants towards adherence to ART by following the steps of adherence. The support systems should be identified and all participants should be part of the interactive session.

Activity 1 - Adherence

1. Question and answer session:
 - What is adherence?
 - What does it mean when you say that someone is or isn't taking their treatment correctly?
 - What steps should you follow?
2. Interactive Power Point Presentation

Essential information

- Adherence to ART by the children is a challenge as the medicines has to be taken life long.
- Adherence means taking doses of drugs and following the treatment plan- exactly as prescribed.
- Stake holders in the treatment program of CLHA are children, caregivers, counselors, medical team and community.
- The important 4 steps in adherence are: Education, preparation, monitoring and support.
- The 5 A's of Adherence preparation for child and the care giver:
 - **Assess**
 - **Advise**
 - **Agree**
 - **Assist**
 - **Arrange**
- To promote “good food and good medicine” concept
- Personalized medication administration as
 - **WHO** will administer the medicines?
 - **WHAT** medicines will be given / taken?
 - **WHEN** medicines will be given/ taken?
 - **HOW** the medicines will be given/ taken?
- Psychosocial Support within the family and community is very important for adherence
- Developing support systems within the community is the key for the success of adherence.

Activity 2 – Tools for adherence

Explain to participants the tools available to overcome the barriers like games, stories, role plays and counseling cards

- Divide the participants into small groups of 5-6.
- Provide one support tool for adherence (game/story/role play/counselling card) to be used among them and ask them to develop on the theme “Overcoming barriers for ART adherence”.

- Tool: My ART Calendar. Explain to the group the usage of the calendar as mentioned and ask at least two participants how they explain so that it is practiced. Present the tool to the total group and get the feedback on the tools.



- Group counseling card 1: ARVs Can Help Children Live Normal Lives- Follow the instructions on the card and ask one of the participants to practice it by explaining to the group.



- Group Counselling Card 10: Importance of Regular Visits to Medical Professionals-Show the card and encourage the participants to describe the picture, what it denotes and follow the instructions as mentioned on the card.



Handout

Adherence

Adherence means taking doses of medicines and sticking to the treatment plan as prescribed. This includes the correct treatment at right time and in the correct way- before or after the food, with fluids——

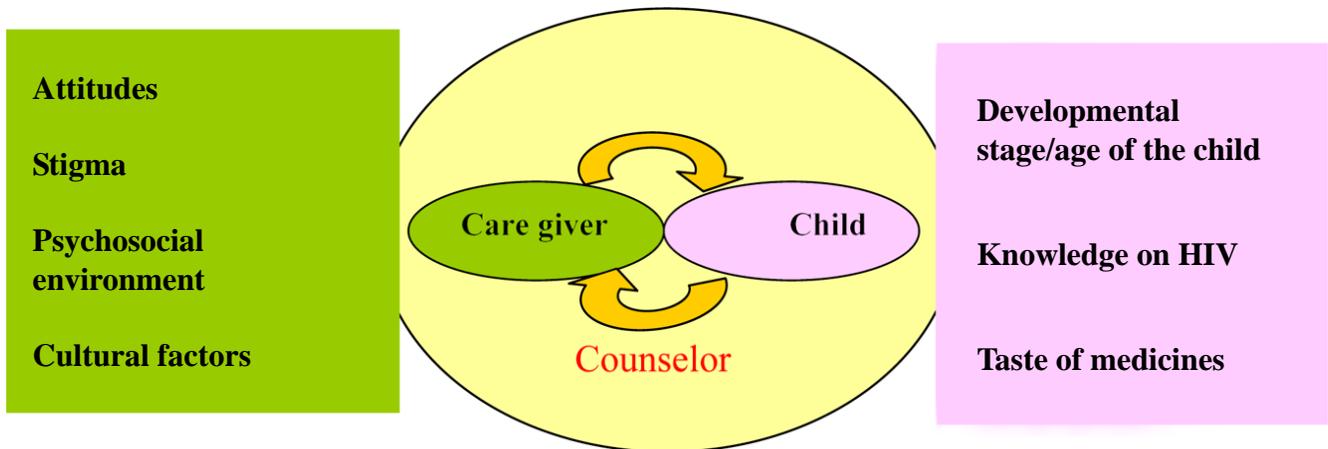
The important part of treatment involves making sure that they are effective and safe to use , avoid exposure to sunlight The problem with syrup bottles is, if the lids are not tightly closed after the use, the insects reach the syrup. If the tablets are kept open they may loose their potency.

Adherence Objectives

- Assessment of child and family
- Identify ways to prepare a family for ART adherence, monitor and support ART adherence

Stake holders in ART for children and the influences

The role of children and adults in ART for children is complex with multiple factors.



The care giver

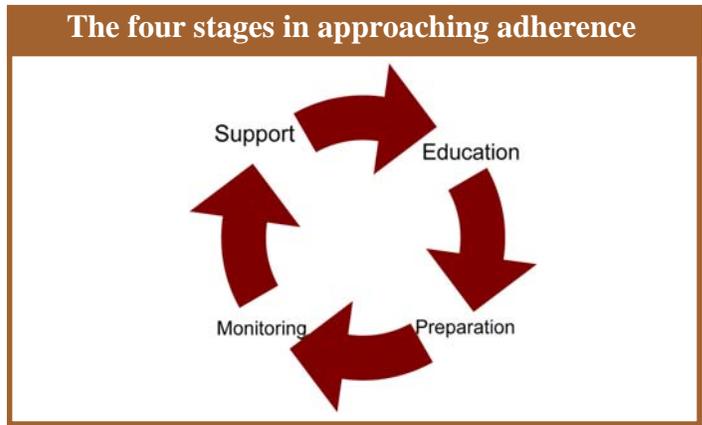
The care giver is a member in the child’s life who is committed to provide care to the child. This could include a parent / guardian / granny / NGO staff member / community member. It is crucial that the care giver has a thorough understanding of what is required of them and is committed for adherence.

A secondary care giver should also be identified in case the primary care giver is unable to perform their duties due to unforeseen circumstances such as illness, death.

Note: Take care that the person accompanying the child may not be the care giver; insist that the care giver accompanies the child to all adherence counseling sessions.

An Approach to Adherence

- **Medical assessment, testing and decision to initiate ART** is in the purview of doctors.
- **Promoting Adherence** is the responsibility of the team involved – family, counselor, NGO/ CBO.



a. Adherence Education

Adherence education is provided in every pre ART / ART / follow up session to the child and caregiver keeping in view of the child's age, psychological growth, health status and the existing knowledge/ compliance among the children and caregivers. Counselor's discretion is important in planning the sessions and information to be provided in each session.

The following issues are the key issues:

- **Importance of adherence:** Regular ART can improve a child's health, quality of life and enable them to live for a long time. Successful ART should result in reduction of viral load by ten-fold in the first eight weeks and then further to undetectable levels in 16-20 weeks (4-5 months). The rate of the viral load decline is affected by the baseline CD4 cell count, the initial viral load, the potency of the regimen, the adherence to treatment, prior antiretroviral medication use, and the presence of OIs.

A very high level of adherence (at least 95%) is necessary for ARV treatment to work effectively. Missing even a few doses can cause failure of treatment and drug resistance.

The child needs an adjustment period when starting a new therapy. This period usually lasts about four to six weeks when the body adapts to the new drug. **The first 2 months is crucial after initiating ART** and the child / family needs increased support and counselling. It should be noted that in certain regimens, missing doses can lead to the subsequent medicine having a sub-therapeutic effect and may lead to the premature development of a drug resistant virus.

- **Types of ARV medicines available in the ART centers and side effects:** The medical team is responsible for the knowledge building on medicines in the initial sessions and follow up by counselors.
- **Care giving to the sick child:** The role of counselor is in capacitating the older child and care giver on home care tips and supporting them during the difficult periods.

- **Identifying and linking CLHA to the support services:** Planning of support services through strong linkages and referrals with the child and caregiver is also needed from pre ART sessions onwards.
- **Strategies for adherence:** listing of strategies by the caregiver and child improves the acceptance of the long term treatment and also an alternate strategy is familiar to the caregiver if one strategy fails like,
 - Who can provide care giving in your absence? Identify the persons.
 - Which NGO is helping you now? Are there any other NGOs working in your area? Identify service providers.
 - And so on ..

b. Adherence Preparation

ARV treatment is rarely an emergency. So take time to prepare the child and the caregiver for a better adherence plan so the best result can be obtained with 2-3 pre ART counseling sessions. The preparatory phase is needed during pre ART sessions mainly. During ART and follow up sessions the preparation may be reinforced when missing doses is noticed. In the established incomplete adherence the sessions start again from the education and preparation.

5 A's of Adherence preparation

- **Assess** the child and care giver's goals; their understanding of the disease and the medications; their interest in receiving therapy
- **Advise** the child and care giver on HIV; the progression of the disease; the drugs and their possible side effects; adherence; and the need for ART therapy
- **Agree** to an adherence plan
- **Assist** the child and care giver in their planning and adherence to ART
- **Arrange** the initiation of treatment with the relevant people involved

Personalized Treatment Administration

To match the specific aspects of a child / family

WHO will administer the medicines?

- Mother/ father / grandmother/ extended family member/ volunteer

WHAT medicines will be given / taken?

- Familiarity with medicines to the care giver and child

WHEN medicines will be given / taken?

- Establish specific times and routines with child depending on the age and the care giver.

HOW the medicines will be given / taken?

- Details of administration
- One or two tablets
- Measured spoons
- Cutting and crushing tablets
- With or without food
- Taking pills together / taking with gaps in a sequence

• Preparatory process

Preparatory process for children can be done individually or in small groups. Participants in the group sessions need to be determined by age, level of understanding and development, the level of disclosure comfort. The preparatory process should include,

- Testing the taste / flavour of the medicines
- Direct Observation
- Training for pill swallowing
- Behavioral reward system – a chocolate or a biscuit (based on Cognitive behavioral therapy – consider the longevity of this method)
- Role plays as group therapy– ask the children to enact his/her behavior while taking the pills or avoiding the pills and ask questions as to why they do so. These role plays in small groups can give a very good response and often enables the child to remember that he/she has to take the medicines in spite of problems. The children tend to relate to the role play whenever they try to miss the pill.

• Concordance

Concordance refers to “the creation of an agreement between caregiver and healthcare provider about whether, when and how medicines are to be taken”. Concordance follow up is particularly important in the case of children, as their caregiver makes the agreement and so responsibility is often in the hands of others. The caregivers may change often and so the concordance is very difficult to follow up in ART to CLHA.

Good food, good medicines

The counselor should discuss the medicine as a part of their food by descriptions like “One pill before / after breakfast or another pill before /after lunch/dinner.”

c. Adherence Monitoring

One single strategy may not be applied in a multicultural, diversified county like India. Monitoring systems should take local issues; partners in to consideration and strategic monitoring plan should be devised by the team members involved in each child’s case.

- Emphasize the importance of honest reporting
- Importance of multidisciplinary approach to monitoring involving NGO/CBO/ Support groups/ Networks/ volunteers
- **The monitoring and assessment team:** A list of team members should be made. They should be notified, understand their responsibility and agree in full to the commitment. This list should be retained by the counselor (along with the information card) and the family, with the relevant contact details. All the members of the team involved should be clear about their roles so that there is no overlapping or missing links.

d Adherence Support

Lifelong adherence to complex regimens is an extremely difficult task which involves many partners. The primary care giver and team will play an important role in this. It is a process which requires constant follow-up and should be clubbed with the monitoring process.

- Strategies for Linkages in effective adherence
- Psychosocial Support within the family and community should be encouraged through disclosure of HIV status for adherence.
- Support groups enable normalization of the illness, encourage, facilitate, provide emotional support and create an environment in which children can voice their concerns. Care givers and grannies can also interact with each other. Adult Support Groups are useful for actual monitoring of pill intake- as in TB DOTS
- Buddies / children support groups can give emotional support.
- Religious leaders can play a major role in adherence through spiritual counseling
- Educational institutions also should be made aware of ART and support in educational institutions can make the adherence much easier as the children follow the teachers.

Strategies to ensure adherence

Strategies for Child/Family

The primary approach is child/caregiver education. Educating families about adherence should begin before ART is initiated and should include a discussion of the goals of therapy, the reasons for making adherence a priority, and the specific plans for supporting and maintaining the child's ART adherence. Strategies for adherence, education to caregivers should include the provision of information and adherence tools, written and visual materials, a daily schedule illustrating two doses of medicines and pill boxes. These adherence tools are of general benefit, should be considered for all caregivers and especially emphasized for those caregivers who are neurologically or cognitively impaired. **This is of much greater concern with orphan children living with HIV/AIDS either in a child headed family or with a granny.**

In addition to caregiver education, a number of behavioral tools can be used to integrate treatment into the HIV infected child's daily routine. The use of behavior modification techniques, especially the application of positive reinforcements and the use of small incentives for taking medications can be effective tools to promote adherence.

In cases of non-adherent children with significant behavioral problems which interfere with the child in taking medicines as per the dosage, support meetings structured to discuss such problems and identify potential solutions can be helpful. In the cases of medical, psychological or social impairment of the caregiver, a nurse / NGO staff can support adherence by visiting the home and making assessments, providing education and directly observing dosage.

Strategies for Healthcare Provider

While many aspects of adherence seem outside the realm of control, providers have the ability to improve adherence through their own behaviors. This process begins early in the provider's relationship with the family when the clinician/counselor obtains explicit agreement to the treatment plan and any further strategies to support adherence. Abilities to foster a trusting relationship and engage in open communication are particularly important. Provider characteristics that have been associated with improved adherence in children include consistency, giving information, asking questions, technical expertise and commitment to follow-up.

Strategies for NGOs

NGOs working with children in Home and Community Based HIV/AIDS Care, Support and treatment have to develop strategies to address adherence to ART. Children support groups/ buddy groups can help in monitoring the adherence to ART.

NGO facilitated Community structures (adult support groups, children support groups, youth clubs, women self help groups and grannies clubs) and religious leaders can be effective in improving the adherence to ART by children and the counselor has to utilize the community structures.

Session 3: Incomplete Adherence

Aim

At the end the session, participants will be able to :

- Acquire knowledge on issues related to incomplete adherence
- Understand possible modes of dealing with child on ART
- Use with the interactive tools

Methodology

- Interactive PPT presentation
- Question and answer session

Time: 15 minutes

Materials needed:

- LCD
- Charts and pens
- Power point presentation
- Handout

Notes for Facilitator

Counselor guides the participant towards the importance of identifying the adherence failure to ART drugs.

Activity 1 – Barriers to adherence

Divide the participants into pairs. Give each pair a sample prescription. Ask the pairs to imagine that they are a person on ARV treatment and that they must follow the treatment as outlined on the prescription.

Ask the participants to imagine honestly and sincerely how this treatment fits into their lifestyle when to take the doses, food etc. They should take into account their current work, social and family situations. They should discuss when and why they think they would find it difficult to adhere, as well as the difficulties that could arise, and note down.

Go around the group and ask each pair to list the difficulties they noted in being adherent on a daily basis.

- Why do these difficulties arise when taking the treatment?
- What reasons would result in skipping a dose or reducing doses (not being adherent)?
- Note down these obstacles on a flip chart, which has to be used as ‘fact sheet’ further in the session.

Present the fact sheet ‘Barriers to adherence’ show the different categories and discuss any other factors that have not been mentioned already by the participants. Discuss any other important obstacles that have not come out of the discussions in pairs.

Essential Information

- **Identify specific barriers to adherence**
- **Begin with counseling for adherence**
 - Adherence education
 - Adherence preparation
 - Adherence monitoring
 - Adherence support
- **Be aware of adherence fatigue**

Handout**Assessing Incomplete Adherence****Review current regimen**

Inquire about problems administering medications – obtain a personalized **descriptive** assessment

Review **WHO, WHAT, WHEN, HOW** the drug administration is observed.

Addressing Adherence Barriers**Identify specific barriers to adherence**

- Consider reviewing the current regimen if the barrier is related to a specific drug
- Identify barriers within the family, where the child is orphaned and the adult care giver is no longer with the child; the orphan has migrated to live with an extended family member/ granny; the adults feel that the child is ‘cured’ after a certain period and have stopped the treatment, etc
- Identify economic barriers
- Assess the child’s life in Toto when looking for barriers – sometimes the reason may not be obvious

Address cultural barriers to adherence

- Gender issues where the girl child is neglected
- Religious issues to be discussed – auspicious days where the drugs are not taken food and medication and so on due to fasting. **Taking drugs without missing a dose is the religion for children on ART; this needs to be instilled in them and religious issues need to be discussed with the family.**

Follow up by ART staff, health care professional or NGO staff

Home visits

A nurse, social worker or staff of HCBCS programme staff member needs to visit the children weekly if adherence problems are suspected. Home visits are very useful and bring support to the home environment.

(Please refer to NACO Module 5, sub-module 2 – The purview of counselling in HIV/ AIDS Home based care)

Begin again for promoting adherence

- Adherence education
- Adherence preparation
- Adherence monitoring
- Adherence support

Adherence Fatigue

- Do not assume “once adherent, always adherent”
- It can be anticipated that with time:
 - Children may tire of taking medications
 - As the child grows, attitudes may change and feel ‘bad’ for being the one who has to take pills within their peer group.
 - Caretakers may tire of administering/supervising medication
 - Providers may tire of monitoring/supporting adherence
 - NGO/CBO and others may phase over from the areas or have funding redistributed

Beware of adherence fatigue! This is very common in all chronically ill people who get fed up and stop bothering about the disease anymore and are psychologically ready for the ‘end’.

Causes of adherence fatigue

- Prolonged stress in the patient
- feelings of dejection (loss of interest, difficulty in concentration, lethargy and feelings of hopelessness), anxiety, fear and psychological distress
- Side effects of the medication
- Side effects of the illness – e.g. anemia
- Sleep disturbances
- Excessive inactivity
- Pain
- Opportunistic infections
- Nutritional depletion (altered ability to process nutrients, increased energy requirements, nausea, vomiting, diarrhea,
- Moods, beliefs, attitudes and reactions
- Environmental and social factors

Assessing adherence fatigue

- When the fatigue was first noticed, and how long has it been prevalent?
- What is causing the fatigue?
- How is the fatigue affecting adherence to treatment?
- How can this be addressed?

Intervening – What can be done to address the fatigue, and ensure adherence to treatment?

- Counseling
- Increase the community support
- Nutritional interventions (high protein foods)
- Treat opportunistic infections and side- effects
- Exercise and recreational activities
- Provide the client with psychosocial-education
- Suggest individual activities and environmental changes that may reduce fatigue
- Address the negative impact of social and psychological stressors
- Evaluate the efficacy of fatigue intervention strategies on a regular basis

Session 4: Review

Aim

At the end the session, participants will be able to :

- Review the session on ART adherence among children

Methodology

Brainstorming with the participants

Time - 10 minutes

Materials needed

Charts and pens
Power point slides

Notes for the Facilitator

The Facilitator should get unbiased information on the session through interaction. If the Counselor feels that the participants respond better if an evaluation form is provided then the idea can be followed up.

Activity

- Question and answer session:
 - what is most useful information in the session
 - Is the content relevant?
 - Is the handout useful for the future reference?
 - How is the facilitation?
- Power point slide with activities