

Module 7: Psychosocial Support Issues in Pediatric HIV

Session 1: Psychosocial Problems in Paediatric HIV



Total Session Time: 45 minutes

Learning Objectives

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

- Identify causes of psychosocial problems related to HIV in children
- Describe psychosocial manifestations in children affected by HIV
- Describe psychological assessment in children affected by HIV
- Describe psychological support and social interventions

Causes of Psychosocial Problems Related to HIV in Children

The following are the causes of Psychosocial Problems Related to HIV in Children

- Cultural factors
- Socio-economic factors
- Spiritual
- Psychological
- Stress and the immune system
- Complications of treatment

Cultural issues may impact communication patterns, attitudes toward HIV infection, and willingness to access social and psychological support systems.

Abnormal Psychosocial Functioning in HIV Affected Children

Manifestations of abnormal functioning:

- Physical
- Behavioural
- Emotional
- Cognitive
- Social

Physical Manifestations

- Multiple pains
- Abdominal pain
- Headache
- Chest pain
- General malaise
- Fatigue

REFER to Handout 6.2.1: Physical, Emotional and Cognitive Development of Adolescents in the Participant Handbook.

Behavioural Manifestations

- Restlessness
- Hyperactivity
- Withdrawal & self-neglect
- Aggressiveness
- Sleep disturbance
- Acting out
- Stealing
- Bed wetting
- Refusal to eat or taking medication
- Refusal to go to school
- Drug abuse and sexual promiscuity

Cognitive Manifestations

- Lack of concentration
- Regression of milestones
- Forgetfulness or poor memory
- Confusion
- Poor academic performance

Emotional Manifestations

- Irritability
- Lack of interest in surroundings
- Depression, sadness and mood changes
- Suicidal tendencies
- Anxiety, fear and anger
- Temper tantrums

Social Manifestation

- Older children
- Low social esteem
- Social withdrawal and isolation
- Antisocial behaviour

Neuro-Psychiatric symptoms

- Anxiety, aggression, depression
- Forgetfulness, confusion
- Agitation, disorientation
- Hallucinations, delusions
- Memory loss
- Personality change

These neuro-psychiatric symptoms can occur due to the damage to neurological system that can be caused by HIV disease.

REFER to Handout 6.2.1: Physical, Emotional and Cognitive Development of Adolescents on page XXX in the Participant Handbook.

Psychosocial Assessment

Definition

A formal evaluation of an individual or family intended to clarify their non-medical needs and priorities. Non-medical needs include social, physical, spiritual etc. It is important for diagnosis and documentation of issues of concern and referral purposes

- Assess
 - Individual child
 - Caretaker and family
 - Household
 - Extended family strengths and supports
 - Resources, needs
 - Community based supports
 - Schooling
 - Spiritual/religious influences
- Assessment is recommended to be conducted at, First visit and again at each follow-up visit as needed. Provider must be fully aware of all aspects of the patient's treatment, stage of the illness and readiness for ART
- Assessment if performed by
 - Trained providers
 - Close family members and care givers staying with children are of great help when performing psychosocial assessment

Types of Psychological Support and Social Intervention

- Psychotherapy
- Play therapy
- Family therapy
- Group therapy
- Support groups (e.g. post-test clubs)
- Spiritual counseling

Psychotherapy

A process between therapist and a child where the child and his/her family are assisted to acknowledge, comprehend, understand and adjust through their feelings, thoughts and behaviour to handle a problem. One-on-one (i.e. between the therapist and the child) is a more intense type of intervention.

Family Therapy

A counselor works with the whole family for the benefit of the child, taking into consideration the family systems, social and cultural values and the environment

Group Therapy

This is a therapeutic process between a counselor and a group with common problems. The group benefits from sharing experiences, learning from others and personal interaction. Group therapy involves a counselor and a group of clients with common problems.

Support Groups

This is an informal group made of clients/patients with similar problems. Not necessarily structured, Can be open or closed. It is a common psychosocial intervention offered to willing participants. Important to prepare the clients in advance. A support group is an informal group made of clients/patients (not with counselor/health care worker) with similar problems.

Play Therapy

This is a therapy directed through play and games using toys and other tools or appropriate media. Art therapy is directed through drawings and paintings

Spiritual Counseling

Spiritual counseling should be explored as part of HIV prevention and care. Chronically ill patients often lose hope and the will to live. Reassurance and spiritual care can help to relieve these concerns

- Spiritual counseling can help to prevent HIV infection by emphasizing risk reduction
- Faith based organizations and religious leaders in the community should be involved in spiritual counseling

Spiritual counseling is accepted positively by many people.

Key Points

- HIV-related psychosocial problems in children result from many different causes
- Psychosocial abnormalities may have physical, behavioral, emotional and cognitive manifestations
- A psychological assessment is a formal evaluation intended to identify a person or family's non-medical needs & priorities
- There are several different types of psychological support and social intervention

Session 2: Communication and Counseling in pediatric HIV



Total Session Time: 90 minutes

Learning Objectives

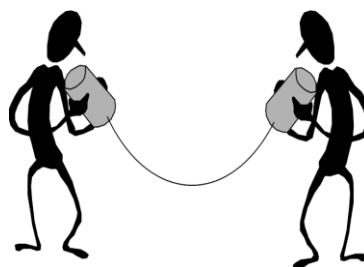
By the end of session, participants will be able to:

- Describe effective communication with children
- Describe counselling
- Describe considerations for counselling children
- Describe methods to help children express themselves
- Describe steps in counseling children

Definition of Communication

Is the process by which information, meaning and feelings are shared by persons through the exchange of verbal or non-verbal messages. It is the transfer of information from one person to another for the purpose of sharing an idea or information. .Communication is the process of exchanging:

- Information
- Thoughts
- Feelings
- Ideas
- Instructions
- Knowledge



Types of Communication

Communication can be:

- **Verbal:** through spoken words (7-11%)
- **Non-verbal:** (89-93%)
 - Gestures (smiling, leaning forward, nodding)
 - The way we stand
 - The way we sit
 - Facial expressions
 - Silence
 - Eye contact

Considerations for Communicating with Children

- Should take into account the child's level of development
- For older children, their personality traits should be considered (e.g. anxious, shy, inhibited, assertive, suspicious)

Key Principles of Effective Communication

- Questions should be open-ended
- Recognize, respect and acknowledge the child's viewpoint and worries

- Meet the child at their level, help them express themselves
- Communication is two-way
- Listen to the child's view point and accept their emotions. The health care provider could be a barrier of communication to children.
- Use reflective listening – look for emotional meaning behind words, identify the feeling and feed it back
- Make eye-contact
- Observe what children do ('non-verbal' communication), as well as what they say
- Allow the child to communicate and follow through – do not interrupt
- Make empathic comments, encourage, give prompts
- Respect the growing need for privacy as the child grows
- Establish boundaries of confidentiality with the child, e.g. they may not wish to discuss certain things in the presence of parents

Methodologies to Help Children Express Themselves

- Make-believe play
- Stories
- Toys
- Drawings and pictures
- Games, music and dance
- Psychodrama about real life experiences
- Support groups

These methods mimic games, and when properly used, they can help children express themselves.

Joining

is a process that enables children to feel comfortable in communicating with someone in a counselor/helper role. The activity should be comfortable for provider and the child or adolescent. Main tips in joining:

- Non judgmental attitude
- Put oneself at the level of the child
- Listen with open eyes!

In essence, "joining" means meeting the client where they are at, or bringing the interaction to the client's level.

Joining Effectively with Children and Adolescents

- Introduce self as a person who talks to and helps children
- Take some time to get to know the child
- Play a game
- Have a friendly conversation
- If child is not verbalizing, divert and introduce the child to other materials in the communication
- Allow child to explore toys/activities/room at his or her own pace.
- Ask about the demographic data of child
- Name, age, no. of siblings, school, favorite food, parents, best friends
- Don't rush when working with the child.
- If provider is impatient, the child will sense this!

REFER to Handout 7.2.1: Examples of Children’s Drawing in Therapy on page 285 in the Participant Handbook for some examples of other communication techniques with children.

Counselling in Children

Counselling of Children in the Context of HIV

HIV counselling is the application of general principles of counseling to facilitate a child’s ability to cope with issues and concerns arising from HIV infection. Includes Pre-test, Post-test, disclosure and adherence counseling. Is often an ongoing process. Cue cards for counseling should be prepared before discussing with client. Whenever possible parents should be involved.

Counselling

- Establishing a helping relationship with children
- Helping children tell their story
- Listening attentively to children
- Giving children correct and appropriate information
- Helping children make informed decisions
- Helping children recognize and build on their strengths
- Helping children develop a positive attitude towards life

Requirements for Counselling Children

- Parent or guardian should be available to give consent
- Clean room with child-friendly colours, pictures, toys and drawing paper
- Mat, carpet or floor
- Relevant story books
- Space for family

It is very important to prepare in advance for counseling children, including setting up the facility environment to be child-friendly.

Process of Counselling

- Joining Phase (begins in 1st session)
- Prepare for 1st session
- Consider: What is my goal for this session?
- Do this for every session
- Create a child-friendly environment
- Welcome the child & caregivers; help them to feel comfortable
- Ensure confidentiality
- Give information about services available

It is very importance to prepare the enabling environment during counseling of children.

Exploration Phase

Gather everybody’s perspective on why they are here today

- Ask: What brings you here today?
- Gather history: Find out about child’s background, guardianship, schooling, social, family, community & spiritual supports

- Discuss the current problems: Obtain everyone's perspective
- Identify what the child knows about the illness
- Explore with caregivers the modalities of counseling the child & family: Time and place
- Build the treatment alliance
 - Let family know we are working together as a team
 - Let them know that they are the experts on their child! It is important to probe children about their personal knowledge on his or her illness.

Understanding Phase

This is a working stage

- Provide age-specific information
- Ask for and respond to questions
- Discuss beliefs, fears, misconceptions and myths which might contribute to the problem
- Utilize active listening skills
 - Actively listen to what child/caregivers are saying and paraphrase. “What I hear you saying is...”
- Encourage family involvement in sessions

Action Phase

- Make predictions about and explore upcoming difficulties, discuss solutions and strategies for such situations
 - Role play difficult scenarios with caregivers
 - Always monitor for emerging psychological symptoms
 - Discuss importance of follow-up visits for treatment & counseling sessions
- Role play should be innovative depending on the child or caregiver.
- Encourage family members to access additional treatment supports
 - e.g. support groups for child & caregivers
 - Make referral to psychiatrist or mental health professional in case of severe psychological symptoms or suicidal ideas
 - Set times for subsequent follow-up counseling sessions
 - In the absence of the child, assess current state of the disclosure process with the caregiver or parent
 - Encourage caregivers to initiate & proceed with disclosure with child
 - Coach caregivers through this process (this process will take time, don't rush)
 - Discuss difficult issues & barriers to disclosure
 - e.g., fears, stigma, cultural beliefs, loss of family/community support
 - Counselling for Children infected with HIV
 - HIV counselling is conducted for children of several different categories:
 - Child with unknown HIV status with clinical signs or risk factors
 - Child with known HIV status
 - With poor response to treatment
 - With good response to treatment

Counselling child with unknown HIV status with Clinical signs or risk factors

Step 1:

- Ascertain the relationship between child & caregiver
- Ascertain child's & caregiver's understanding of reason for referral

- Discuss the presumptive diagnosis of HIV in light of existing signs and symptoms
- Explain the benefits of early awareness of HIV status for child and family
- Request permission from caregiver to arrange for HIV test
- Counselling child with unknown HIV status with clinical signs or risk factors (2)

Step 2:

- If parents refuse or decide to postpone the test, accept their decision and reassure them
- Inform them that their decision will not compromise the management of the child's current condition
- Emphasize that they will miss the opportunity to plan for the child's optimum care and support
- Review decision at subsequent visits

Counselling child with known HIV status with poor response to treatment

Step 1:

- Ascertain child's & caregiver's understanding of the HIV infection and specifically MTCT
- Discuss the management of current problems and the reasons for poor response to treatment
- Assess adherence to medication

Step 2:

- Refer child for further investigations and community-based or home-based care program, if necessary
- Discuss psychological implications of HIV for the parents and other family members
- Provide continuing psychosocial support on coping with a chronic illness such as HIV

Counselling child with known HIV status with good response to treatment

- Discuss follow-up and care
- Risk factors for future illness
- Discuss shared confidentiality
- Social well-being of the child and family
- Adherence counseling
- Refer to support groups and post test clubs where available

Challenges of Counselling Children

- Not encourage children to talk about themselves
- Children finding it hard to talk about their feelings because they don't know the counsellor well
- The adult talking too much
- Being critical, judgmental, aggressive or harassing discourages communication
- Adult making child uncomfortable by
- Laughing or humiliating a child
- Getting upset or arguing
- Being uncomfortable or embarrassed when a child is upset
- Not respecting the child's beliefs

- For example, in a healthcare setting or even during home visits, we often get information about children through third parties, like caregivers, even when the child is present and able to provide the same information.
- Cultural and traditional factors may contribute to this difficulty in communicating.
- A girl who was raped, for example, may feel comfortable talking about it only to her grandmother or, in her absence, to an older woman.

REFER to the following handouts to see more examples of children’s drawings in therapy:

- **Handouts 7.2.2: The Story of Miki** on page 287 in the Participant Handbook
- **Handout 7.2.3: The Orphan Head of Family** on page 289 in the Participant Handbook

Drawings can be used as a way to facilitate communication in counseling for children.

Key Points

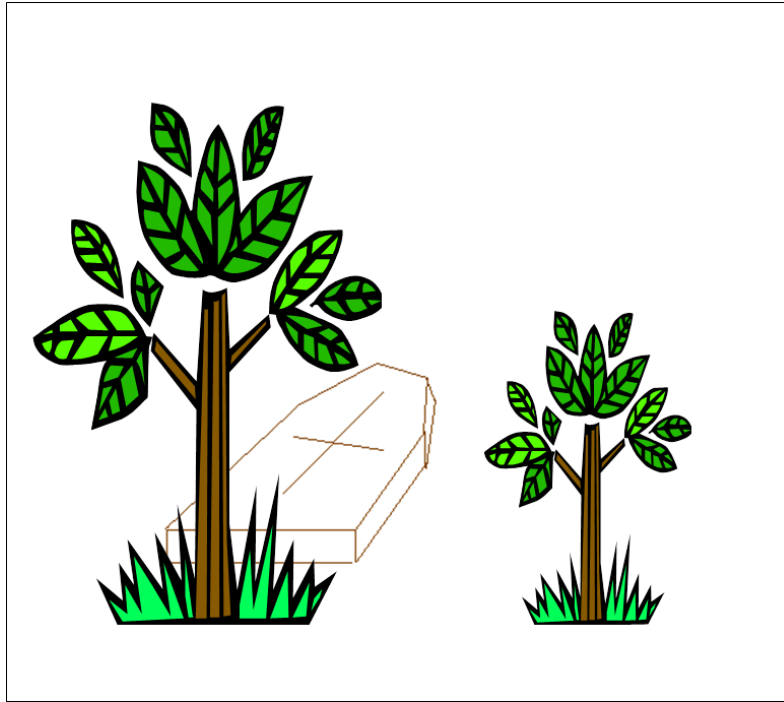
- Communication with children requires understanding their thoughts and feelings
- Effective communication is the foundation for establishing a helping relationship with the child & family
- Counselling aims to help child & family cope with the many emotions of HIV and AIDS
- Counselling should be done in the presence of the parent or caregiver



Handout 7.2.1: Examples of Children's Drawing in Therapy

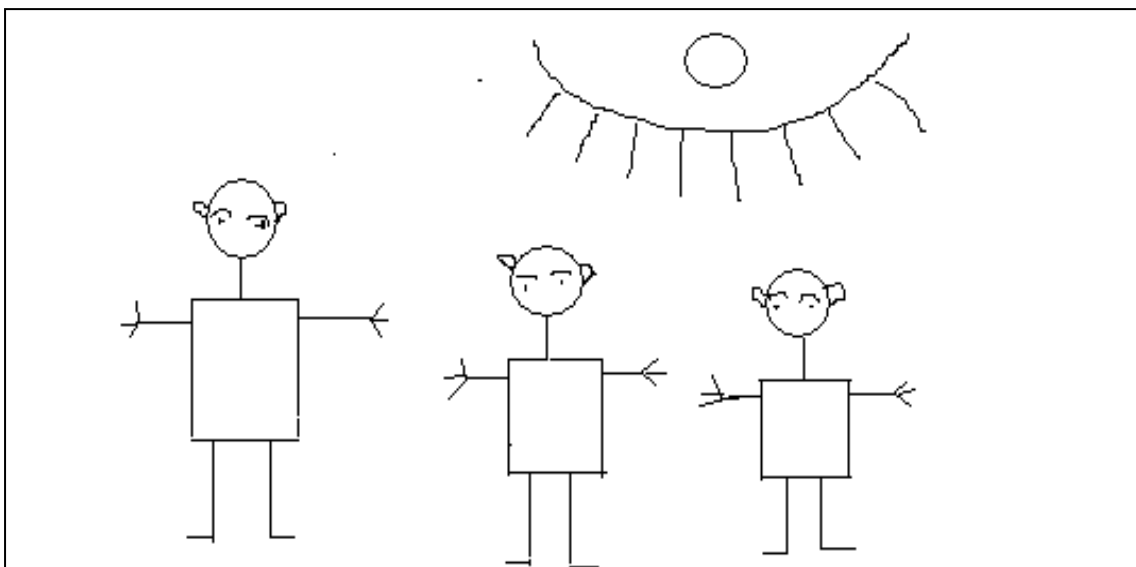
Example 1:

Representation of a child who has lost a parent but could not articulate

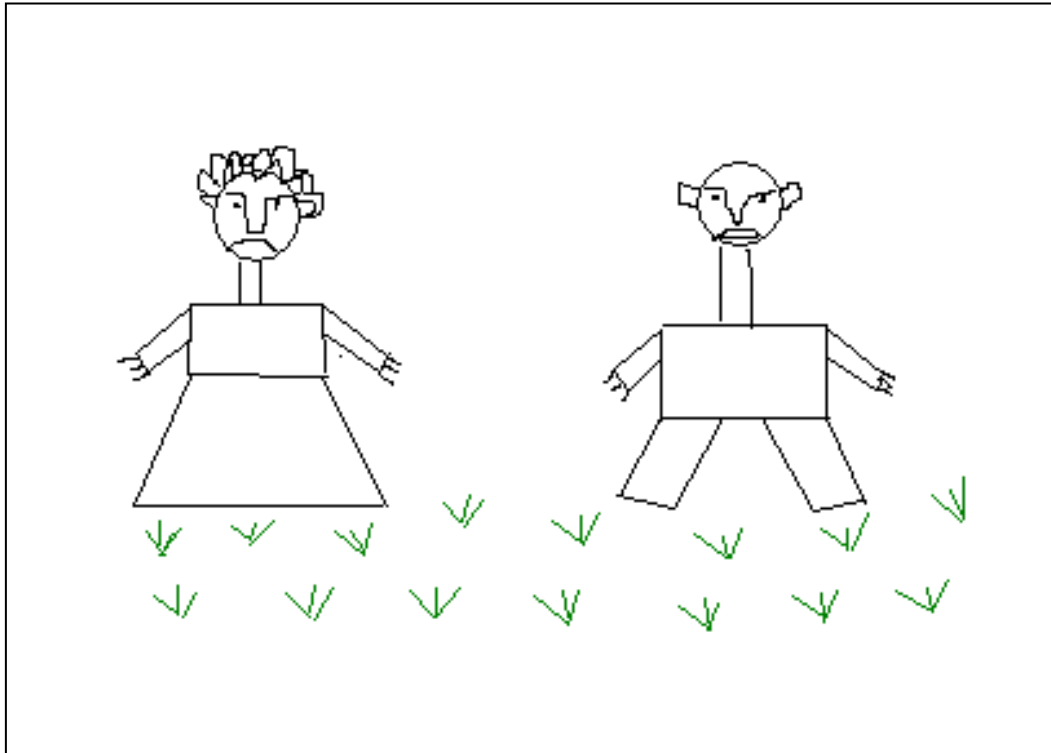


Example 2:

Overwhelming emotions and guarding against external emotions



Example 3:
Child who is chronically ill and deteriorating and is losing control





Handout 7.2.2: The Story of Miki



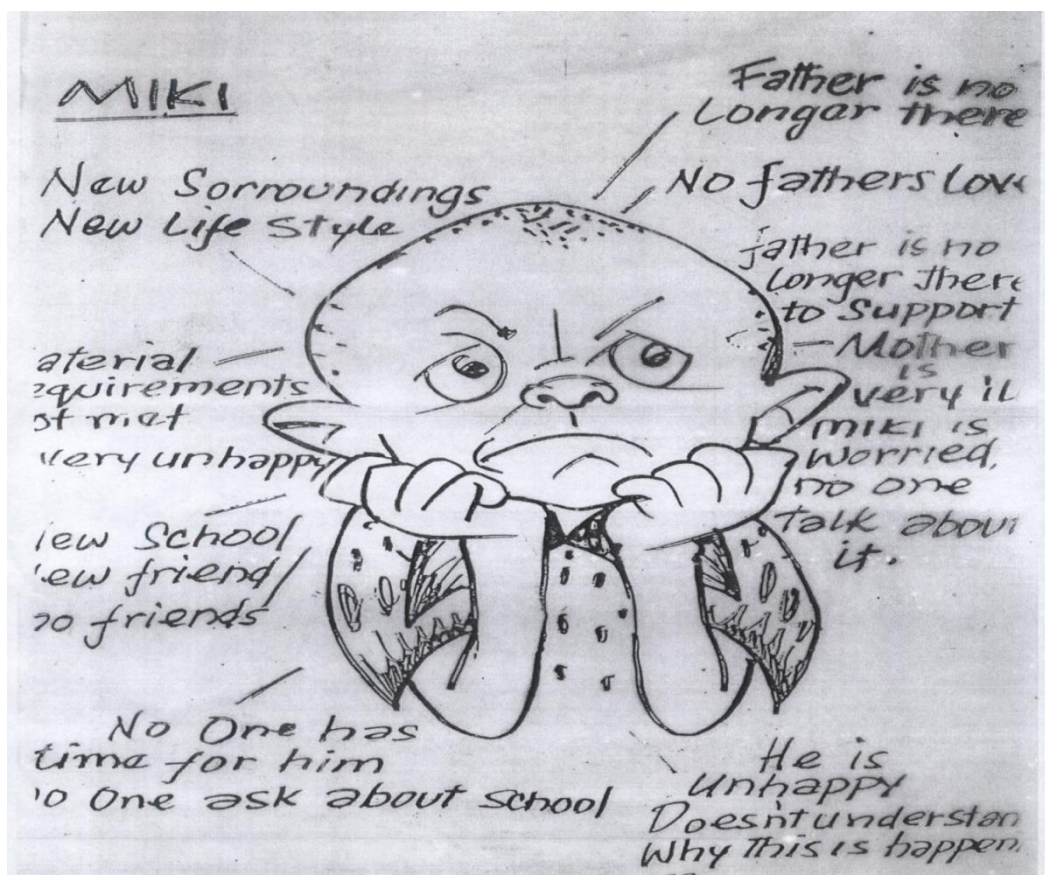
The family was living in town and parents of Miki were working, had a good income and were living in a nice house. Children had good care.



Miki's father passed away and children and other family members are seen mourning.



After the death of Miki's father, since the mother was not employed they had to vacate the house and moved to the village.





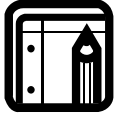
Handout 7.2.3: The Orphan Head of Family



Soon Miki's mother passed away and her sister had to assume the role of a mother and take care of her younger siblings at the same time she had to continue going to school.



Miki's sister is late at school because had to prepare porridge for her young siblings but her teacher does not understand and he starts beating her.



Worksheet 7.2.1: Case Studies for Counselling Children with HIV

Instructions:

- In small groups, read the case studies below and answer the questions.
 - Be prepared to share and discuss your responses in plenary.
-

Case Study 1: Malia

Malia is 14 years old. Her parents have both died, and she is the head of the household taking care of 3 younger siblings. She is trying to stay in school, but she cannot earn money if she stays in school. She has been getting sick frequently and goes to the doctor with a severe case of malaria and a bad cough.

1A. What category of HIV-infected child does Malia pertain to?

1B. As Malia's health care provider, what are the steps that you would take in counselling her?

1C. Summarise the phases that you would pass through when counselling any child.

Case Study 2: Bobby

Bobby is 7 years old. He was born with HIV, and his mother passed away shortly after he was born. He has been taking ARVs for most of his life, and he is not growing as he should for his age; he appears to be much younger. He frequently gets sick, and his grandmother (his caregiver) is very worried about him.

2A. What category of HIV-infected child does Bobby pertain to?

2B. As Bobby's health care provider, what are the steps that you would take in counselling him and his family?

2C. Summarise the phases that you would pass through when counselling any child.

Continued on next page

Case Study 3: George

George is 11 years old. He loves playing soccer and running. He is in the normal height and weight range for his age. He does very well in school and enjoys spending time with his friends. He was born with HIV, and has been taking ARVs for most of his life.

2A. What category of HIV-infected child does George pertain to?

2B. As George's health care provider, what are the steps that you would take in counselling him and his family?

2C. Summarise the phases that you would pass through when counselling any child.

Session 3: Disclosure



Total Session Time: 90 minutes

Learning Objectives

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

- Define disclosure
- Explain the different levels of disclosure
- Discuss the advantages and challenges of disclosure
- Describe strategies to facilitate disclosure for children infected with HIV

Definition of Disclosure

Disclosure is the act of informing an individual or organization of the HIV sero-status of an infected person. A client who tests HIV positive has the right to privacy, as well as the right to exercise informed consent in all decisions about disclosure in respect of his/her status. Organisations for disclosure include the health authority, an employer or a school.

Disclosure in Children Infected with HIV

Disclosure is an integral part of comprehensive paediatric HIV and AIDS care. It is a slow process, part of counselling which starts with first contact.

Levels of disclosure:

- Disclosure of the child's HIV diagnosis to the child
- Disclosure of the HIV status of the parent(s) or siblings to the child
- Disclosure to others in the family, school, community

Advantages of Disclosure to Children Infected with HIV

- Empowers the child to participate in healthcare
- Enables choices and self protection
- Increases hope as disclosure is accompanied with information about healthier living
- Reflects a child's individual rights
- Improves adherence
- Greater ability to cope and support each other, especially as the disease progresses
- Increased openness between parent and child
- Often results in stronger family ties
- Parents feel relieved of the burden of keeping a secret, less anxious about medical visits and the possibility of accidental disclosure
- Prevention of transmission of the disease to other people in the family / community

Several studies show that increased knowledge and understanding about HIV helps to:

- Facilitate children's adjustment within the family, to the illness itself, within society and its views and to treatment regimens
- Boost self-esteem

- Increase adherence to medications, treatment regimens, scheduled outpatient clinic visits, and hospitalizations
- Decrease risky behaviours especially for adolescents e.g. unprotected sex, multiple partners, and intravenous drug use
- Builds stronger family ties to tackle more challenging issues in the future

Disadvantages of Non-Disclosure

The negative consequences of non-disclosure include

- Children will sense that something is not right
- Impaired understanding of HIV
- Poor health maintenance e.g. personal hygiene
- Less participation in treatment and poor adherence
- Increased psychological and behavioural problems
- Decreased desire to access support services
- Continuation of risky behaviours

The consequences are very risky if the child accidentally finds out that s/he has HIV infected

By not talking to the child about his/her health the child will feel like:

- Something is wrong
- Something bad happened and it is child's fault.

Barriers to Disclosure

- **Individual:** Self blame, anxiety, cognitive capacity and development stage, too sick
- **Caregiver:** Fear of isolation, belief that child is too sick or small to receive the information
- **Healthcare provider:** Lack of skills, hesitant to address disclosure
- **Social-cultural:** Stigma, discrimination, taboos and religion, discussion of sexual issues with children
- Parents feel protective responsible, guilty, to blame for their children's HIV infection
- Fear of the child's reaction: anger, negative impact on will to live, not able to control what the child will say to others
- Parents must cope with their own illness and declining health at the same time

HIV positive parents often feel shame or guilt for passing on their "illness," the HIV virus with all its social and medical problems, to their children. As an attempt to decrease their own pain and suffering, they unconsciously or consciously avoid discussing HIV with their children. At the same time parents are worried that the young children will discuss their HIV status openly, innocently, regardless of social context. So they want to protect children from social stigma of HIV.

Approach to Disclosure

All children need information about their health Telling a child that s/he has HIV is important but before doing it, think about:

- **When** to tell the child?
- **What and how much** to tell the child?

- **Who** should tell the child?
- And **how**? (the 'how' especially matters)
- And **to who else** is disclosure to be done?

Disclosure: When to tell the child

- Depends on individual child's understanding and emotional maturity
- For most children the process can begin from about 5-7 years of age
- Readiness & comfort of parents is also key
 - Delay disclosure in children with severe emotional disturbances
 - Children who ask direct questions are ready to hear about their diagnosis

The 'right time' may never come

To determine the proper time to disclose, one must assess:

- Caretakers' readiness to deal with situation
- Cognitive and emotional status of the child
- Family's communication style
- Community relationship
- Additional potential stressors
- Individualized approach

One should disclose over time to allow slow processing and understanding, but should be complete and answer all questions with each informational session

- Children's understanding of their illness does not start at a particular age but becomes *more sophisticated with age*.

Disclosure: What and how much to tell the child

Take time to think about what you will say:

- Depends on age and how much a child can understand
- Give a young child simple information
- As understanding increases, give more details
- Be guided by the child's questions and body language
- The child's actions and questions provide opportunities to talk about his/her health

Children do not need to understand the specifics of the diagnosis, but its effect on their life and the illness manifestations. Disclosure should be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances.

Disclosure: How to tell the child

- Help parents understand importance of giving information to the child
- First get parental consent to discuss sensitive information with the child
- During disclosure do not start by using the words 'HIV,' 'AIDS' which have little meaning for a young child

Never Lie to a Child

Give the information in a hopeful/positive way

- Example: For a 4 year old: ‘you have a problem with your blood and need to take medicines to keep you healthy’

Disclosure is an ongoing process

- It starts with simple explanations, which are built upon with increasing complexity and sophistication as the child grows older. Works best if started when child is young
- The rate at which information is shared will depend on the individual child and circumstances (medical, social, family etc.)
- There are specific events which punctuate the process, such as ‘naming’ HIV which carry particular significance
- Giving the diagnosis is not an end point, but a starting point for continuing discussion about HIV and its implications
- Keep giving the child information about HIV whenever there is an opportunity
- Parents will also need:
 - Support to cope with managing the process of disclosure
 - To manage disclosure of their own diagnosis
 - Access to peer and other support

Disclosure: Who should tell the child?

- Ideally parents should be the ones to tell their children their HIV-infections status.
- Parents may need or request support of a counsellor
 - Responsibility for initiating the conversation about what children need to know about their condition sometimes lies with professionals
- Health workers should advocate that all children need to be given developmentally appropriate explanations for events like clinic visits, blood tests, medications etc. Counseling should be done for parents and guardians by a knowledgeable health care professional about disclosure to the child of their infection status.

Actual Disclosure Process

Goal: For child and family to fully understand child’s HIV status

- Is a lengthy process of addressing barriers (stigma, cultural beliefs, fears) prior to disclosure occurring
- Caregivers require ongoing supportive coaching leading to actual disclosure
- The health care provider should be available to coach them through this process
- Explore what the child and caregiver know about HIV, then move from the known to the unknown
- Child may already have some knowledge of his/her HIV status, unknown to the caregivers
- When ready, always encourage parents/ caregivers to initiate/lead process of disclosure with their child
- Be ready to deal with denial, distortion, fear, outbursts, pain and/or tears from child and caregivers

- Allow clients to move through this process at their own pace
- Discuss the pain and distress after disclosure
 - Otherwise, pain will become internalized
- Assess emerging psychological symptoms regularly, particularly during and after disclosure process
- Health care provider should be available and offer continued support
- Discuss the importance of having a continued counseling sessions on regular basis
- Predict and plan for difficult situations involving the post-disclosure period

REFER to **Worksheet 7.3.1: Roles Plays for Disclosure** on page 299 of their Participant Handbook.

Possible Questions and Answers on Disclosure to Children

- Why do I have to go to the doctor/clinic so much?
 - ‘The doctor wants to see how big you are getting’ ‘The doctor wants to see how well your medicines are working’
 - ‘The doctor wants to keep you healthy’
- Why do I have to take medicines?
 - ‘The medicines you take will help you to stay healthy’

These questions are common questions that a child with HIV might ask his/her parent or caretaker. The responses provide an example of what someone could say.

Sample Questions on Disclosure to Children

- Will I get an injection? Will it hurt?
- Why am I smaller than xxx (her best friend of the same age)?
- Why do I have HIV?

Disclosure of the infected child to siblings

Other children will sense that something is wrong with their sister/brother/parent They need to know that:

- They did not cause the problem
- They will not catch HIV from the person by playing together, sharing toys, etc.
- The sister/brother/parent is getting good care from the doctors and nurses

REFER to Handout 7.3.1: Tools to Assist Disclosure in Children on page 299 in the Participant Handbook to see pictures that can be used for explanation to children during disclosure.

Tools to Assist in Disclosure for Children

Example of Sequential Disclosure and Empowerment of Children

- Know that your medicines make you healthy by increasing the ‘good soldiers’ in your body
- Recognize that your health problems are fewer or will be fewer because you have more ‘good soldiers’ and they are stronger



The picture and text on the slide is an example guide of a way to introduce disclosure to children using illustrations and description.

- Know that as long as you keep your ‘good soldiers’ strong, you can do whatever you want in life
- Know that your ‘good soldiers’ became weak because some ‘bad soldiers’ were attacking them (can use ‘virus’, or other terms as appropriate for the child)
- Learn the “proper names” for ‘good soldiers’ (CD4 cells) and ‘bad soldiers’ (HIV)
- Talk about ARVs and their role in protecting the body
- Dispel misconceptions
- Take time to make sure caregiver and child have correct understanding of HIV

REFER to Handout 7.3.1: Tools to Assist Disclosure in Children on page 299 of their Participant Handbook.

Dealing with Barriers to HIV Disclosure

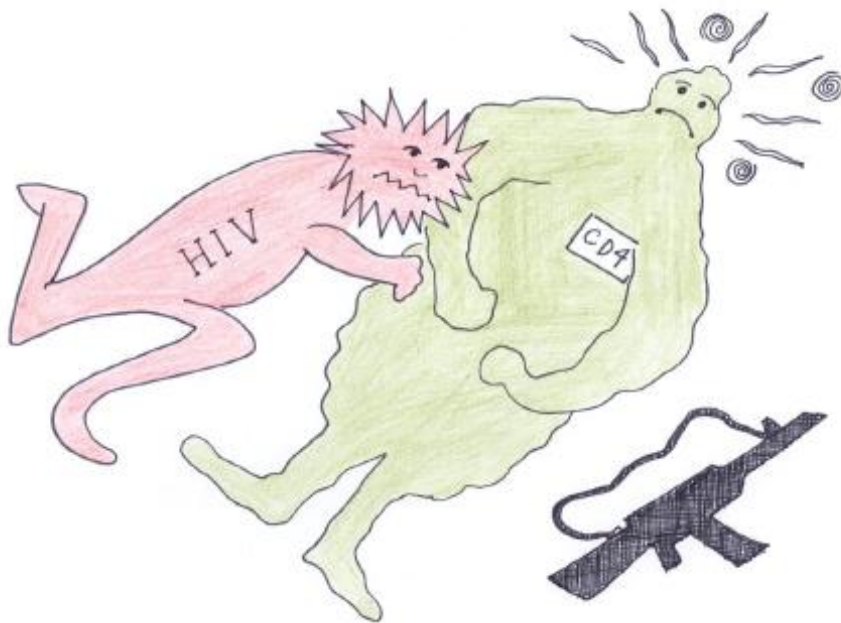
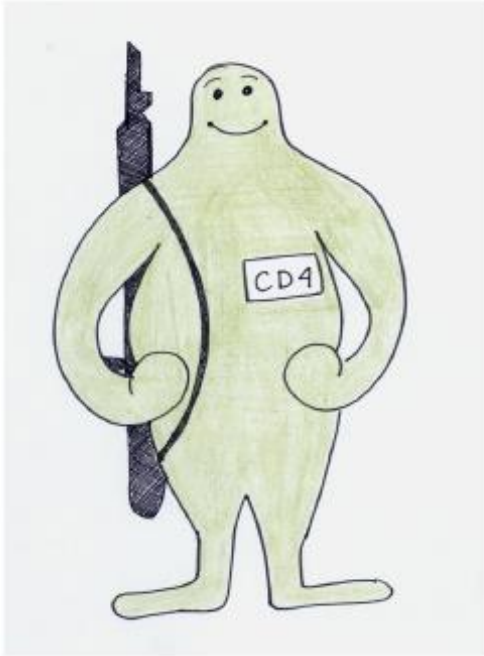
- Address child’s thoughts, feelings, self-perception, fear related to his/her HIV status
- Assess child’s knowledge regarding HIV, correct misconceptions and provide current information
- Address caregivers perceptions, thoughts, feelings, fears regarding HIV; particularly related to their family/community system

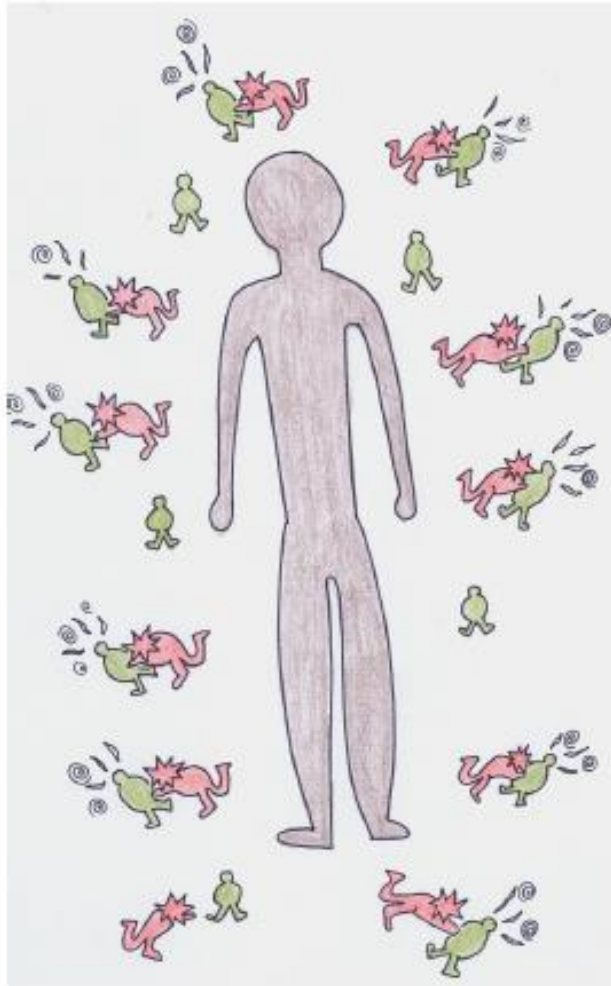
Key Points

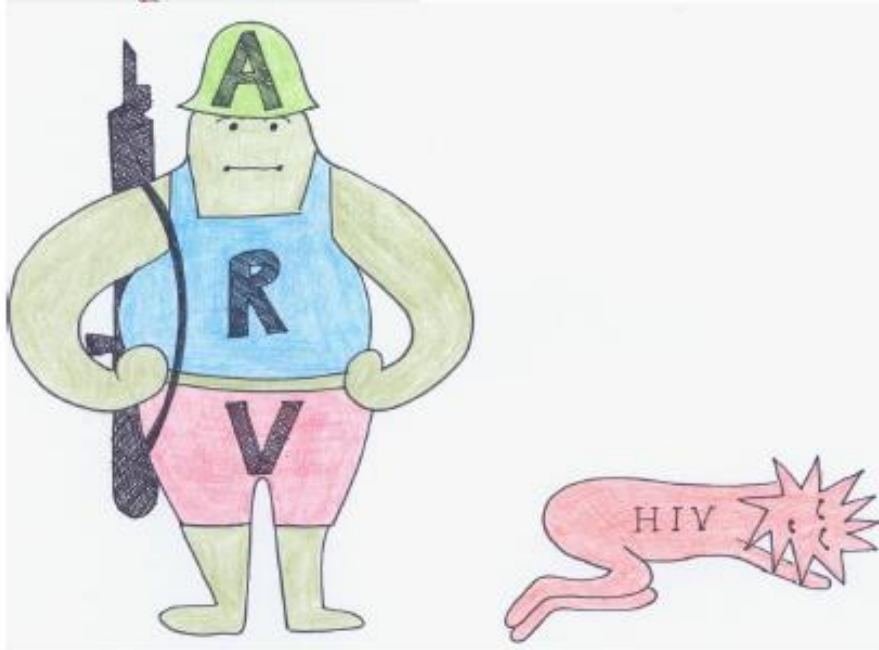
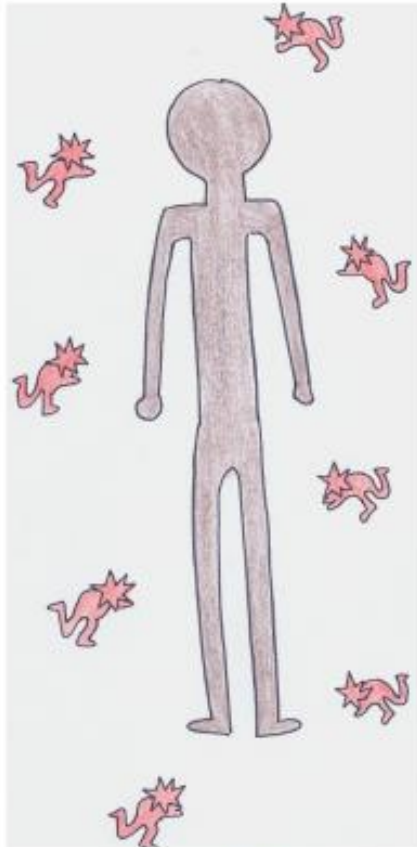
- Disclosure is an integral part of comprehensive care in pediatric HIV
- Disclosure can start as early as 5-7 years of age but must be done gradually, in a culturally sensitive manner, and with the consent and participation of the parents or caregivers
- The disclosure process involves specific steps
- Tools such as drawings and pictures are helpful in explaining disclosure and facts about HIV to children

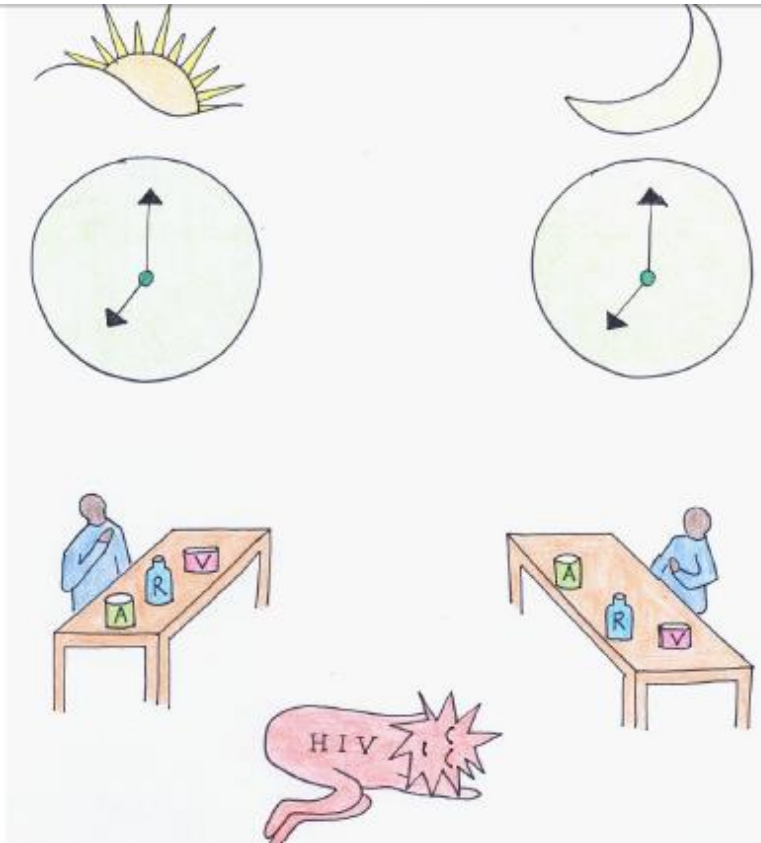




Handout 7.3.1: Tools to Assist Disclosure in Children

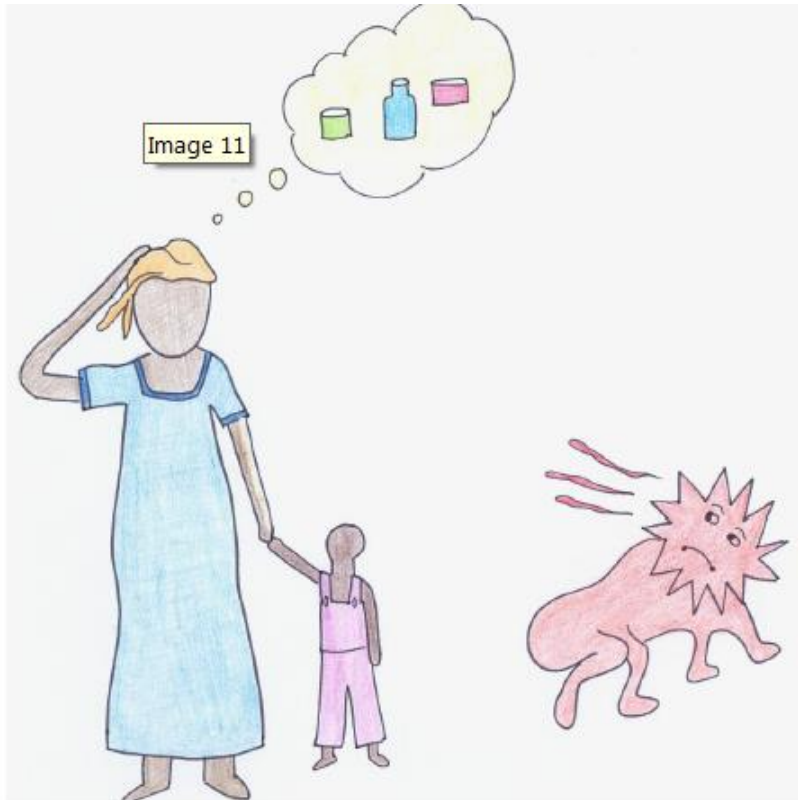


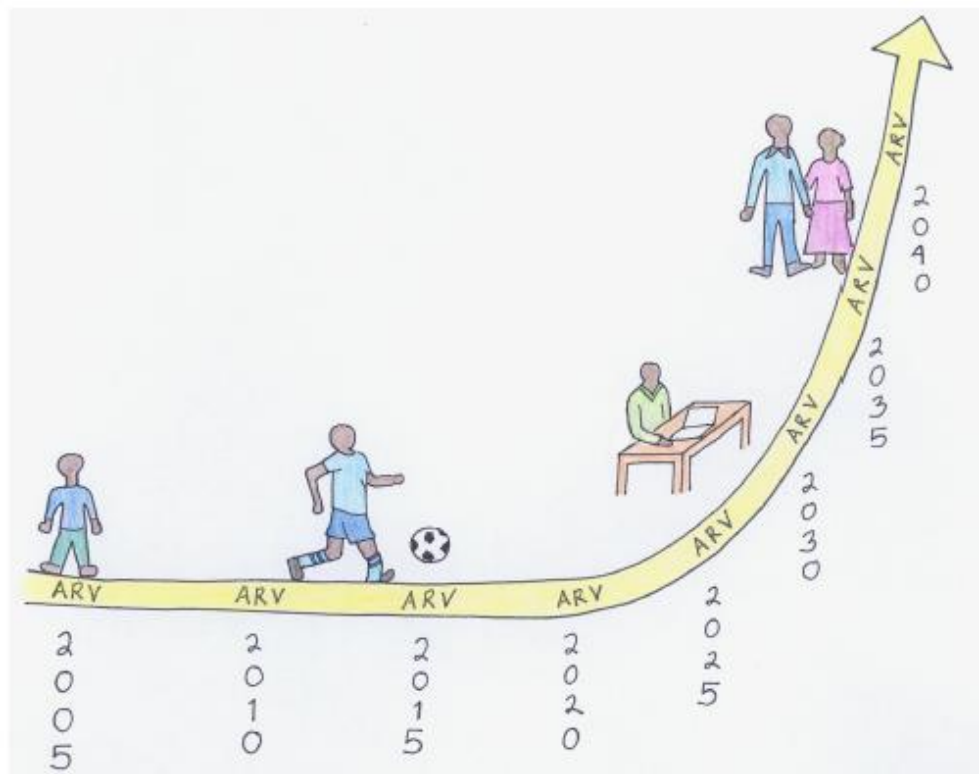


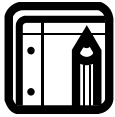




		
Monday		
Tuesday		
Wednesday		
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Saturday		
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Worksheet 7.3.1: Role Plays for Disclosure

Instructions:

- In small groups, conduct role plays using the scenarios below.
- Each person in the group should take one turn as the health care provider. You should switch roles after each scenario.
- Any group member without an active role will serve as an observer.

Scenario 1: Malia

Malia is 14 years old. Her parents have both died, and she is the head of the household taking care of 3 younger siblings. She is trying to stay in school, but she cannot earn money if she stays in school. She has been getting sick frequently and goes to the doctor with a severe case of malaria and a bad cough.

She has tested positive for HIV. She does not know very much about HIV but she has heard the word before. She goes with her uncle to the hospital, and she starts to ask the nurse some questions about what is wrong with her.

Instructions:

Practice role playing a scenario of disclosure between Malia, her uncle and the health care provider.

Roles:(1) Malia, (2) Health Care Provider, (3) Uncle, (4) Observer

Consider the following:

- How much to tell the child?
- Is this the right time?
- How to tell the child?
- What process should you follow to disclose? (Refer to Participant Handbook as needed)

Scenario 2: Bobby

Bobby is 7 years old. He was born with HIV, and his mother passed away shortly after he was born. He has been taking ARVs for most of his life, and he is not growing as he should for his age; he appears to be much younger. He frequently gets sick, and his grandmother (his caregiver) is very worried about him.

Bobby's grandmother takes him to the hospital.

Instructions:

Practice a role play scenario between Bobby, his grandmother and the health care provider.

Roles:(1) Bobby, (2) Health Care Provider, (3) Grandmother, (4) Observer

Consider the following:

- How much to tell the child?
- Is this the right time?
- How to tell the child?
- What process should you follow to disclose? (Refer to Participant Handbook as needed)

Scenario 3: George

George is 11 years old. He loves playing soccer and running. He is in the normal height and weight range for his age. He does very well in school and enjoys spending time with his friends. He was born with HIV, and has been taking ARVs for most of his life.

His mother is still alive and is his caretaker. She thinks that it is time that George understands more about his HIV status.

Instructions:

Practice a role play scenario between George, his mother and the health care provider.

Roles:(1) George, (2) Health Care Provider, (3) Mother, (4) Observer

Consider the following:

- How much to tell the child?
- Is this the right time?
- How to tell the child?
- What process should you follow to disclose? (Refer to Participant Handbook as needed)

Session 4: Support Services for Orphans and Vulnerable Children



Total Session Time: 60 minutes

Learning Objectives

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

- Describe the rights of orphans and vulnerable children
- Describe bereavement
- Explain palliative care and pain management
- Describe the needs for care of the dying
- Describe legal and ethical issues related to HIV infection in children

Definition of Terms

Orphan: A child who lost one or both parents or guardians before reaching 18 years of age, and who is dependent.

Vulnerable means susceptible to harm:

- Physical (sexual abuse, physical injuries)
- Emotional (verbal insult, deprivation of respect and love)
- All children to some extent are vulnerable

OVC refers to Orphans & Vulnerable Children

Vulnerable Children

All children can be vulnerable given certain conditions. For example:

- Orphaned children
- Street children
- Child Labour
- Children with disabilities
- Children from families with chronic illnesses
- Children from poor families
- Displaced and refugee children

A child often needs protection but especially in these situation it is more vulnerable.

Orphans Affected with HIV/AIDS

Evidence shows that AIDS orphans living with extended families or in foster care are frequently subject to discrimination and are unlikely to receive health, education and other needed services. The situation is yet more desperate for those living in child headed households or on their own on streets

Rights for Orphans and Vulnerable Children in the Context of HIV

- Access to care
- Confidentiality
- Consent
- Testing
- Right to know their status

Access to care

Orphans and vulnerable children should have access to care as any other child including

- HIV prevention services
- HIV testing and counselling
- HIV treatment including ART

Confidentiality

- All information obtained is confidential even towards caregiver
- This allows child to be open and discuss issues freely

Absolute confidentiality also applies when carrying for children, not just for adults.

Consent

- Informed consent required by law
- Parents or legal guardian to consent
- Emancipated/mature minors might not need parental consent (i.e. pregnant, married or sexually active teenagers). Confidentiality applies for consent. That informed consent is required by law to all above 18 years of age. Children below 18 years requires parental consent and child's assent.

HIV Testing

- Should be voluntary
- Testing regulations have to be followed:
- Pre-test counselling
- Testing
- Post-test counselling
- Referral when needed
- The child should be accompanied by guardian

Right to know their status

Orphans and Vulnerable children have the right to know their HIV status to enable them

- Initiate or maintain behaviours to prevent acquisition or further transmission of HIV
- Gain early access to HIV-specific care, treatment and support
- To have access interventions early
- To better cope with HIV infection
- To plan for the future.

Existing Support Structures

- Child-headed households
- Extended families
- Foster homes, orphanages
- Children's department
- Child welfare societies
- NGOs/ CBOs /Faith Based Organisations

It is important to strengthen linkage between health system and existing support structure in the community

Support Systems and Referrals

- Family systems
- Social welfare department
- Hospital for medical care
- Local administration
- Legal system
- Others

Referrals should be made to benefit the child and family. Service provider should be aware of available non -medical services. Other options include support groups, religious/faith based groups or traditional support groups.

Roles and Responsibilities of Health Care Workers

- Observe children's rights
 - Schooling, shelter, food, protection
 - Throughout the process of testing, care and treatment, including consent and confidentiality
- Protect from sexual exploitation and abuse
- Reduce stigma and discrimination
 - Peer groups, recreation activities
- Empower and strengthen care givers with appropriate information
- Refer for appropriate linkage systems and support

Other OVC Support Services

- Bereavement
- Care of a dying child
- Legal and ethical issues

Bereavement

Bereavement is the physical loss or deprivation of a person or object to whom is emotionally attached (e.g. parents, job, toys)

- ‘Mourning’ is an external expression of loss.
- Communities mourn differently
- Rituals bring healing/closure for bereaved

Children’s Needs in Bereavement

After death, children need:

- Information
- Reassurance
- Safe place to express their feelings
- To be involved in what is important to them during counseling

Bereavement Counselling

- Children may not express their unhappiness or bereavement through words.
- Children have different understanding of death at different ages and this affects the way they will react to it.
- Counselling can help children and parents cope with the situation:
 - Gives support and dignity to the bereaved
 - Provides continued support and counselling after death of a loved one
- Children will continue to ask questions and repeatedly:
 - Answers should be given in simplest form
 - There should be continuous counselling and help after death of loved one.
 - Use of memory book to facilitate discussion about the child’s family history and how to prepare for the future.
 - Use of spiritual support to facilitate recovery

Memory book is a tool for a child to know his background, parents and growth and development.

Palliative Care

“...[A]n approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

Principles of Palliative Care

- Provide relief from pain and other distressing symptoms
- Integrate the psychological, spiritual, and social aspects of patient care
- Offer social and welfare support systems
- Use a team approach to address the needs of patients and their families, including bereavement counseling

REFER to Handout 7.4.1: Principles of Palliative Care on page 315 of the Participants Handbook for more information on palliative care.

Benefits of Palliative Care in HIV

- Treatment of antiretroviral side effects
- Management of HIV complications
- Relief of psychosocial challenges
- Improved ART adherence
- Reduction of drug resistance in the individual and community
- Preparation for end-of-life

Palliative care services can greatly enhance outcomes for people on ART through promoting better health outcomes, adherence, and service retention.

Management of Pain

Pain is one of the most common symptoms addressed with palliative care. It is important to address pain: when a patient says “it hurts, it really does hurt”!

- Causes of pain:
- Physical, psychological, social, spiritual, emotional
- Acute and chronic pain management requires multidisciplinary and multimodal approach
- While pain is prevalent among people living with HIV, it is often underdiagnosed and therefore undertreated.
- All patients with pain should be assessed for pain to identify the nature, type and severity of pain, to help develop a management and monitoring plan. Assessment includes:
- Assess pain severity
- Identify the pain mechanism;
- Detect acute pain syndromes, underlying pathology, or features that predict progression to chronic pain;
- Identify patterns of baseline, breakthrough and incident chronic pain; and
- Document co-morbidities, medication, drug and alcohol history.

REFER to Handout 7.4.2: Approach to Pain Management on page 317 of the Participants handbook for more information on approach to pain management.

Care of a Dying Child

- Need to help child and family cope with the situation and accept that the child is dying
- Ensure least amount of suffering and plenty of support and dignity
- It includes basic nursing care and effective pain management
- Terminal care is a long term process that requires proper preparation
- Provide support to parents and child
- Establish appropriate acute care facilities
- Discuss with the family about preferred place of death

- This is a long term process which should be planned
- Parents may react with rejection by withdrawing from care of the child, this a contrast from the needs of the child.
- Nursing care aims at symptom relief
 - -Pain control with medication
 - Non-pharmacological methods such as massage, aromatherapy etc.
- Grief management
- Acute care facilities--May be neglected because is deemed as competing with other ill patients for resources.
- Place of death--Discuss with family about preferred place of death

Behavioural and Psychological Reactions of Grieving/Dying Child

- Denial
- Blame
- Guilt
- Depression
- Anxiety
- Possible suicidal thoughts
- Anger
- Bargaining
- Fear and shock
- Increased responsibility
- Rebellious behaviour

Preparing Children for their Own or a Loved One's Death

- Communicate openly, honestly and factually
- Allow child to express their anger and fear without harming themselves
- Acknowledge issues of denial
- Enable child to express fears and ask questions
- Encourage family members to openly discuss issues around death and bereavement
- Let child say how they would like to be remembered (e.g. memory book, drawing, poems)

Legal and Ethical Issues

Legal support means support to ensure legal protection of human and individual rights, including the rights of children

- Inheritance
- Development
- Protection from abuse, exploitation and discrimination
- Right to shelter, food and care)

Human Rights and HIV

- Knowledge of human rights in relation to HIV is essential so as to:
- Protect the child from violence and discrimination
- Ensure quality health care services to HIV infected children
- Help children exercise autonomy; autonomy means independence or freedom, as of the will or one's action.

Legal and Ethical Issues

- Child's rights
- Basic needs, care, health
- Protection of children against abuse
- Always consider the best interest of the child
- Inheritance issues, including property management by Trust
- Adoption process
- Testing for HIV
- Confidentiality of HIV test results
- Discrimination of children with HIV
- Deliberate infection of minors with HIV
- Research ethics
- Harmful cultural practice (uvulectomy, etc)
- Inheritance of property for orphaned child
- Child labour

Refer to **Handout 7.4.3.: Tanzania Child Act** on page 319 of the participant's handbook.

Key Points

- Skilled health workers should provide quality care and support for children and families
- Palliative care
- Is integral to HIV care from the time of diagnosis
- Must be patient-centered
- Evolves over the course of a patient's lifespan
- Pain is common in HIV and should be managed based on the principles of pain management
- Delivering bad news and talking about death is part of effective palliative care
- Health care workers should have relevant knowledge on legal and ethical procedures
- Ensure protection of the child during testing, care and treatment



Handout 7.4.1: Principles of Palliative Care

The overall guiding principles for palliative care in resource-limited settings are:

- **Emphasis on quality of life.** Quality of life is defined by the individual, not by the service provider. Serious effort must be made to improve quality of life, regardless of the stage of illness or individual circumstances.
- **Respectful and participatory.** Palliative care services must respect the rights of the patient and family to make choices, exercise their unique cultural and personal values, receive confidential services, and be treated with dignity.
- **Holistic.** Needs are viewed holistically, with physical, emotional, spiritual, and social aspects of care and support equally attended. Services are provided by interdisciplinary teams, which are better equipped to address diverse needs. They support people living with HIV to shape, lead, and provide services.
- **Family centered.** The unit of care is the family (as defined by the patient). Providers involve families in the care process, providing them with needed confidence, information, and skills to support their loved one with HIV.
- **Sustainable.** The provision of services can be accessed, sustained, and integrated into the local system, community, and environment. Services must strive to be cost-effective to ensure the greatest benefit for all.
- **Integrated.** Palliative care services are provided through existing health, psychosocial, and spiritual support services, including HIV and orphans and vulnerable children (OVC) programs.

Palliative care services are sometimes provided in stand-alone facilities such as hospices or specialized palliative care units in tertiary hospitals. While there is a place for these services, palliative care can be more effective when it is provided in combination with services that offer treatment of OIs and underlying disease. This approach ensures that care is holistic and helps people with HIV to live both longer and better lives.

Benefits of Palliative Care include:

1. Improving Quality of Life

Addressing physical, emotional, social, and spiritual needs, and helping people achieve a sense of peace and life meaning, can prevent end-of-life suffering and despair.

2. Promoting Better Health Outcomes, Adherence, and Service Retention

Palliative care services can greatly enhance outcomes for people on ART.

3. Reducing Stigma

Palliative care offers an opportunity for providers to help family members and neighbors better understand HIV and learn how to provide care for loved ones living with HIV. It has helped reduce stigma and discrimination in some settings

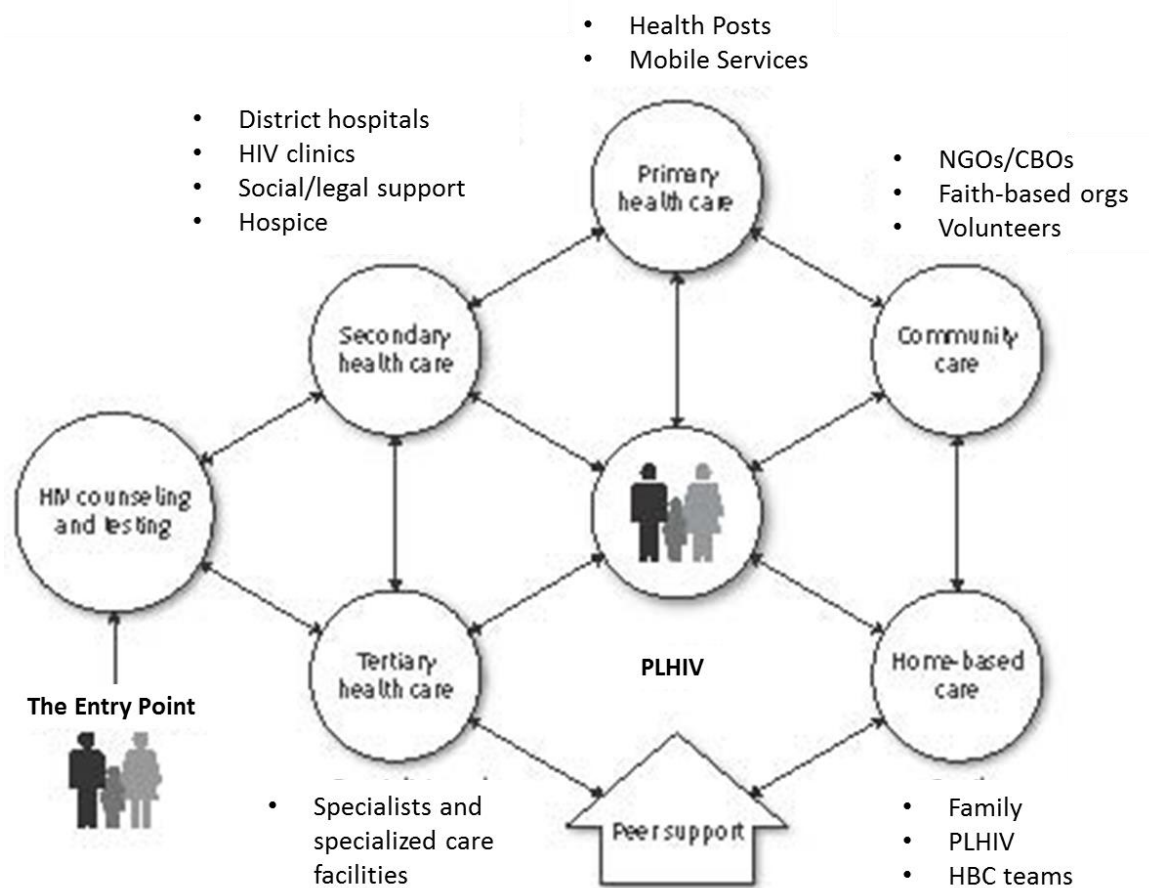
4. Providing Cost-Effective Services

Comprehensive palliative care, where people have access to inpatient and outpatient care and home-based care when they need it, has proved cost-effective. The evidence also shows related improvements in daily adjusted life years, increased rational use of health-care services, reductions in hospitalization, and improved quality of care.

Palliative Care and Continuum of Care

Palliative care is, in essence, a continuum of care because it focuses on relieving suffering throughout the course of HIV and through all stages of life (Figure 1). Therefore, palliative care services need to be available to people with HIV at all levels of the health-care system. This includes tertiary, secondary, primary, and community levels of care. As a person moves through the continuum of care, palliative care must be available at each point to provide relief and support for the client and affected family members.

Figure: Continuum of Palliative Care



Source: Adapted from Van Praag and Tarantola



Handout 7.4.2: Approach to Pain Management

Treat pain early and effectively, before it can become established and more difficult to treat. A multidisciplinary and multimodal approach is often required for both acute and chronic pain. Management includes:

- Analgesics and adjuvant medications.
- Local anaesthetic techniques.
- Disease specific treatments.
- Non pharmacological strategies.
- Attention to psychosocial issues.

Management of pain should be individualised taking into account the type of pain, culture, beliefs and treatment preferences. Before beginning treatment, establish realistic treatment goals with the patient and relatives. Is the aim to eradicate the pain or reduce it to tolerable levels so that mobility and independence can be restored or maintained? For example, a patient receiving End of Life care may require complete pain relief even though mental and physical function is compromised. Adequate pain control can avoid secondary consequences such as: confusion, depression, sleep disturbance, reduced appetite and nutrition, impaired mobility, social isolation, worsening pain, slowed rehabilitation and increased risk of falls.

Care planning

The GP and nurse are responsible for assessing the patient with pain and developing a written pain management plan, including, conditions causing pain, goals of therapy, interventions, and regime for monitoring /reassessment. A pain care plan will reduce the incidence and severity of uncontrolled pain and alert all care givers to the treatment regime. This will help to eliminate the need for seeking after hours assistance.

Education of patient and family

Family input into pain management of the patient is important and should be encouraged. Some relatives become concerned about adverse effects or dependency from morphine.

Education will improve their understanding that:

- Adequate pain relief is important as a pre-emptive measure rather than waiting for the pain to become severe when larger doses of the drug may be required;
- Pain can in most cases be controlled and has subsequent benefits to the patient's quality of life;
- Adverse effects can be prevented or treated; AND
- If the pain improves or resolves the opioid can be reduced or withdrawn.

Non pharmacological strategies

Non-pharmacological strategies may be used by themselves or in conjunction with pharmacological strategies. The combination of the two approaches often results in lower drug doses being used.

Showing an interest in and having a sincere concern for the person's pain can have a therapeutic effect. Usually the patient will benefit from family involvement and the emotional support that it provides.

Physical Therapies

These are generally free of significant adverse effects and are best provided in consultation with a physiotherapist. They include TENS; walking programs; specific strengthening exercises and massage. Heat or cold packs need to be used with care to avoid burns or hyperalgesia. Surgery or nerve blocks are other options.

Cognitive- Behavioural Therapies (CBT)

There is good evidence that individual and group CBT programs are beneficial for older adults with persistent pain, including long term care residents who have no dementia or very mild dementia. Alleviating concerns, explaining the cause of pain as well as teaching behaviours and positive thoughts will enhance their capacity to manage their pain. Psychologists and many GPs have training in these CBT techniques.

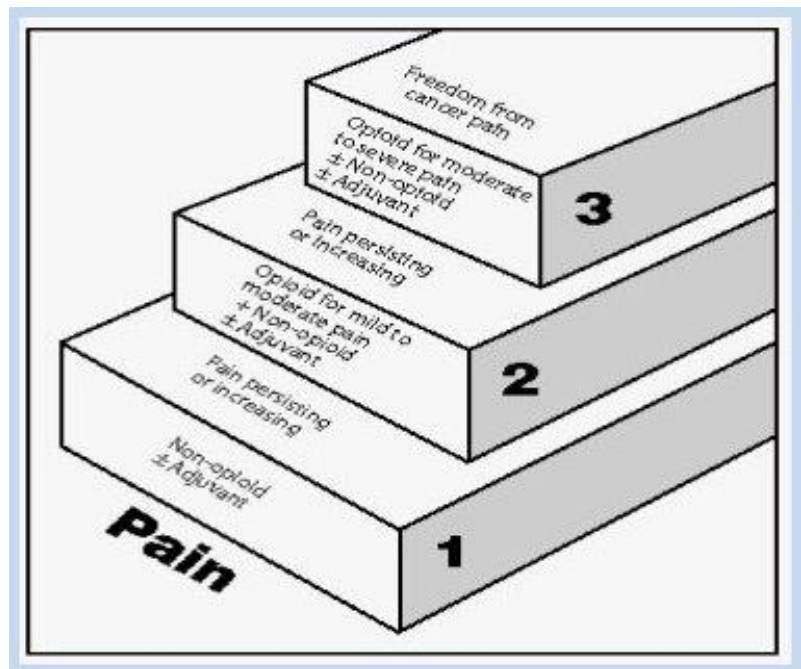
Other Strategies

Alternative or complementary therapies are useful in many cases e.g. aromatherapy, guided Imagery (not usually suitable for cognitively impaired patients), acupuncture, music. Diversional therapies should be initiated to the extent the patient can tolerate. Offer nutrition and fluids, ensure the patient is warm and comfortable, and reduce lighting and surrounding noise.

Medication

Drug therapy needs to be flexible and tailored to the patient, and the mechanism and severity of pain. Adequate pain relief is more important than strict adherence to a fixed regime. Placebos should never be used to assess or treat pain.

The World Health Organisation ladder for cancer pain is often also used for acute and chronic non-cancer pain. The WHO analgesic ladder recommends that choice of medication is based on the mechanism and severity of the pain. Treatment starts at the step appropriate for the severity of the pain, e.g. a mild analgesic such as Paracetamol, and builds up stepwise to opioids for severe unrelieved pain, as shown in the Figure.



A regimen of analgesia ‘round the clock’ is more beneficial than administering analgesia when the patient asks for it or as the nurse considers it necessary. This will have the effect of maintaining a therapeutic level of the drug in the blood stream achieving more constant pain relief and avoiding the peaks and troughs associated with ‘as required’ administration. It also circumvents the need for the patient to request analgesia. Analgesia ‘as required’ can be added once a pain treatment regime has been established.

Elderly people usually require lower doses of analgesics. NSAIDs should only be used with caution. Paracetamol and/or low dose opioids are generally preferred. Opioid dose requirement decreases progressively with age. In the elderly, use a lower initial dose and titrate to effect. There is an increased risk of adverse effects including cognitive impairment and falls.



Handout 7.4.3.: Tanzania Child Act

The Law of the Child Act 2009

Introduction

1. The Tanzania Law of the Child Act 2009 brings together child specific provisions from a range of national laws into one document. For the first time, the Law enshrines key child rights, drawn from international and regional agreements. It establishes a framework for protection of children from abuse, violence and neglect at local and national levels, and sets standards for juvenile justice. Existing provisions for children who need care outside their own homes, as well as restrictions on child employment have been strengthened in this new law.
2. The purpose of this booklet is to provide a clear, easy to understand guide to the Tanzanian Law of the Child Act 2009. It is written in sections which group together the main themes of the Act. The booklet is designed primarily for young people, but may also be useful to those who work with children in all areas of care, education, health and employment. It is not a definitive version of the law, and should not be used as a legal document. Please refer to the Act for all points of law.

Know your rights

3. Children have the right to a name and a nationality and to be registered at birth.
4. It is against the law for anyone to treat a child unfairly because they are a girl or a boy, or because of their age or religion or where they come from or because they are poor.
5. Children have the right to express their opinions on decisions that affect their lives and adults must consider their views when taking these decisions.

Family Life

6. Children have the right to know and live with their parents in a caring, peaceful home. Children also have a responsibility to respect and help their families.
7. If parents divorce, the Court will decide where the child will live. Children under seven years usually live with their mothers. A child has the right to visit and stay with the other parent, unless this interferes with going to school.
8. Fathers should contribute to the upkeep of their children until they are 18 years old. If a child's parents die, and there are no other relatives to care for the child, or if a child is neglected, abandoned or abused by their parents, the State should ensure they have a safe place to stay.
9. Children found begging or living on the streets may be returned to their families. If it is not safe for children to live with their parents, the authorities may arrange for the child to live with a foster family or in an approved residential home.
10. Children may also be adopted if the adopted parents are approved and show they can take proper care of the child.

Food, shelter, health care and school

11. Parents and guardians must protect children from harm. They must also make sure children have food, clothing and a safe place to live.
12. Parents must make sure children are immunized against diseases. Children who are sick should be taken to a clinic.
13. Parents must send children to school and give them time to play and rest. Special care and treatment should be given to children with disabilities so that they can go to school like any other child.

Work and children

14. Children only have a right to work after they are 14 years old. Work must not stop a child from going to school or having time for study and rest. Children must not be employed to work at night.
15. Anyone who makes a child work too hard, or does not pay them properly, is breaking the law.
16. It is illegal to employ a child if the work is dangerous. Children are not allowed to work at sea, work in a mine or quarry, carry heavy loads or work with chemicals or machines. Children are not allowed to work in hotels or bars.

Protection of children

17. No one is allowed to harm, injure or exploit a child. Anybody who knows that a child is being abused or badly treated must report it.
18. Punishment of a child should not be harsh or humiliating.

Justice for children

19. Special courts called Juvenile Courts are supposed to be set up to deal only with children. These Courts do not deal with all children's cases, rather they focus on child protection, child care and children in conflict with the law. At these special courts, Magistrates try to make sure children are not frightened, that they understand what is happening and can give their views. At the Juvenile Court, children have the right to be defended by a lawyer.
20. They must also be allowed to express their own opinions and give their own account of what has happened. Children who are accused of a crime and are brought to a police station may be released to their parents or may be sent to a retention home to wait for the court case. Children who are found guilty of a crime may be released on condition of good behavior, or sent to an approved school. Children are not allowed to be put in prison.